FACTLY

HEALTH MISINFORMATION REPORT

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About this Report

The creation of the **Health Misinformation Report** was made possible through funding provided by **Facebook** to place a Health fellow in a yearlong fellowship programme at **Factly.**

Factly works towards making public data and information more accessible to people through a variety of methods.

Factly

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Thank You,

Team Factly

FOREWORD

Professor Kang is a physician scientist working on vaccines and public health, particularly focused on children and enteric infectious disease in India. She is an elected Fellow of all the Indian science academies, is the first Indian woman to be elected to Fellowship of the American Academy of Microbiology and to the Royal Society, and the only physician-scientist to receive the Infosys Award in Life Sciences.

In the past 21 months, we have dealt with a deluge of information about viruses, infection, treatments, vaccines, and the people who make, use, or evaluate them. While the pandemic was a fire hose of information, some true and reliable, some inaccurate and some completely false, the spectrum of information, misinformation and disinformation is no different for any aspect of public health. It is important to recognise that while accurate information matters for all of society, information asymmetry, and exposure to misinformation disproportionately affects the populations that have traditionally been marginalised.

Factly, which aims to change the public information landscape by providing to the public both access and explainers about important and relevant information across a range of topics, has undertaken a critically important exercise in the past year. In partnership with Facebook, Factly has trained a Health Fellow and deployed her to explore the misinformation landscape in India. Through detailed analysis of available sources of data, checks with experts and interviews with key leaders, Factly has developed a Health Misinformation Report covering myths and misconceptions in 10 sectors including immunisation, nutrition, maternal health, menstrual health, sexual reproductive health, cancer, COVID-19, public health concerns, mental health, and non-communicable diseases.

From the known myths around menstruation to the beliefs and practices of those who believe that cancer can be addressed by diet alone, the Factly-Facebook Health Fellow has undertaken a listing of common misinformation in India, identified the correct information and discussed current practices and potential communication strategies with experts from multiple disciplines. The areas chosen by the Fellow are critical to public health, where an understanding of the range and scale of misinformation is immense, and the potential for damage and impairment is large. It is clear from many of the myths that she describes that there is a particular focus on the deliberate disempowerment of women, couched in the language and practice of a specific culture or tradition. The laying out of the construct and countering of this misinformation is essential if we are to use an understanding of human physiology and pathology to address health and medical needs with the best available data and tools.

The value of this effort to create a landscape, provide accurate information and obtain inputs from experts cannot be overstated. With the flood of information that fills every media channel to the information networks within families and communities, it is important to understand not only what information is reliable, where to check on its accuracy and how to counter misinformation, but also to think about what this means for our society as a whole. India has had many people's science movements that have sought to counter the 'escape into magical beliefs and instant solutions' and Factly uses new communication channels to scan and counter the burgeoning of belief in unproven associations and treatments.

Trust is hard to establish and easy to lose. For science, and particularly health related science, this report is a key building block in an approach to establish society's trust based on a solid foundation of carefully evaluated information. The processes followed by the Fellow in each of the 10 areas describe a careful approach undertaken for the benefit of Indian society.

Factly has recognised and addressed a critical need and should be congratulated and recognised. Look forward to more efforts to further build science in our society.

Gagandeep Kang, FRS
Professor, Christian Medical College, Vellore

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ACRONYMS

229E	Named after a student specimen coded 229E
AIDS	Acquired Immunodeficiency Syndrome
AIIMS	All India Institute of Medical Sciences
ANC	Antenatal Care
ASHA	Accredited Social Health Activist
AWS	Anganwadi Services
BCC	Behavioural Change Communication
BMJ	British Medical Journal
CDC	Centers for Disease Control and Prevention
COPD	Chronic Obstructive Pulmonary Disorders
COTPA	The Cigarettes and Other Tobacco Products Act
COVID-19	Coronavirus Disease 2019
DALY	Disability Adjusted Life Years
DF/HCC	Dana-Farber/Harvard Cancer Center
DIP	Disciplined and Intelligent People
DRI	Deendayal Research Institute
ECHO	Enhancing Communications for Health Outcomes
FNAAS	Fellow of the National Academy of Agriculture Sciences
FRSPH	Fellow of Royal Society for Public Health
FSSAI	Food Safety and Standards Authority of India
GATS	Global Adults Tobacco Survey
GDM	Gestational Diabetes Mellitus
GDP	Gross Domestic Product

HCoV	Human Coronavirus
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
HSPH	Harvard T.H. Chan School of Public Health
IARC	International Agency for Research on Cancer
ICMR	Indian Council of Medical Research
IEC	Information, Education and Communication
IFPRI	International Food Policy Research Institute
IMR	Infant Mortality Rate
IPA	International Psychogeriatric Association
IUD	Intrauterine Devices
KHU1	Hong Kong University 1
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer and intersex, asexual, pansexual and allies
LMIC	Low- and Middle-Income Countries
M&E	Monitoring & Evaluation
MCH	Maternal and Child Health
MMR	Maternal Mortality Rate
MMR	Measles, Mumps and Rubella
MoHFW	Ministry of Health and Family Welfare
MR-VAC	Measles Rubella vaccine
MSG	Monosodium glutamate
MTP	Medical Termination of Pregnancy
NACO	National AIDS Control Organisation
NCBI	National Centre for Biotechnology Information

NCDIR	National Centre for Disease Informatics and Research
NCDs	Non-Communicable Diseases
NCI	National Cancer Institute
NCRP	National Cancer Registry Programme
NFHS	National Family Health Survey
NGO	Non-governmental Organisation
NICHE	Nutrition Information, Communication & Health Education
NIH	Nationals Institutes of Health
NIMHANS	National Institute of Mental Health & Neuro Sciences
NIN	National Institute of Nutrition
NITI Aayog	National Institution for Transforming India
NL63	NetherLand 63
NMAP	National Monitoring and Action Plan
NMHS	National Mental Health Survey
NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke
NRI	Non-Resident of India
OC43	Organ Culture 43
PCOS	Polycystic Ovary Syndrome
PGIMER	Post Graduate Institute of Medical Education and Research
PHFI	Public Health Foundation of India
PLOS	Public Library of Sciences
PMS	Premenstrual Syndrome
RSS	Rashtriya Swayamsevak Sangh

RTI	Reproductive Tract Infections
RTI International	Research Triangle Institute
SARS-CoV-2	Severe Acute Respiratory Syndrome -Coronavirus
SHG	Self-help Groups
SHSS	School of Health System Studies
SMART	Specific, Measurable, Attainable, Relevant, Time-based
SNEHA	Society for Nutrition, Education & Health Action
SSD	Samaj Shilpi Dampatis
STI	Sexually Transmitted Diseases
TB	Tuberculosis
TISS	Tata Institute of Social Sciences
UIP	Universal Immunisation Programme
UK	United KIngdom
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
UNPF	United Nations Population Fund
USD	United States Dollar
UV	Ultraviolet
VPD	Vaccine Preventable Diseases
WASH	Water, Sanitation and Hygiene
WCD	Ministry of Women and Child Development
WHO	World Health Organization

EXECUTIVE SUMMARY

'Post-truth' was declared as Oxford Dictionary's word of the year for 2016. Since then, the concerns of debunking fake news and containing the spread of misinformation have only been increasing dramatically across the globe. Amidst the overwhelm of social information in the digital world, user traffic, clickbait content, sentimental analysis, and rumours set out by confusion (misinformation) or on purpose (disinformation) have taken the centre stage. One of the largest, daunting, and unseen effects of the widespread use of technology (social media) has been the incessant and persistent bombardment of misinformation on varied topics. In the wake of the ongoing pandemic, the rampant spread of health misinformation has translated into real-time consequences where people have either resorted to attempting unscientific cures and delaying treatment or refusing to take the vaccine, among other things.

While COVID-19 is not the first pandemic the world has known, it is the first to exist in the age of technological and information explosion. Owing to the over-sharing and over-abundance of opinions available both online and offline, we are now dealing with the dual burden of both the pandemic and the infodemic. While this phenomenon of health misinformation is not novel, this form of fake news directly affects the health of millions of Indians who desperately depend on social media as the main source of information. If unchecked, this will snowball and severely impact the overall wellbeing and access to the right healthcare services. "In this social media absorbed ecosystem we dispense with depth and discussion at the expense of brevity, but in that brevity, we dispense with rationality", writes Amitabh Kant, Chief Executive Officer of the NITI Aayog. Case in point being that during the COVID-19 breakout, in the chasm of uncertainty, people were particularly susceptible to misinformation due to an intricate combination of cognitive, social, and algorithmic biases, i.e., information overload and limited attention spans. Social media had become a medium of hope to people information of any and every kind was overshared in the hope that something out there will prove to be useful. Instead, misinformation was amplified to such an extent that it has become a threat to public health. The subsequent lockdowns only added to the uncertainty.

People often laud social media for its democratised content. In the age of information, as Joan Donovan, Research Director of the Shorenstein Center on Media, Politics and Public Policy says, "where information is extremely cheap, knowledge is expensive." While it is imperative to stay informed, one should not fall prey to misinformation that includes falsification of certain facts in order to propagate a certain individualistic or collective interest. The Centers for Disease Control and Prevention (CDC) has rightly pointed that "one of the global problems we deal with today is the viral spread of medical myths", which is in no way less scarier than a viral epidemic. Widespread medical misinformation goes beyond the prospect of personal beliefs and, in fact, affects people at the psychological and physical levels. This is because it

quickly catches public attention and leads to panic and confusion. Some of the most relevant instances include the MMR vaccine being linked to autism, promotion of e-cigarettes as a safe alternative to tobacco, the propaganda of anti-vaccination (influenza, pneumonia and HPV vaccines), widespread misinformation and stigma surrounding bad menstrual practices that leads to school dropouts, reinforcing gender discrimination and many others that incur severe social, economic, physical and environmental costs. Similarly, while the conversation around mental health has just started to get the required attention, the rampant misinformation has only added misery to the existing layers of social stigma.

The Health Misinformation Report is, therefore, authored in a hope to become a seed or **starting point**, and not the end, for health-related misinformation in the Indian context. As the foundation to solidify and enhance the misinformation knowledge in the health domain, the exercise undertaken is to essentially understand the myths, misconceptions, stigma, superstitions, and taboos in the chosen 10 priority health sectors. The overall goal is to map the entire health misinformation landscape to shape public knowledge, attitudes, and concerns in the health sector.

"Misinformation is not like a plumbing problem you fix. It is a social condition, like crime, that you must constantly monitor and adjust to", says Tom Rosenstiel, Author, Director of the American Press Institute and Senior Fellow at Brookings. While social media has been a catalyst in the spread of misinformation, it is, however, also important to note that merely expecting social media platforms to fix the crisis is a deeply flawed approach because most of the disinformation is shared in a decentralised manner through messaging. The real challenge is to ensure the teasing out of misinformation and help consumers decipher the facts. In this context, the role of fact-checkers, especially in the field of medical news owing to the ongoing pandemic, cannot be over-emphasised.

As part of their fact-checking programme, social media giant Facebook has launched a Global Fellowship to combat health misinformation. Factly Media & Research has been shortlisted among the 10 fact-checking organisations across the globe to be offered this fellowship. The fellowship announcement was made at a time when the world was reeling under the repercussions of misinformation owing to the ongoing COVID-19 pandemic. On account of being their credible fact-checking partner, the aim of this report is to map the misinformation landscape in India and accordingly develop methodologies and strategies to combat health-related misinformation in the country.

The plan/methodology to combat health misinformation followed in this report is a three-fold strategy:

1 *Literature Review:* Through a literature review of research papers, credible articles, consequential data, and insights, we have prioritised the 10 areas/sectors under the health domain where misinformation is prevalent and affects a larger population.

2 *Personal Interviews:* For the report analysis, we have undertaken thorough primary research to interview sectoral experts including academicians, professors, doctors, and social media influencers for first-hand and ground-level relevant insights; this, combined with the secondary research, has provided authentication and holistic understanding of the misinformation in each of the sectors.

3 *Social Media Analysis:* For the report, we have used CrowdTangle, a public-insights tool which essentially identified the prevalence of health misinformation and outlined strategies to be adopted to effectively contain misinformation through deep-rooted stakeholder partnerships.

The report covers basic misinformation (myths and misconceptions) in the following sectors: immunisation, nutrition, menstrual health, maternal health, sexual reproductive health, cancer, public health concerns, non-communicable diseases, mental health, and COVID-19. Each chapter has five parts including an introduction/literature review, common myths and misconceptions, a case study, excerpts of the interviews done with the sectoral experts, and a conclusion.

The idea was to provide a fundamental understanding of the core subject of each of the chapters and through secondary research, identify and map the kind of existing misinformation in that area. The secondary research coupled with the interviews of the relevant sectoral experts and organisations have been invaluable to triangulate and validate the research so far. In this regard, we reached out to stakeholders who are experts and organisations that work in each of these sectors for their insights. We conducted 21 expert interviews, reached out to 64 stakeholders (experts/organisations) and created a repository of over 500 myths and misconceptions panning across these 10 health sectors.

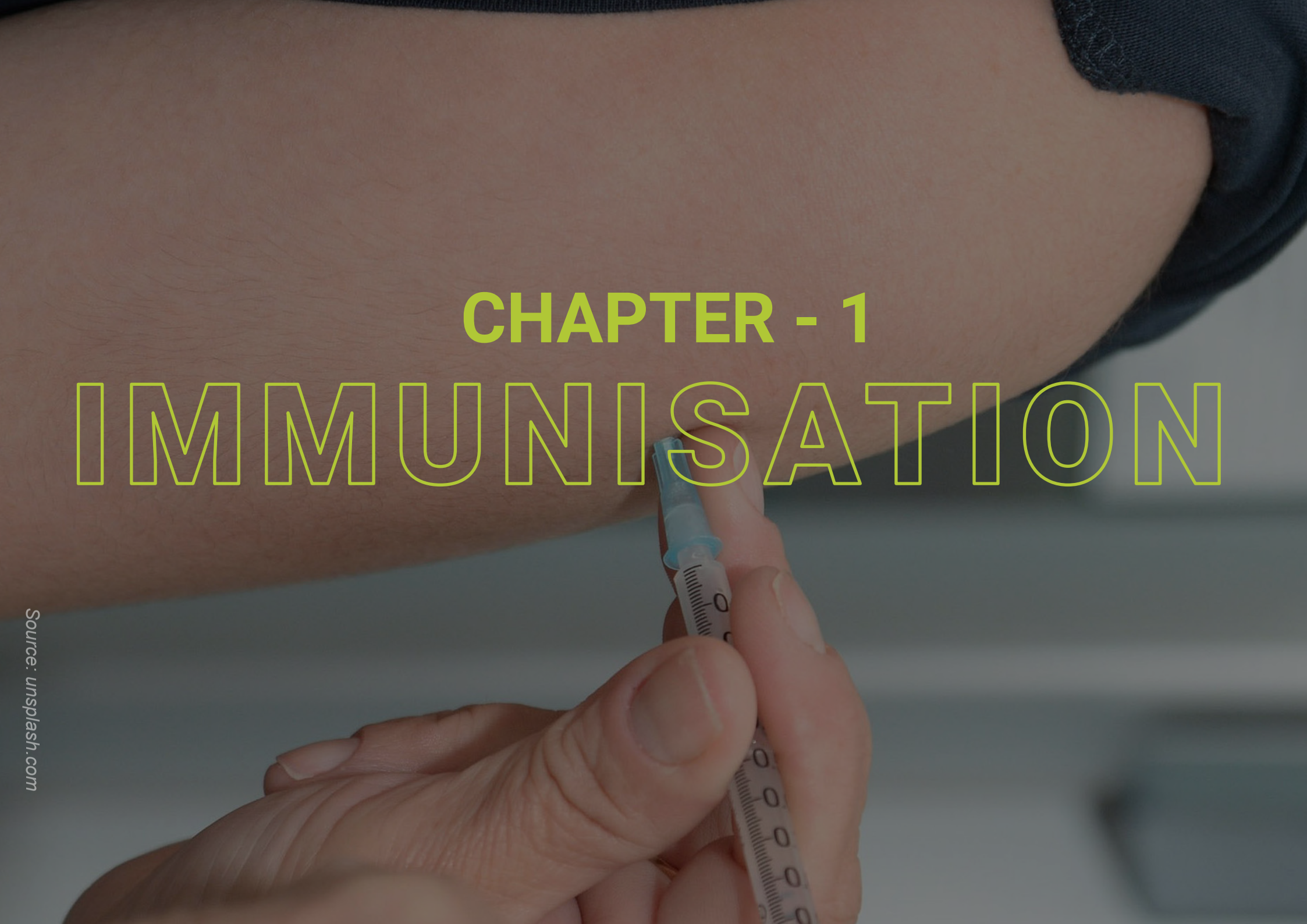
The overarching understanding of this report is that misinformation is not a homogenous entity but, in fact, manifests over time, generations, geographies, and communities. Therefore, there exists no 'one-size-fits-all' approach and solutions must be tailor-made for each of the

problem statements. The complexity of the problem is further compounded by the fact that medical misinformation is particularly layered, i.e., the myths and misconceptions are often couched in ambiguous medical terms and traditional practices. For instance, bad menstrual practices continue to be followed till date owing to the stigma and the lack of awareness of a natural physiological process. Therefore, to begin with, it is pertinent to address the root cause of the problem of misinformation and the entire research points towards education and awareness being the antidote to misinformation. However, owing to the grey areas and the intricacy of the layered problem, the solution is not so straightforward. Amidst the disparate information overload, the prerequisite is to contextualise and simplify the correct information. In the sme breath, given the layers of the problem, the challenge is also not to oversimply or misrepresent it. In this regard, the participation of the local stakeholders/actors who understand the behavioural, social, linguistic, and practical norms of the region coupled with effective messaging from the state is *one* of the most efficient and suggested pragmatic solutions.

However, the onus to weed out the extent and the depth of misinformation does not lie with one stakeholder like the state or fact-checkers, but is a collective effort that includes educating oneself, trusting science as an evolving and self-correcting mechanism, to rely on credible sources for consumption, separating fact from emotion, approaching fact-checkers when in doubt and questioning the authenticity of information, among others. Please do take cognisance of the fact that while fact-checkers might not hold all the answers, the public can be rest assured that they will be guided with credible sources and methodology, and be provided with a clarification, if not a conclusion. Therefore, a starting point to weed out misinformation is the added layer of responsibility to fact-check before consuming, and especially sharing, any information.

Limitations

The Health Misinformation Report strives to serve only as a starting point and is not an exhaustive literature in understanding and combating health-related misinformation. Given that misinformation is heterogenous and affects the psychology of people sharing and consuming it, the report does not undertake a quantitative investigation of the extent and depth of misinformation in the health sectors. Taking into account the complexity of the issue and the time constraint, the qualitative aspect of the research is subjective and the criteria for the selection of experts hung on their prior work in their respective sectors and the closest association to understanding misinformation. Owing to the uncertainties of the pandemic, timelines and the subsequent lockdowns, the primary research is limited to the interviews with the experts. We hope that future research will continue to investigate evidence-based data to gain insights into especially pressing topics such as medical misinformation in the developing world.



CHAPTER - 1

IMMUNISATION

Source: unsplash.com

1.1. Literature Review

In developing countries like India—the second most populous country in the world—vaccine-preventable diseases trigger a high incidence of disease-related deaths, both among children and in adults. According to the UNICEF, "immunisation is one of the most cost-effective public health interventions to date, averting an estimated 2 to 3 million deaths every year" (UNICEF 2021)[1]. Yet, in 2019 alone, an estimated 14 million infants remained unimmunised. On average, nearly 20 million children are still unvaccinated and under-vaccinated worldwide (Portal 2020)[2]. According to Niti Aayog and the National Family Health Survey for 2015-16 (NFHS-4), only 62% of children in India were fully immunised and less than 60% receive the entire basket of vaccines (Dr Rakesh Sarwal n.d.)[3] (Welfare, 2018)[4]. For a country that is a leading producer and exporter of vaccines, India is home to one-third of the world's unimmunised children and sees tens of thousands of birth defects every year (Ramanan Laxminarayan 2011)[5]. Adding to this, according to the Morbidity and Mortality Weekly Report 2018, at 2.3 million, India has the second highest number of children who are not vaccinated against measles, a number that has doubled in 2018 from the earlier 1.1 million (Minal K. Patel, et al. 2019)[6] (Prasad, 2019)[7] (Nations 2019)[8]. This number is alarming considering that measles can be easily prevented through only two doses of vaccination. Consequently, there were approximately 70,000 cases of measles in India in 2018, the third highest in the world (news 2019)[9]. In 2019, the World Health Organization (WHO) reported nearly 29,000 confirmed cases.

Katherine O'Brien, Director of Immunization, Vaccines and Biologicals at the WHO says, "Measles is not going anywhere. It's everyone's responsibility (Nations 2019)[8]. For one person infected, up to nine or 10 people could catch the virus." She adds, "In addition to being potentially fatal, measles symptoms include rashes, blindness and inflammation of the brain. The virus can be transmitted extremely easily, by coughing and sneezing, and it can also survive for hours in a droplet of water". In India, the first dose of the measles vaccine is given at 9-12 months and the second dose is given at 16-24 months through the national immunisation programme. But it appears that millions of children in India do not receive the measles vaccine through routine immunisation activities. Although the true burden of vaccine-preventable diseases (VPDs) among children and adults is unknown, they are particularly vulnerable during outbreaks. While significant steps have been taken through policies including Mission Indradhanush and the Universal Immunisation Programme (UIP) to ensure full immunisation with all available vaccines for children up to two years and pregnant women, there are other challenges to the problem (Dr Aruna Rastogi 2018)[10] (Welfare, Universal Immunization Program n.d.)[11]. In the recent MR mass vaccination that was introduced in the high-performing south Indian states, India has faced a new challenge of vaccination resistance/refusal in response to negative

propaganda on social media platforms like Facebook and also on messaging app, WhatsApp. In fact, in 2019, the WHO listed vaccine hesitancy among the top 10 threats to global health. Thus, the aim of this report is to both present the challenges of such misinformation and suggest the necessary strategies as the way forward to promote and ensure universal immunisation.

1.2. Common Myths and Misconceptions

MYTH: 01 | **Vaccine intake has been linked to autism.**

FACT: Andrew Wakefield's 1998 paper on the MMR vaccine raised some serious concerns on vaccination linked to autism. As a result of this study, vaccination rates dropped significantly leading to an outbreak of diseases. However, this study was later found to be flawed and the journal retracted the published paper refuting the posited link between MMR vaccination and autism (T. S. Sathyanarayana Rao 2011)[12].

MYTH: 02 | **Natural immunity is better than vaccination.**

FACT: A child left to natural immunity is more likely to increase the risk of complications. Vaccination is a better option to fight diseases. For instance, polio infection without vaccination can cause permanent paralysis (Prevention n.d.)[13].

MYTH: 03 | **Vaccines will induce disorders affecting a child's memory and learning capacities, and are pushed in the country at the behest of foreign pharma companies.**

FACT: The fear of side effects is one of the primary reasons for people to refuse vaccines. All the vaccines present in the market are lab-tested and the ingredients present in them are medically approved, making them safe for human use. Vaccines are manufactured to protect a human body from illness and nothing else.

MYTH: 04 | **Vaccines are anti-religious and poisonous (contain traces of mercury).**

FACT: While religious beliefs are subjective, there is no scientific research till date to prove that mercury that is added as a preservative only in trace amounts can prove to be dangerous to health.

MYTH: 05 | **Vaccines induce infertility in both men and women, especially the vaccines for COVID-19.**

FACT: Possible vaccines and those undergoing clinical trials are being monitored by the WHO. It is also false to say there are different gender-specific COVID-19 vaccines. The claims about infertility chemicals are highly misleading, and appear to have been taken from decades-old studies on completely unrelated topics (Staff 2020)[14].

MYTH: 06 | **Diseases can be prevented through hygiene and sanitation instead of vaccinations.**

FACT: While hygienic habits and healthy living conditions can help against infectious diseases, there are infections that spread despite maintaining hygiene and cleanliness. Avoiding vaccination will only make the preventable diseases return and may turn fatal.

MYTH: 07 | **Vaccines can overwhelm the immune system, thus rendering it ineffective.**

FACT: A child is exposed to far more antigens from a common cold or sore throat than from vaccines. There are no side effects on a child's immune system due to vaccination. In fact, multiple vaccines act as a better mechanism to build strong immunity at an early age. The immune system can never saturate as cells are constantly being replenished and vaccines further strengthen it to fight diseases.

MYTH: 08 | **Administering vaccines during pregnancy may harm mother/child/both.**

FACT: Immunisation is part of preventive medical care and flu shots are extremely important for pregnant women as catching flu during pregnancy can lead to serious pregnancy complications like preterm labour and preterm birth.

1.3. Case Study- Misinformation on Vaccines in Malappuram District, Kerala

According to the WHO, vaccine hesitancy is defined as a reluctance or refusal to vaccinate despite the availability of vaccines. Like in the Western nations, vaccine hesitancy has been a cause of concern in India as well. For instance, one of the main reasons for five times low uptake of oral polio vaccine in the early 2000s among poor Muslim communities in Uttar Pradesh was the fear and the misconception that the polio vaccine caused illness and infertility, and that is was ineffective (Prasad, 2019)[15]. When it was introduced in 2017, a dip in vaccine uptake was noticed even in states like Karnataka and Tamil Nadu, which otherwise have high vaccine uptake.

Vaccine hesitancy was sufficiently high in certain districts of Kerala to render community immunity a challenging goal. The following case study is the curious case of Malappuram district in Kerala where, in 2017, there was significant resistance during the MR vaccine drive. With the sudden rise in cases of diphtheria and measles, the state government was rendered clueless as to how to tackle the danger in store. According to news reports, some people in Malappuram, where Muslims make up over 70% of the population, opposed the vaccination saying it was a 'Modi-RSS vaccine'—a political conspiracy—when an audio clip went viral claiming rumours targeting Muslim population (Subramani 2018)[16] (Patel 2020)[17]. It was believed that the vaccine injections made the Muslim population impotent; that the globally-banned MR-VAC vaccine against measles and rubella was a Modi government-RSS conspiracy to regulate the population growth of the Muslim community. Driven by fake news (including that the vaccines are derived from animal tissue and pork-based gelatine, making it haram or forbidden), vaccine coverage has been abysmally low in states with high Muslim populations until May 2017: 77.2% in Lakshadweep (96.58% Muslim population), 84.6% in Kerala (26.56% Muslims), and 87.92% in Manipur (8.32% Muslims). The District Health Department staff had to face angry protesters (News 2016)[18]. A group opposing vaccination twisted the arm of a nurse (Varma 2017)[19]. As a result, parents of more than 2,40,000 children refused to give their children the combined measles, mumps, and rubella (MMR) vaccine and thus, the immunisation drive was stalled for two months (Deepika Khurana 2019)[20]. The viral

> *When the District Collector issued orders from time to time denying chances for the vaccine baiters to proceed, the health officials made best use of social media to reach out to the masses with correct information and to weigh down the negative campaigns.* ***(The Hindu)***

wave of fake news on vaccines causing infertility was felt in states like Gujarat and Maharashtra as well, where inoculation drives were halted in many schools.

Despite the religious orthodoxy, conspiracy theories, superstitions, and lack of information and trust in modern medicine, Malappuram had not lost its momentum. The district has soared to 92.5% immunisation coverage in 2019 from a mere 57% in 2017 and has been further exempted from the central government's Mission Indradhanush, a vaccination drive with an aim to achieve 90% vaccination across the country (Naha 2019)[21]. This staggering feat was possible through the efforts of the Health Department to involve and coordinate with various stakeholders including the district administration, district panchayat, grama panchayats and municipalities, mass media, police, NRIs, religious groups and leaders, students, teachers and parents, voluntary and non-government organisations, and doctors' bodies like the Indian Medical Association and the Indian Association of Paediatrics. Vaccine resistance was cleverly circumvented through persistent means of awareness programmes. According to a report by The Hindu, "When the District Collector issued orders from time to time denying chances for the vaccine baiters to proceed, the health officials made best use of social media to reach out to the masses with correct information and to weigh down the negative campaigns" (Naha 2019)[21].

Medical misinformation and vaccine hesitancy have been growing exponentially and have become alarming public health concerns, putting the lives of countless children at risk. In this context, we interviewed Dr Shimna Azeez, who has been the face of the immunisation campaign wherein, during an awareness campaign at a school in Kondotty, she accepted a parent's challenge to inject herself the vaccine to prove its safety and efficacy (Varier 2017)[22].

1.4. Expert Speaks

Dr Shimna Azeez, a doctor at Manjeri Medical College, Malappuram and widely read author in print and social media, has been the face of the Kerala Government for various community health initiatives including multiple pro-vaccination campaigns and COVID-19 awareness drives. Despite being the most literate state with a good track record on health indicators, the critical challenge identified in Kerala is that misinformation is deeply rooted in the cultural and religious sentiments through tight-knit family hierarchical structures. This accompanied by the lack of scientific temper among the families to not question but consume content on various social media platforms has only resulted in rapid penetration of misinformation and misguidance in vaccine hesitancy.

Excerpts from the interview

DR SHIMNA AZEEZ

She is a Public Health worker from Manjeri, Kerala. She is a published writer who has two popular books to her credit, and a social media influencer who is widely read online and in print media. A pro-vaccination exponent, she has been the face of the Kerala Government's pro-vaccination campaigns, and multiple COVID-19 awareness drives. Dr Shimna has been involved in various community health initiatives including the Kerala Government's Measles-Rubella Vaccine Campaign in 2017 and medical camps during the mega Kerala floods of 2018 and 2019.

01 What are some of the crucial challenges with immunisation coverage owing to misinformation in Kerala?

In Kerala, we are an extremely educated and significantly different society; our health indicators are better than the rest of the country. Even with the coronavirus, we have been a step ahead. Social media is saturated by sugar-coated messages and are easily accessible to everyone. When it comes to immunisation, they are very attracted to conspiracy theory because it is easy to follow, so much so that they prefer WhatsApp forwards over doctors or science. Thus, misinformation has nothing to do with intellect but rather the belief system of the people. Other potential challenges include misinformation that is in local slang that is easy to consume, and people do not have the scientific temper or the inquisitiveness to question things. They blindly follow what the misinformation leads on to. On one hand, there were rumours of infertility and vaccines causing cancers while on the other hand, there was the issue of religion—multiple groups were against vaccination because if it's God's prerogative to give the disease, then vaccination would imply interfering with the work of God, thus making vaccination an act that is unfaithful to God.

Also, given that out-of-pocket health expenditure is higher in India, the common man is always on the lookout for easy solutions or cures that are easily available through misinformation.

02

Why was there so much resistance to vaccines, specifically in Malappuram, compared to other districts in Kerala?

In our district, family structures are a little tighter with a higher proportion of Muslim population—these are essentially the main factors that backlashed the vaccine campaign here in Malappuram. But with open discussions and communication, a lot of people had come forward seeking vaccinations. Also, this is a difficult ground for science to grow, especially because a lot of quacks spouting pseudo-science take our place. Despite this, we have managed to communicate with people and there have been good results here. It was definitely a difficult task, but we did attain our MR vaccination goals.

03

What is the effect of alternative medicine in Kerala? People tend to believe in alternative medicine than in modern medicine. Owing to the lack of scientific evidence, it is even more difficult to weigh in the effects of traditional medicine. According to you, what kind of misinformation is prevalent and is there more misinformation in alternate medicine?

In most of the cases, there is a lack of scientific evidence and people tend to have a notion that all modern medicines have side effects, but the fact is that even disproportional use of authentic Ayurvedic medicines can lead to side effects (verified by qualified Ayurveda practitioners). There is unwanted hatred towards modern medicine owing to the issues with negligence and mistrust in our hospitals (owing to low healthcare budgets). In fact, professional Ayurvedic practitioners have the courtesy to redirect their patients to modern medicine when the issue cannot be treated through alternative practices. Recently, there was misinformation around Homeopathy preventive medicine for COVID-19 which was circulating in the market. Ayurveda tends to attract a lot of unwanted popularity. Anything that is leaf and root does not qualify as Ayurveda; it has its own traditional methods that are not tested scientifically like that of modern medicine. Therefore, while one should respect alternative medicine, it must not be administered without scientific evidence. Its use must be limited, and people should not fall prey to the quacks in the market.

04

Kerala happens to be one of the most literate states in the country with good health indicators and even in such a state, people are falling prey to misinformation. So, how deep do you think is the problem of misinformation when compared to other states?

Misinformation has become a real menace. It is a deep-rooted problem that runs in extremely close circles like family, friends, religion, and other sentiments that cannot be questioned. However, the younger generation is using social media widely and wisely, and they do have the ability to differentiate right from wrong and educate their families. Therefore, it has nothing to do with literacy or how well-informed families or health indicators are, but misinformation has penetrated our cultural beliefs and systems. In Kerala's society, there is a large proportion of expats in the Middle East who aid in the spread of such misinformation on social media and WhatsApp groups through rapid sharing in their free time, post work hours. They also share the misinformation from their respective countries and mix it with the culture back home, making it even more difficult to distinguish the misinformation. There is no direct link between education and spread of misinformation; fundamentally, human beings are emotional and not scientific in nature. Social media uses this psychology to make an impact and that is what makes identifying and combating misinformation more challenging.

05

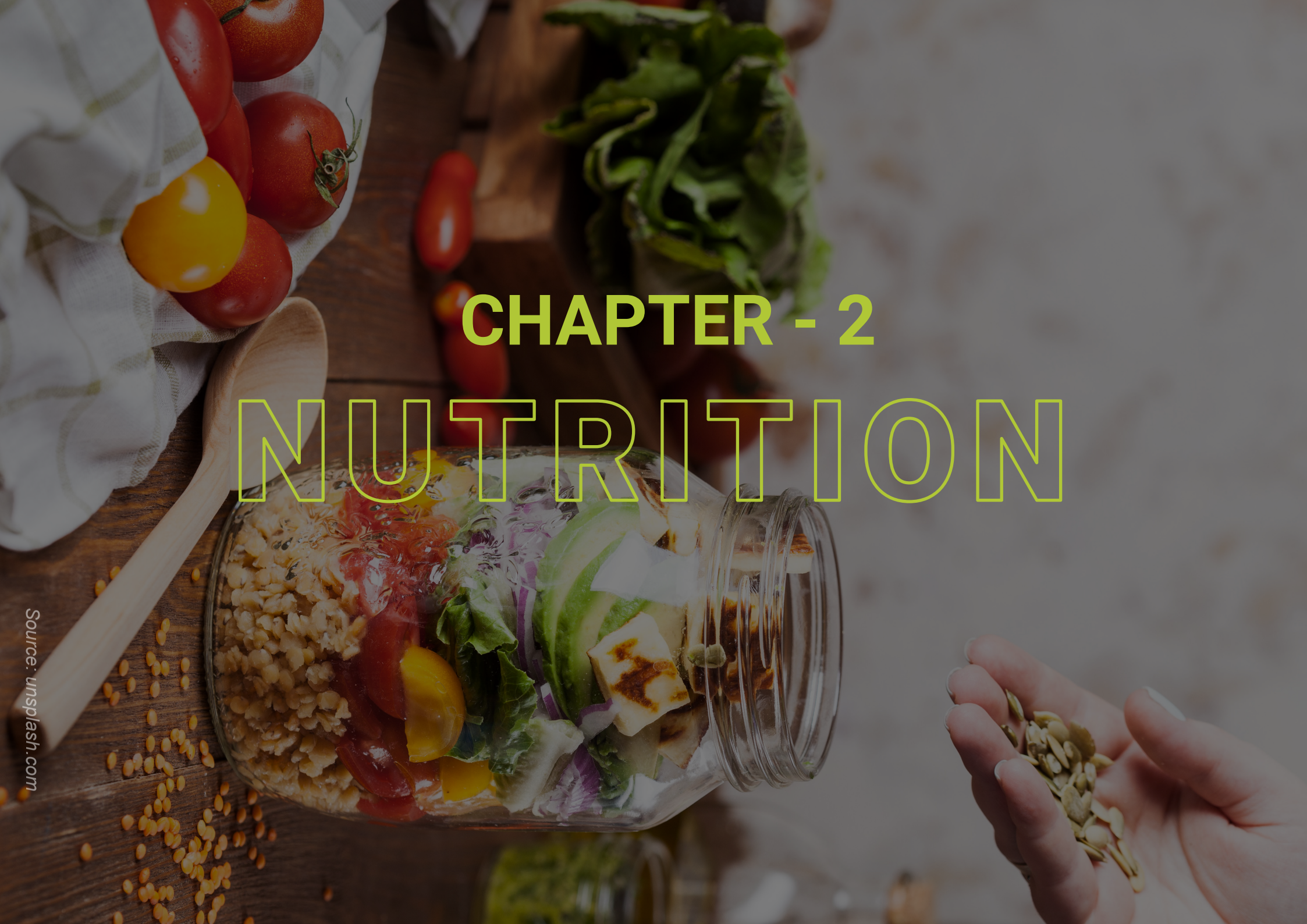
Considering the problem runs deep, what kind of strategies should the Centre and state governments adopt to tackle the problem?

People have unlimited access to the internet, but that freedom should not be absolute. Of course, governments must intervene in regulating content; why I say this is because you cannot stop anyone from posting content but once posted, there must be consequences, considering that especially, shared misinformation tends to have an impact on others. Stringent action must be taken, especially against those who post unnecessary and unverified information. Unlike other types of misinformation, health misinformation can have detrimental effects in terms of ignoring proper treatment. This strict action should correct others' behaviour and accordingly, pause and take a step back before sharing. We have laws for everything, it is all about implementation, and such actions will set a precedence for others.

1.5. Conclusion

Misinformation around vaccination is often associated with adverse public health consequences, including serious disease outbreaks and epidemics. Moreover, vaccine hesitancy has always been a convoluted issue, since the myths/conspiracies touch the most delicate chord with people, which is the safety of their children. In addition to the need for more educational material for healthcare workers, vaccination strategies need to be contextualised (Rajasekharan K Nayar 2019)[23]. The challenge is to combat the deep-rooted psychological and emotional needs of parents, leaving little room for health officials to manoeuvre short-term solutions. Even for the Kerala Health Department, it was a long game, but within two years, the tables have been turned. The strategy was to leverage the same social media platforms as an opportunity to promote and propagate vaccination knowledge just like the misinformation propagated by anti-vaccine groups. One such effort has been undertaken by Dr Shimna Azeez along with a group of other doctors, who started Info clinic, a Facebook page in the regional language (Malayalam) to combat health misinformation in Kerala (Azeez 2016)[24]. Although misinformation/misleading content is extensively shared, this initiative with the tagline, "The cure for Ignorance is Knowledge", is a starting point for the combat. The page has seen a consistent increase in its reach to wider audience, thus solidifying the way forward—that a strong communication strategy encompassing awareness and debunking campaigns is the only tangible way forward in addressing health misinformation.

In our experience, there is no one-size-fits-all approach, specially to combat medical misinformation. While existing and introducing new laws such as the amendment of the Kerala Police Act that provides for a five-year jail term for any social media or cyber post that is deemed 'offensive' or threatening can be a plausible way forward, it becomes discretionary and often short-sighted in implementation (Philip 2020)[25]. Therefore, it is important to perceive vaccination strategies beyond short-term goals and it becomes crucial that contextual social realities are understood, i.e., each state should identify, define, approach, and combat vaccine hesitancy through proper and feasible communication strategies to succeed in the long run.



CHAPTER - 2

NUTRITION

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2.1. Literature Review

Hunger, under-nutrition and malnutrition continue to plague the developing countries and this is especially true in the Indian context. Despite India's rapid growth development, it faces a triple challenge with the burden of under-nutrition and communicable diseases on one end of the spectrum, while on the other hand is the challenge of over nutrition, non-communicable diseases and micronutrient deficiencies. These extremities are the manifestation of a growing inequality. In fact, India has been identified as the country with the highest rates of domestic inequalities in malnutrition. Therefore, it becomes critical to address this problem at its intersection that can further perpetuate poverty and undermine economic growth. Case in point being, according to the Global Nutrition Report, India is among 88 countries that are likely to miss global nutrition targets by 2025 (Report n.d.)[26]. In fact, India is set to miss targets for all four nutritional indicators for which there is data available, i.e., stunting among under-5 children, anaemia among women of reproductive age, childhood overweight and exclusive breastfeeding (Correspondent 2020)[27]. Over half (51%) of Indian women of reproductive age (15 to 49 years) are anaemic, mostly caused by nutritional deficiencies, with six in 10 women in India facing the risk of anaemia, according to the Global Nutrition Report (Correspondent 2020)[27]. India is distinguished as among the three worst countries, along with Nigeria and Indonesia, for steep within-country disparities on stunting, where the levels varied four-fold across communities.

While the overall investment on nutrition research is still limited, IFPRI notes that, "Far too many people around the world are afflicted by the triple burden of malnutrition—the coexistence of undernutrition, micronutrient deficiency, and overweight and obesity (IFPRI n.d.)[28]. Failing to ensure good nutrition in the critical first 1,000 days of life (from conception to a child's second birthday) harms children's physical and cognitive development and can have other lasting consequences, including undereducation and lowered economic productivity." However, the sector is fundamentally driven by challenges in multiple sectors and there arises a need to develop contextually relevant, high-impact strategies to tackle the triple burden of malnutrition.
In a sector that is already burgeoning with its own set of challenges, the widespread prevalence of misinformation is not only under-debated but a huge matter of concern affecting the balance of lifestyles. Constant misbeliefs are directly influencing a conscious under-consumption of protein in the daily diet. According to survey findings by Right to Protein in collaboration with research agency Neilsen, over 70% of the mothers surveyed held incorrect beliefs that protein is hard to digest, leads to weight gain, is unaffordable and is only required by physically active people (Itapu 2020)[29]. On the supply side, over 85% of the mothers agreed that they would value carbohydrates and multivitamins over protein consumption while the demand side is bridled with food brands' labelling misinformation (e.g. MSG, salts in Maggi noodles), wrong claims on zero trans fats, sugar content in honey, etc. (Sivani 2015)[30] (Barman 2020)[31].

2.2. Common Myths and Misconceptions

MYTH: 01 | **Protein is hard to digest, leads to weight gain and is not as vital as vitamins or carbohydrates.**

FACT: Haemoglobin, a primary carrier of oxygen in the blood, is, in fact, a protein and thus, protein in the diet becomes utmost crucial. Proteins are also crucial for body growth, muscle strength and its recovery, can act as neurotransmitters, and are vital for muscles, skin, bones, and hair.

MYTH: 02 | **Protein only comes from a non-vegetarian diet/Proteins are unaffordable/expensive and only required by physically active people.**

FACT: A plant-based diet comprising vegetables, beans (soybeans, black soybean), grains, nuts, and seeds can adequately meet the suggested protein intake,meaning that there are several affordable options available to vegetarians.

MYTH: 03 | **Lemon-water is a quick fix for fat loss.**

FACT: While lemon juice contains Vitamin C and small amount of micro-nutrients, the lemon water merely restricts the calorie intake but there is no evidence that lemon water can result in fat-loss (Ashok 2019)[32].

MYTH: 04 | **Food fads and fad diets promote weight loss.**

FACT: Often, these trendy diets may be popular for short periods of time. Most fad diets promote quick/short-term weight loss by promoting ideas of consuming (or not consuming) certain food items & supplements without taking into consideration the required macro & micronutrients for the body (L. Bellows n.d.)[33].

MYTH: 05 | **Carbohydrates are bad for health.**

FACT: Carbohydrates which are naturally occurring sugars, starches and fibre have been blamed for weight-gain problems. However, it must be noted that carbs are an essential energy source for the body and must be consumed in limited yet adequate amounts for sustained energy.

MYTH: 06 | **Eating fats always leads to weight gain.**

FACT: Balance is the key to good nutrition. Although comsumption of lesser fat is better, one must not eliminate fat from their diet, given that healthy monosaturated fats are required to absorb vital nutrients in the body.

MYTH: 07 | **Eggs increase your cholesterol.**

FACT: Eggs surely contain cholesterol. However, people with high blood cholestrol and cardiovascular diseases can consume eggs in limited quantity. In fact, eggs help in providing other nutrients to the body and help reduce weight. People with high cholestrol must instead limit the amount of saturated fat consumption.

MYTH: 08 | **Non-nutritive sweeteners are healthy.**

FACT: On the contrary, non-nutritive sweeteners may lead to adverse health outcomes, such as an increased risk of type-2 diabetes, negative changes to gut bacteria, and promoting blood sugar dysregulation.

2.3. Case Study- Superstition of Daagna in Umaria, Madhya Pradesh

The perils of hunger can be witnessed in the small district of Umaria, home to the Bandhavgarh National Park. The following case study is a gruesome evidence of malpractice which has its roots in superstition. Despite increasing administrative pressure and targets to address malnutrition, NFHS-5 fact sheets hold distressing truths and further highlight the diminutive progress made in tackling the issue of malnutrition (Welfare 2020)[119]. With persistent cases of respiratory issues including pneumonia, cold and malnutrition, the village has resorted to superstition instead of science. Daagna is a ritual where the village elders or local healers, in case of malnutrition, singe the sick child's belly with hot iron, a piece of bangle, sharp end of a sickle or neem wood in the hope that it will bring relief to the child's problem. However, things started to change when the district collector Swarochish Somavanshi decided to take things into his hand. "The practice has a direct connection to nutrition—poor nutrition leads to kwashiorkor, which results in a protruding belly, and marasmus, which causes stomach shrinkage, thereby increasing the chances of their being subjected to daagna. There have been cases where hot iron was put on genitals", said Swarochish Somavanshi in his statement to Outlook (Ahmad 2020)[34]. By then, over 500 children were found to have been singed through daagna in Umaria. The cruelty continues, since the child not only suffers from malnutrition, but is further deprived of any medical attention in the belief that the burning will eventually heal them. This is, in fact, quite dangerous since the serious wound inflicted on the child can prove to be fatal.

> *With no scientific evidence, children were subjected to this brutal 'cure' called Daagna to cure their problems of malnourishment.*
> *(Ahmad 2020)*[34]

In this regard, the District Collector launched Project Sanjeevani which entailed regular examining of children. Mangal Diwas was celebrated in the region every Tuesday to check on the nutrition status and that the children were not being branded by the practice. The initiative was an opportunity to cater to and provide necessary healthcare for malnourished and underweight children in the region.

2.4. Experts Speak

DR SHWETA KHANDELWAL

She is a trained and experienced public health nutrition researcher and serves as the Head Nutrition Research at the Public Health Foundation of India (PHFI). She serves on several expert government panels constituted by FSSAI and MoHFW including oils and fats, sustainable healthy diets, and combating high fat, sugar and salt in Indian population. She is currently the Program manager for India Taskforce and Lancet COVID-19 commission.

DR SUBBARAO M GAVARAVARAPU

He is Scientist E and heads the Nutrition Information, Communication & Health Education (NICHE) Division at ICMR-National Institute of Nutrition. He has widely researched and published in the areas of health, nutrition, and food safety communitarian. He is on the editorial board of the Journal of Nutrition Education and Behaviour; review editor for Frontiers in Communication; and has served as Asian Editor for American Journal of Health Behaviour. He chairs the Health Communication Working Group of International Association of Media and Communication Research (IAMCR), serves on expert committees of FSSAI, Codex, UNICEF, and some universities. He is a fellow of the National Academy of Agriculture Sciences (FNAAS) and Royal Society for Public Health (FRSPH), UK.

01

In your research, has there been evidence on misinformation or myths that have affected the outcomes of nutrition? If so, can you please describe in detail the nature of such misinformation/myths?

Dr Khandelwal: I have personally not undertaken any research on health misinformation, but I do have general knowledge and can summarise the research evidence on this. Like Dr Sowmya Swaminathan has written on the 'infodemic', when people do not know what and where to access correct information, they consume everything given to them. This is a definite concern for Public Health Nutrition - they access videos and posts on WhatsApp and believe that Vitamin C is the cure for everything, or a yoga posture will heal ailments. Please know that such random advice can actually do more harm than good. It is important to take advice from certified professionals or confirm what you have found out with the help of experts in the field. However, I can't speak from first-hand knowledge as I have not done direct research in the area of misinformation.

Dr SubbaRao: We do come across a lot of misinformation related to nutrition. It is not necessarily misinformation, but it is often unverified information being given out in some media. We encounter misinformation on a day-to-day basis. It could be as simple as highlighting or projecting a single nutrient or a food item as a panacea for different problems, which is against the basic tenet of describing nutrition as a holistic approach. For example, with COVID-19, you would have seen people talk about pepper being good or ginger as something that builds immunity; but eating only ginger or adding ginger to your regular meal does not, in any way, directly protect one from infection. Of course, it could regulate immunity a bit, but when taken in, its association with other foods matters. Such partial information is unauthentic. Therefore, it doesn't tantamount to deliberate misinformation, but as it is not scientifically validated information, it can be categorised as misinformation. The infodemic also witnessed misinformation, imposter content, sometimes disinformation, or sometimes even all these together.

02

What are some of the major challenges in the nutrition sector faced by the following risk groups:

Dr Khandelwal:

2.1. Nutrition challenges for pregnant women

This is an important question from the nutrition, health and economic standpoints given that they give birth to the future citizens. So, it is imperative to acknowledge their importance but the buck must not stop at the pregnancy, but give equal weightage to early childhood development.

The nutritional challenges arise mainly because of loss of livelihoods or fear of infections since that will impact what and how much they will eat. For instance, some people assume that packaged food is safer than fresh fruits and vegetables sold by hawkers, so such decisions alter their nutrition preferences, which is usually for the worse. Access to timely and routine antenatal care has also been highlighted quite a bit. The help/rest at home is also usually compromised given their financial status and the fact that their access to domestic help is almost negligible. In addition, a nutritious meal takes a lot of ingredients, time and effort, and it becomes even more daunting if the expecting mother has other children to take care of. Even with breastfeeding, despite constant advertising and WHO guidelines, there is hesitancy, especially in the COVID-19 times. Mothers do not want to take that risk so they ultimately opt for formula milk which is not completely healthy/nutritious. To summarise this, the barriers to nutrition are lack of livelihoods (thereby leading to lack of incomes), lack of rest/help, routine antenatal care, stress-free environment, nutritious meals, and proper breastfeeding.

2.2. Early Childhood

There are 6Es that I'd like to focus on here:

1 Early Childhood Development- As we know, India ranks high in several childhood health indicators including wasting, stunting, low birth weight, etc. The first 1,000 days are crucial for children and they have to be provided with ample opportunities to grow. This has been a huge challenge for India and it is important to address this through innovative and culturally acceptable methods to grow, stimulation strategies, optimal nutrition, and healthy growth opportunities. But unfortunately, children are often not in the radar and we have focused only on certain issues like weight gain for AWS and government functionaries. Thus, approach towards early childhood must be more inclusive. The first few years are extremely crucial for healthy, optimal cognitive growth, and feeding only biscuits and milk is detrimental to it. Thus, the focus must be on healthy food including healthy proteins, healthy fats, and micronutrients. As per the current reports, the diet diversity for children is one of the worst.

2 Education & Expression- Education influences choices and decision making. Thus, it becomes a crucial indicator in the nutrition sector. As per Pratham reports, the education indicators reflect the true and disturbing state of the current education system. And COVID-19 has only made it worse by leaps. Children should be well exposed to skill-building exercises, technology, toys to play with, creative art forms to push their boundaries of imagination in different ways, and especially physical activity. This is important considering the fact that child marriages and child labour are still prevalent in India.

3 Equity- UNICEF defines equity as a fair chance for each child. Whether it is a gender, caste or religion issue, COVID-19 has only pushed the boundaries of these further.

4 Environment- Discussions on any sector is incomplete if the sustainability aspect is left out. Whether it is water distress, air pollution, or water and sanitation hygiene, it is important to provide optimal environment to nurture their growth. Thus, we have to use resources sustainably for the future generation. Therefore, it is a two-way street and we have to be cognitive of this fact.

5 Emergency Preparedness Services- When COVID-19 struck, we were struck hard. In fact, we still do not have answers as to what to do and how to improve the access. This kind of unpreparedness proves detrimental to the work that has been done so far for all these years. How many policies are pandemic/disaster resistant? And you'd be surprised to learn that 95% of these policies do not even mention the word 'disaster' in their briefs. It is here that the government must be applauded that in a quick span of time, they pulled out and provided guidelines like the Ministry of Women and Child Development did. We must enhance and strengthen emergency preparedness services.

6 Economic Commitment- Economics and financial burden must be in tandem to achieve any kind of goals. Nutrition has garnered this kind of attention only in the last decade through national and international aid, but the economic commitment is still vague, unclear, and masked under other schemes. Other domains like HIV have definitely had better economic commitment but issues like nutrition, whose effect is seen in the long term and probably 20 years later, does not get enough economic commitment. Thus, it becomes pertinent to provide economic commitment at the early stages and provide nutritional opportunities for the mainstream children to grow equally.

Dr SubbaRao: In the Indian context, undernutrition persists. Stunting and wasting persist despite concerted government programmes and a lot of efforts from a range of other stakeholders, including NGOs or research organisations and academics. If you see the upcoming data of NFHS-V, you can see that there is some reduction in stunting among children, but it is not commensurate with the kind of efforts we are putting in. Similarly, among micronutrient deficiency disorders, there is anaemia. It persists as a big problem among women, especially of reproductive age, who in turn pass on undernutrition to the next generation not just in terms of iron deficiency (anaemia), but also in terms of low birth weight of the children. The impacts of this follow through in the subsequent phases of life. If the child happens to be a girl, then she grows up to be an undernourished adolescent and an undernourished mother who passes on these issues to the next generation and thus the cycle continues. If you see the upcoming NFHS data, you can see that there is a definite increase in overweight and obesity in many states. There are states where obesity increased by about 2-3% in the last

five to six years, and there are states where it has gone up by as much as 11%. On an all-India basis, we are witnessing an increase in overweight and obesity. The coexistence of the dual challenges of undernutrition and overnutrition is cutting across all economic categories now, and also, micronutrient malnutrition, especially of iron, zinc, and folate, are coexisting in the Indian population and that's a bigger challenge for us to handle. Again, consider the existing challenge of low birth weight among children, i.e., children born below 2.5 kg at birth. Three decades ago, it was about 30% and today, it stands at 26-27%, which is almost the same, despite all our efforts. And of course, there are several other problems like not initiating exclusive breastfeeding soon after the birth of the child. While the progress on some of these issues is optimistic, they are not commensurate with the efforts that we are putting in.

03 What kind of large-scale behavioural change communication intervention is to be designed to combat misinformation in maternal and child nutrition?

Dr Khandelwal: We usually tend to focus a lot on delivery but not on implementation, and implementation is of paramount significance. Change will come only through a combination of people-centric policies, programmes using a participatory approach, working with the communities, involving women through SHGs, and working together to make them understand the objectives, and accordingly, the goals will be met. My two cents here are:

1. Models are available, but they need to be customised and use local evidence and capacity to address the community's needs. The community has to be in the driver's seat to be able to make things more relevant for them.

2. Use mass media for communication, i.e., a community participatory approach.

3. Local solutions, local leaders and local evidence for catering to local problems- This will enhance uptake and optimal utilisation of services or interventions designed to improve MCH and nutrition.

04 Misinformation around food is an under-debated topic. So, how should we start an effective conversation around it and inform people to consume the right diet?

Dr SubbaRao: In my experience as a communication researcher in the field of nutrition, what I often come across is that people always look for easy remedies to their problems. If somebody says that having a particular food items helps one reduce weight, or that having green tea helps one burn calories, what it means is that they don't want to do what actually needs to be done to

burn calories. The best way to go about it is to endeavour to develop certain necessary nutrition life skills among people: First, choose wisely from what is available in your area in the given season. Dispelling the myth that good nutrition is always costly is necessary. Second, nutrition should be taught as a life skill, and it can start in schools. Second, like you learn swimming and cycling, you should also learn nutrition and that it is no rocket science. I think the new National Education Policy can give ample scope to enable this learning and prepare our kids towards building the nation. Third, the media also has a great role to play. While the media has its own interests in terms of ad revenues from the food companies, they can promote healthy living including foods like fruit, vegetable, fish, meat and eggs on a regular basis through social service advertising. I think these three steps can be taken up immediately as a national movement. The Agriculture Ministry and/or the WCD are currently, I believe, in the process of documenting different foods that are available in different parts of the country along with their nutritional values. If we have that database, we can draw a roadmap of a nutritious diet based on what is available in a certain region. Take exotic fruits like dragon fruit or kiwis, for example. These are not needed in our regular diet. You can find easy and simple alternatives from what is cheap and locally available. In fact, one of the studies conducted by the NIN has shown that adding 25 grams of guava in the mid-day meal improved iron absorption and haemoglobin levels among children. The media must cover stories like these and such initiatives can help go a long way in improving children's diets. Therefore, it is significant to not only provide people with the right kind of information but also make these things available, accessible, affordable, and approachable to people.

05

Considering the problem runs deep, what kind of strategies should the state governments adopt to accelerate the reduction in nutrition deficiency?

Dr Khandelwal: We propose a F-O-O-D F-I-X to accelerate India's attainment of Swastha Suposhit Bharat vision (Bureau 2019)[35].

Fix food systems and accountability issues for making healthy diets accessible to all – oppose conflict of interest and uphold public health and nutrition. Access to healthy food and human basic needs- opportunity to maximally tap the human potential, uncompromised growth and development coming from food and nutrition security, clean drinking water, education, safe pollution free environment, etc. Financial levers by politicians- encourage favourable price packaging promotion placement.

Opportunity for win-win engagement education, empowerment of consumers at all levels – This will not only motivate masses to make informed choices but to help understand the implications. Parents are usually running out of time. Quick fixes from markets and food systems thriving on cheap calories from ultra-processed foods are predisposing us towards malnutrition, especially childhood obesity. To have an effective Jan Andolan, start early and start nutrition education everywhere possible – public places, schools, workplaces, hospitals, even prisons. Use of multimedia should be to spread positive nutrition messages around how to choose healthy and not merely to advertise high fat, sugary and salty ultra-processed foods. Education modules or media stories should be impactful and pegged to provide guidance for all actors.

Orchestrate multi-sectoral policies on food and nutrition security and promotion of health food is increasingly understood as an interconnected system involving multiple sectors, but policies targeting different parts of the food system are typically made in isolation. Poshan Abhiyaan has tried to bring together 17 or more ministries and departments to develop strong, cohesive policies. However, inter-ministerial coordination and smooth functioning remain challenging. Efforts to improve processes around priority-setting, meeting timelines, fund allocation, disbursement, documentation, and robust monitoring must be continued.

Develop, design, document local solutions for local nutrition problems while imbibing wisdom or direction from published work or interventions. Align life-course perspective for healthy living by use of robust technology, sound feedback loop for queries, suggestions, strong independent, monitoring. One problem's solution should not fuel some other issue, and this can be checked by taking everyone together and making each voice heard. Push for transparency, open access of nationally collected data to researchers and academia.

Focus and forward work on benefits of healthy diets on all forms of malnutrition- Several economic benefits have been discussed (e.g., $1 investment yields $16-18 returns). The vulnerable need more attention and urgent action.

Invest in and incentivise capacity to do research and pilot interventions around healthy diets – In addition to philanthropies and private donors, it is important for the government to accord priority to train and/or upgrade the skill set of their programme personnel. In addition, partnerships with academia and research bodies should be established and used symbiotically. Financial help must be earmarked for testing innovative ideas and/or scaling up as necessary. Without trained staff and upgraded technology, we will not have far-reaching, sustainable and replicable impact on public health and nutrition.

Exchange case studies, document success and failure lessons to build a robust evidence pool –Trained teams must collate good, quality evidence and feed into the government system. High-quality reviews should be commissioned or periodically conducted and used in planning new ideas or improving the course of ongoing action.

06 Has your research covered food and nutrition misinformation that can be a serious threat to public health?

Dr Khandelwal: My research has not particularly looked at this problem. However, I am aware of the issue through multiple panels and expert discussions. For example, anaemia has been one of the biggest battles for decades and we continue to struggle so at 60-70% improvement. The reason is that there is a lot of misinformation associated with it; this discourages mothers from consuming iron folic tablets, thus seriously affecting public health outcomes. There is also the fat vs sugar debate; people often mistake baked, low-fat foods to be healthy. However, they fail to read the food information and understand the misinformation that the industry is easily masking behind the foods through added sugars and salts. Misinformation has percolated everywhere, and it is important to correct it on every medium possible.

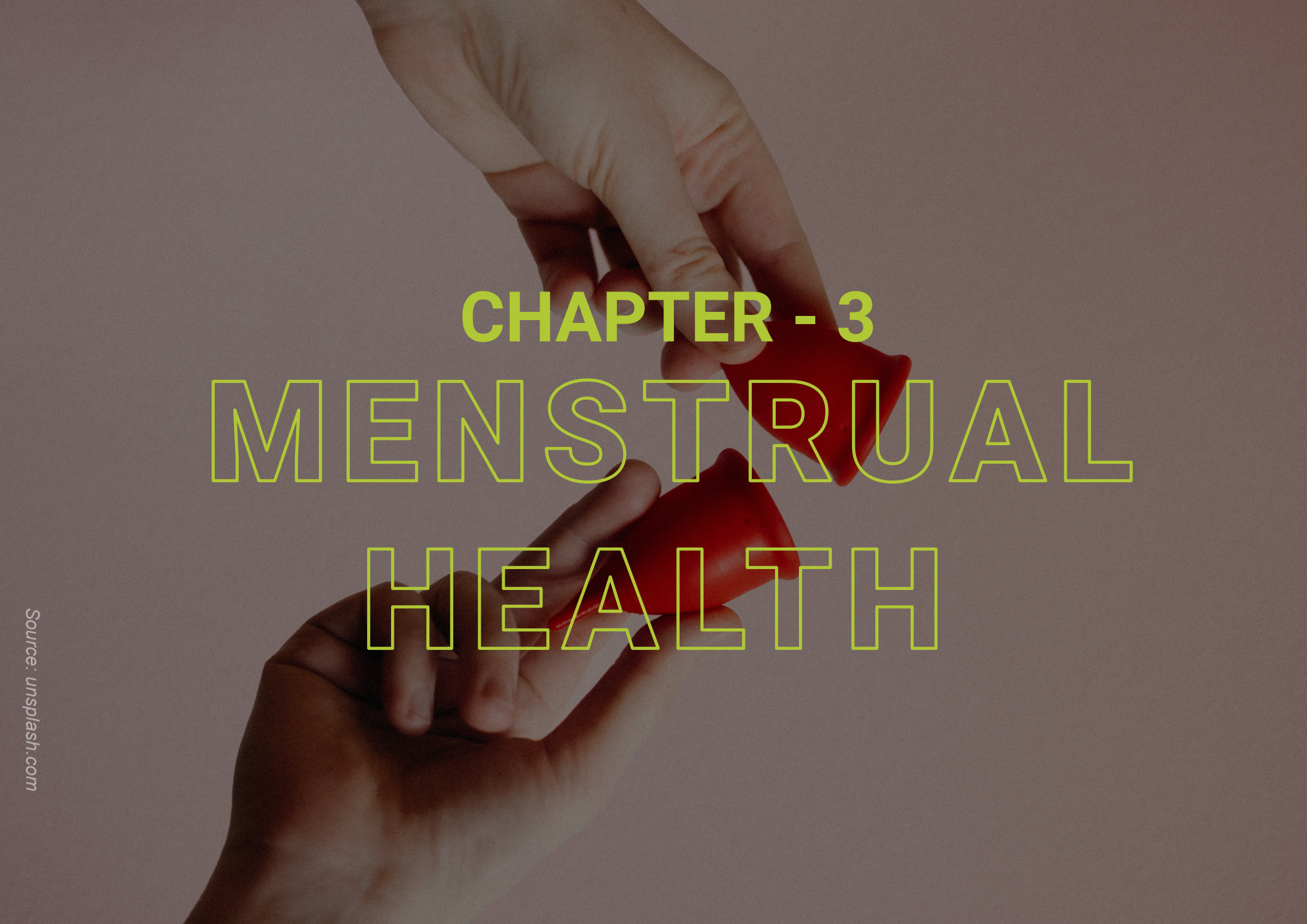
2.5. Conclusion

There is a growing body of knowledge and evidence-based research to support and demonstrate the correlation between diet and the overall health. While nutrition is a convoluted topic with multiple factors, there is no straight answer to the question on how to reduce the nutrition deficiencies among varied groups. However, Dr SubbaRao suggests a way forward:

> Looking at nutrition, especially maternal nutrition or underweight or stunting or anaemia, these are multifactorial, which means they occur not just because of one principal reason like not having a diversified diet. When we say diversified diet, we mean that no one food can adequately give you all the nutrients required for a day. So, one has to have different categories or groups of foods, which will account for diversity, and that diversity will, in turn, we hope, build nutrition. Sometimes, there are also genetic factors at play; a child's nutritional status is programmed right in the stage of being in the mother's womb. So if the mother is undernourished, the child may naturally be born undernourished or with a low birth weight, and can have a catch up growth very easily. But that catch up growth does not necessarily ensure good health. And the child who is born underweight is also susceptible to be overweight or obese or contract non communicable diseases at a later point of time. So, it is multifactorial. Availability, accessibility and affordability of foods for

diversifying diets is to be ensured. Supplementation is definitely one of the ways but it is not the only way. *The long-term goal should be diversifying diets and ensuring a food-based approach* so that people know how to choose healthy and eat healthy. Our approach to combat these problems should also be multi-pronged. One is that the availability, accessibility and affordability of foods for diversifying diets is to be ensured. Food supplementation and fortification are certainly helpful measures but they are not the only way; the long-term goal should be to diversify diets and ensure that a food-based approach is popularised, so that people can choose healthy and eat healthy. Repeated infections among children can also compromise nutrition and these are directly related to WASH (water, sanitation and hygiene). Of course, with initiatives like the Swacch Bharat Mission, many more people have access to toilets and piped water facilities. These definitely will have a positive impact in the long run, probably in the years to come. But as of now, there are a lot of things to handle including continuously endeavouring to increase awareness and prompt action. The most educated and literate people in this country are often nutritionally illiterate. Nutrition literacy is the most important thing that needs to be worked on, and I am sure the media can play a tremendous role in this. One has to be extremely cautious that one doesn't end up highlighting the greatness of one nutrient or a food that results in people looking down upon the greatness of other nutrients or foods. One should take a holistic approach. And of course, there are other aspects to it like physical activity, stress and screentime which do matter for improving the nutrition status of an individual. It's a long story, but it has to begin somewhere.

It is a mammoth task to make a vast sector like nutrition misinformation-proof, especially with the shift of information online from traditional media. While health initiatives have taken the internet by storm, there is still a lack of clarity as to what kind of food can or cannot be consumed. Given the diversity of food availability in India based on season, crops and festivals, a sustainable nutrition guideline is the need of the hour. Proactive efforts must be undertaken to both correct the wrong information on the internet and also have a nutrition strategy in place by the relevant and concerned authorities to guide the people. Nutrition misinformation comes in many forms such as erroneous information, false food labels, misinterpreted labels, and fraud and fad diets. Therefore, in order to correct this misinformation, the media, nutritionists, universities, research organisations, national, state and local governments, and, finally, consumers must work in tandem to think critically and seek evidence-based nutrition information. While it is going to be a long way before all nutritional misinformation is weeded out, it is important to inculcate the habit of seeking the right information about food from the right sources and therefore combat misinformation, so that one can make positively influenced food choices for better public health outcomes



CHAPTER - 3

MENSTRUAL HEALTH

Source: unsplash.com

3.1. Literature Review

The beginning of menstruation pronounces the most integral physiological changes to happen to young women from their adolescent period until menopause. Every month, 355 million adolescent girls and women, i.e., 30% the country's population, face a miserable cycle of pain, distress, discrimination, discomfort, shame, anxiety, and isolation owing to their monthly menstrual cycles (Alexandra Geertz 2016)[36]. Even today, access to sanitary products including pads, tampons and cups is bridled, and often mothers, who are the primary stakeholders and the point of contact for period education, resort to using proxy materials including dried leaves, animal skin, ash, husk, sand, old fabric, rags, wood shavings, newspapers, hay, and plastic, among other unhygienic materials, to absorb the menstrual flow.

Apart from the physiological changes, the phenomenon bears much more implications on the social side, making it one of the most misunderstood subjects guided by stigma, myths, and misconceptions. Obliviousness and superstition deprive adoloscent girls of critical information on menstruation and the importance of menstrual hygiene, so much so that menstruation is considered a sign of illness. Studies show that 71% of adolescent girls remain unaware of menstruation until their first menstrual cycle (Gopalan 2019)[37]. Mothers, who are the source of information on menstruation, have little knowledge to begin with, to impart to their adolescent daughters. Thus, much of the information is imparted as restrictions on movement and social behaviours. The same is reflected in the fact that 70% of mothers consider menstruation 'dirty', perpetuating a culture of shame and ignorance (Masoodi 2017)[38]. According to the National Family Health Survey (NFHS 2015-16) report, only 57.6% of women in India use sanitary napkins—48.5% in rural areas and 77.5% in urban areas (Welfare 2017)[39]. Further, the impact of poor menstrual health and hygiene is often overlooked as a part of the menstrual process but in fact contributes significantly to female morbidity. According to a 2012 United Nations Population Fund (UNPF) study, around 60% of women diagnosed with common reproductive tract infections reported poor menstrual hygiene (Sarah House 2012)[40]. In most parts of the country, menstrual hygiene is deeply deplorable with several issues like itching, whitish discharge, and reproductive tract infections, among others.

Owing to stigma and the lack of sexual education, menstruation knowledge remains limited, leaving many girls with negative and ambivalent feelings and experiencing psycho-social stress, which also impacts their ability to learn, according to a UN study (U. N. Desk 2019)[41]. For example, adolescent girls are made to take off from school and college during their period, forcing them to miss at least 60-100 days in an academic year—girls are typically absent for

at least 20% of the school year, which is the second major reason, after household work, for girls to miss school (Azmat 2019)[42]. On the other hand, 31% of women in India miss an average of 2.2 days of work when they menstruate (Dasra n.d.)[43]. According to a Dasra report, 63 million adolescent girls in India live in homes without toilets (Dasra n.d.)[43]. The report further details that two out of five schools do not have separate toilets for girls. The lack of functioning toilets results in 23 million girls dropping out of school every year. Women in prisons, refugee camps, and in impoverished rural communities are often the most neglected with regard to sanitation practices as they struggle with poor access to water and sanitation (U. Desk 2018)[44]. Owing to the untimely lockdowns and economic collapse during COVID-19, the effects ranged from lack of menstrual supplies (pads, tampons, among other things), to elevated stress levels affecting & distorting the menstrual cycles and related physical, mental & emotional issues. Further research is required to assess the impact of COVID-19 on menstruation across the country. Menstruation has given rise to several physical, psychological, social, economic, health, and environmental concerns.

On the social side, menstruation restricted the social life of over 89.5% students to an extent that one out of five did not participate in social activities or in doing housework during menstruation.

The environmental impact is seen in the fact that a woman throws away 125-150 kilograms of non-biodegradable absorbents used during menstruation in her lifetime (Shrivastava 2019)[45]. Commercial menstrual napkins take 500-800 years to decompose as they are 90% plastic.

The economic cost of such stigma, if tackled well, may ensure that girls do not drop out of school, thus delaying early marriages and pregnancies, having the potential to add $100 billion to India's GDP over their lifetimes. Tackling the challenges of menstrual health and hygiene issue generates a triple return on investment with improved outcomes in education, health, and environment.

3.2. Common Myths and Misconceptions

MYTH: 01 | **Menstruation is a matter of shame and is a result of sin/Menstruation is a taboo and embarrassment, and girls/women should not talk/share about it with others.**

FACT: Menstruation is a natural part of the reproductive cycle in which blood from the uterus exits through the vagina. It is a natural process that first occurs in girls usually between ages 11 and 14, and is one of the indicators of the onset of puberty among them (H. Desk 2018)[46].

MYTH: 02 | **Menstruation implies impurity where the woman must stay separately and not enter the kitchen or temples.**

FACT: Menstruation is merely a natural process and there is nothing impure about periods. The myth that women cannot enter temples and holy ground has been a sensitive issue and a point of cultural controversy. Differential treatment of a natural process creates shame, taboos, and embarrassment towards menstruation.

MYTH: 03 | **-Women should never wash the cloth used during menstrual cycles. It is a sin to throw stained cloth in the dustbin.**
- Bathing and hair wash in the first three days of menstruation is a taboo/ will lead to difficulty in conceiving and mental illnesses.
- Sanitary pads lead to infertility.
- Menstruating women/girls must not touch the tulsi plant as it will wither.

FACT: Cultural and religious norms around menstruation often equate and perpetuate menstrual blood with evil spirits, humiliation and embarrassment around sexual reproduction. The inherent source for these myths is also the cultural belief of impurity associated with menstruation, which is again false. These superstitions are often spread by word of mouth and are passed on from generations of menstrual practices. Thus, owing to the lack of right awareness and education, these traditions/myths continue to persist.

MYTH: 04 | **Touching/eating pickle during one's period will lead to arrhythmias.**

FACT: If general hygiene measures are considered, no scientific test has shown menstruation as the reason for spoilage of any food.

MYTH: 05 | **Girls/women on period must be on a five-day exile and use different utensils and separate beds.**

FACT: Menstruation is not contagious and causes no harm to anyone in the vicinity. This practice was mostly a result of cultural controversy and the lack of supply of menstrual hygiene products.

MYTH: 06 | **Adolescent girls can pass out from period blood loss.**

FACT: Menstruators experience dizziness before periods for a multitude of reasons including iron deficiency, low blood pressure and sugar levels. The fluctuation of hormones, i.e., oestrogen and progesterone level drops, with the start of periods causes an effect on the circulation, leading to a feeling of dizziness. Most women will lose less than 16 teaspoons of blood (80 ml) during their period, with the average being around 6-8 teaspoons, and not faint as a result.

MYTH: 07 | **Girls/women should not exercise or perform strenuous activities during their period.**

FACT: Exercise and playing sports can, in fact, relieve period pains (H. Desk 2018)[47].

MYTH: 08 | **Girls/women cannot get pregnant during menstruation.**

FACT: Periods do not protect women from pregnancy since sperm can remain active in the body for up to three days, meaning that conception during period is possible.

MYTH: 09 | **Girls should not use tampons, menstrual cups, or any other penetrative product during their first periods since it implies losing virginity.**

FACT: Virginity is a social construct and a misunderstood term. The hymen is like a rubber-band at the front of the vaginal opening, which means that it is elastic, it can stretch and can accommodate things. Research suggests that cups or tampons do not affect virginity (Manorama Eti 2019)[48].

3.3. Case Study- Water Wives, an Odd Solution to the Problem of Water Scarcity and Women's Health

It is true that water, or the lack of it, is where our inequalities stand naked. Parched areas with extreme water shortage face the dual challenges of safe drinking water and women's health. While polygamy is illegal for non-Muslims in India, the barren villages of Maharashtra and Rajasthan hold another intriguing story. 'Water wives' is a phenomenon unique to these arid regions and an odd solution to water scarcity problems. In Rajasthan, in areas of extremely scarce availability and accessibility of water, the responsibility of fetching water from the nearest source to one's household relies solely on the woman/women of the house. This 'nearest' source may be 200 metres away or it may be over one-and-a-half kilometre away. Data from the 2011 Census tells us that around 21 million Indian women reportedly walk these long distances for the most basic need—water. This puts the health and safety of these women at risk. As data suggests, a lot of time and energy is spent in bringing pots of water up and down the hills of Aravalli, often traversing great distances. Meanwhile, if the woman of the house fails to do so owing to menstrual health or pregnancy, the man marries another woman specifically to perform the job of fetching water. The men in these areas take a second, and sometimes a third, wife so that their water supply stays uninterrupted.

> *The poor understanding of menstrual and maternal health coupled with the issue of water scarcity has proved to be detrimental to the sanctity of the marriages of the women in these arid villages*

This second woman is usually from a poor family and her family/father wants to get her married off, to relieve themselves of the responsibility. These 'water wives' are often widows or single mothers wishing to 'regain respect' in their communities. The poor understanding of menstrual and maternal health coupled with the issue of water scarcity has proved to be detrimental to the sanctity of the marriages of the women in these arid villages.

3.4. Experts Speak

Ms Bharti is the founder of Boondh (Boondh n.d.)[49], and Ms Ananya Chhaochharia is the founder of Paint It Red (Paint It Red n.d.)[50]. These are among the leading organisations working at the grassroots to combat the challenges of menstrual stigma and to create access to sustainable menstrual products.

Dr Tanaya Narendra, popularly known as Dr Cuterus on Instagram, is an award-winning, internationally trained medical doctor, embryologist and women's health content creator busting medical myths for her half a million followers on social media platforms.

01 What has been your biggest challenge in this sector and how did you/your team deal with it?

Boondh: Evangelisation of the concept of healthier, sustainable and economical consumption, and reduction in usage has been the biggest challenge and continues to be, keeping intact feminist values of agency, consent, and informed choice. Our workshops, information, education, and communication (IEC) language, programmes are all focused on taking all these concepts and values together.

Paint It Red: The challenges in this sector are two-fold. First, the deep rooted stigmatisation requires us to be extremely sensitive in our educational approach. While debunking myths and taboos, we have to be mindful of not disrespecting cultural and religious beliefs. Second, often it can be difficult to create a collaborative space between civil society organisations and government initiatives. There is a lack of understanding of the intersectional demands of the space.

02

A lot of menstrual misinformation tends to be couched in medical terms, which makes in inaccessible to the majority of the menstruators. What has been your experience in busting menstrual myths on social media platforms?

Dr Narendra: A lot of misinformation stems from people who are not menstruators. In my experience, this has mainly been from accounts that are run by cis-men who will say things like the gel in the core of the pad contains something that will give you cancer or wearing a pad for over two hours will make you ill. Yes, of course there's a limit on how long you should be wearing the pad but it's not two hours. It's more like six or eight hours. There are a lot of myths around the use of tampons, that people shouldn't use tampons because they will cause Toxic Shock Syndrome. In my experience so far, it is important that the conversation is very approachable. People don't care for big things like the anatomy of your pelvis. People care about very basic things like can I wash my head on my period? Is it okay if I eat pickle on my period? How long can I use a pad for? Is a menstrual cup going to give me an infection? It's very simple questions that people seek answers to and we don't have to get caught up in making elaborate 15-minute videos or 35-page explanations. We need simple, to-the-point answers that are accessible to people of all levels of intelligence, all levels of socio-economic status, and all levels of comprehension.

03

Mothers, who are the primary stakeholders and the point of contact for period education, often lack the relevant and required knowledge. What has your experience been with this at the grassroots level?

Boondh: This is true. A 'Spot On' report[43] by Dasra stated that over 88% mothers think menstruation is a disease. This is reflective in the way mothers in India perpetuate stigma, taboo, and restrictions in public and private spaces.

Paint It Red: Mothers play a pivotal role in period education. There exists a huge gap in their knowledge of how and why people get periods. Most mothers, in fact, do not explain the same to their children except reinstating the existing norms. However, a change can be seen amongst young mothers who are willing to be more informed and even try new products which will be convenient for their daughters. They are less hesitant in taking their children to doctors in case of anomalies. Educating mothers is, therefore, of primary importance to ensure that archaic ideas are not carried forward and an intergenerational empowerment can be established.

04

Given that rural India still struggles with meeting basic needs like water, health, and sanitation, what should be at the core of sustainable change on menstrual health in rural India?

Boondh: The core is realisation of our fundamental right to health which, in turn, is access to WASH (water, sanitation and hygiene), products, information, clinical access, etc. Just providing one of these can never be a standalone solution.

Paint It Red: Every community is unique and needs a unique solution. An understanding of the WASH facilities helps provide them with adequate sustainable solutions. For instance, a lot of them use community bathrooms but wash clothes in their houses, making it easier for them to use cloth pads, while some are still defecating and urinating in the fields. Where privacy is so important, we try and talk about menstrual cups as a convenient alternative.

05

Menstruators in the cities usually say that they already use good-quality pads or tampons and don't need to switch to cups, or that they are scared to put cups inside their bodies. What is your take on this transition from pads to menstrual cups?

Dr Narendra: The crotch is a very moist environment. And large parts of India being humid, the issue is that using pads or tampons can lead to the area becoming very moist and this can lead to bacterial infections. It can lead to a lot of itching and pad rashes, which are common problems with menstruators in India. However, the menstrual cup drastically reduces/elimates these problems because there's something that's sitting inside your vagina. The silicone (of the cup) itself provides such a smooth surface that it is hard for bacteria to colonise and grow there. That is not to say it never happens, which is why you have to be careful while using products related to menstrual health.

Coming to the point of whether putting a cup inside you for that long is safe or not, the answer is that it is wonderfully safe because it is made of a material called medical-grade silicone. When something is medical grade, it means it is tested to not react to your body. For example, a pacemaker contains medical-grade plastic. You put a pacemaker inside your body because it's integral to your health. Nobody will chide you for putting a foreign substance inside your body with a pacemaker, but when it comes to policing women's bodies, everyone will jump up and tell you that putting a menstrual cup inside you is a bad idea because it is putting something foreign inside you. Cups are a very sustainable, very body-friendly way

of collecting your menstrual blood instead of the discomfort that comes with wearing pads and tampons. But there is a lot of disinformation regarding cups; the other common myth is that a menstrual cup ruptures the hymen hence takes away a girl's virginity. First of all, virginity is a social construct, but I do understand that in our country and the prevalent socio-cultural practices, virginity is important to certain people. That said, putting a menstrual cup inside won't take away your virginity and it won't destroy your hymen. Your hymen is elastic; it has a ring that you can insert the menstrual cup through; it already has a hole in it.

06

Behavioural change is one of the toughest goals to achieve, especially with a menstrual cup. How do we address this problem considering that lack of awareness is the first hurdle here?

Boondh: Information, education and awareness dissemination programmes, using creative tools like digital advocacy, arts, media, etc., apart from regular programming, are important. Working with influential stakeholders towards advocating the same is another way forward.

Paint It Red: Stimulating behaviour change is a mammoth task. We have set SMART (smart, measurable, attainable, relevant, time-based) targets which are achievable. For example, teaching young girls to track their periods, creating low dependency on medicines for period pain, ensuring their hygiene practices are healthy. When it comes to behavioural change, I truly believe that 'small ripples can create big waves'.

07

Menstrual health is a taboo and has many negative socio-cultural and religious attributes attached to it. How did you deal with this stigma when you started off and how do continue to battle this crucial challenge?

Paint It Red: For centuries, menstruators have been convinced that their periods are dirty and impure. We use innovative tools like interactive games to stimulate critical thinking which is geared towards undoing these indoctrinated principles. It would be insensitive towards their faith if we simply declare all their existing knowledge as false. We try and build stories, experiments, and even discuss the good practices from the ancient knowledge which has been passed on to them intergenerationally.

08

One of the most important aspects of menstrual health is to seek the right information from medical sources. However, a lot of women (married and unmarried) hesitate to speak freely with gynaecologists owing to the fear of judgement from them. How do we navigate through these fears and seek the right guidance?

Dr Narendra: Gynaecologists are a product of the society we live in. And our society is deeply patriarchal, deeply misogynistic, and deeply superstitious. We have to accept that. These gynaecologists are people coming from the same background; sure, they have scientific training, but the people who train them also come from the same deeply patriarchal, deeply misogynistic, deeply superstitious backgrounds. This is a systemic change, and it will take time. It is an uphill task and I know it is difficult to find a good gynaecologist to listen to your problems without judging you and shaming you, and I completely understand and respect the fact that this is genuinely a problem in the world and not just our country. But health is a priority, and we must prioritise it in that way. We spend hours searching for the perfect mascara, and hours searching for whatever bra fits best, or hours searching for a good movie on Netflix or a good book. In the same vein, we should spend hours and a certain amount of money searching for a good gynaecologist who prioritises our health.

09

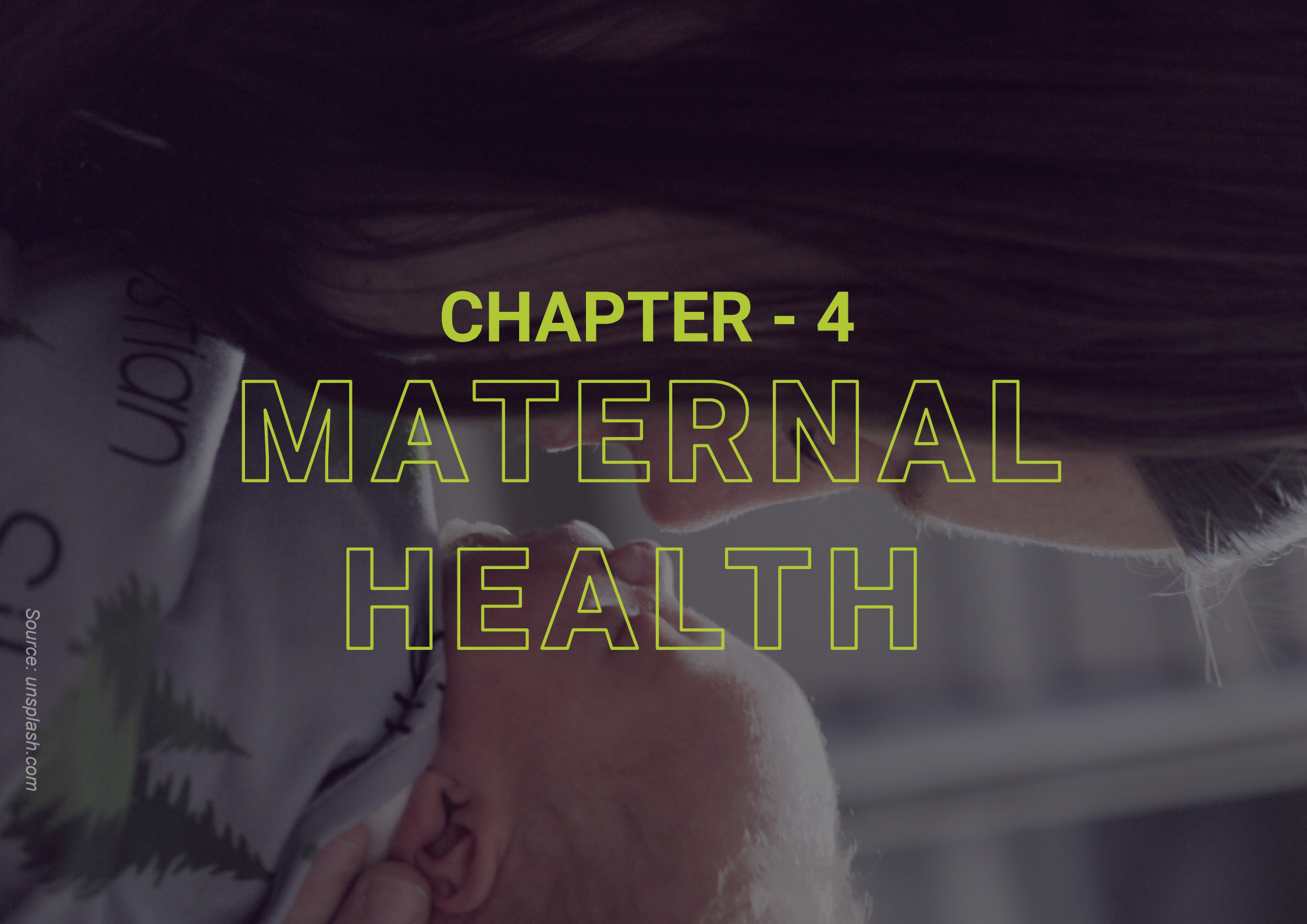
Considering the problem runs deep, what kind of strategies should the state/local governments adopt to tackle this important challenge? Have you tried to partner with any of the state/local governments to aid your cause?

Paint It Red: Menstrual health and hygiene is an intersectional domain requiring coordination between several state/central agencies. It also demands a deeper look into WASH facilities and infrastructure. Currently, governments are fixated with the idea of providing 'free' products only without taking into account the other corollary issues that need to be addressed. In a country as diverse as India, a one-size-fits-all solution will never work. A collaborative effort with civil society members and grassroots agencies would help governments design effective, impactful, and, most importantly, inclusive policies. I think that is one of the biggest things that needs to be done to address the problems in this sector.

3.5. Conclusion

Lack of access to sanitary pads is only the tip of the iceberg when it comes to solving the issues with menstrual health in India. While sanitary pads still struggle to make the cut in the government's list of essential items, young girls continue to be shamed and made to feel guilty about this natural part of the reproductive cycle. Taboos surrounding menstruation exclude women and girls from many aspects of social and cultural life. The persistence of misinformation owes both to the psychological responses and to the social contexts under which misinformation spread; potential interventions should target both fronts. At the individual level, although interventions to correct misperceptions are proven effective at times, efforts to retract misinformation need to be carried out with caution to prevent backfiring. A more constructive approach may be to cultivate critical thinking and to improve health and media literacy, thereby equipping individuals with the faculty to critically assess the credibility of information. While the good news is that a lot of groundwork is already being done at the grassroots, it is crucial to pursue how these efforts are translating into real-time impact on adolescent girls.

This will include a multi-sectoral approach and continuous Information, Education, Communication (IEC) techniques to spread and improve awareness. Stakeholders including parents and teachers, especially men, who are the primary decision-makers, are crucial to the process and must be included in menstrual hygiene trainings. Another huge potential is to tap into the role of ASHA and Anganwadi workers, who have social capital with the local communities, in facilitating menstrual hygiene and awareness among the communities, and mobilise social support against busting menstruation-related myths. The pandemic has only added further layers to the existing problem. Given today's access to scientific knowledge, the conversation around menstruation must be normalised and understood as a natural biological process. It is indeed a long battle ahead but introducing relevant menstrual education for both adolescent boys and girls must be prioritised so that we can slowly work towards a behavioural change in the perception and acceptance of menstruation as a normal process.



CHAPTER - 4

MATERNAL HEALTH

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4.1. Literature Review

By definition, maternal health refers to the health of women during pregnancy, childbirth, and the postnatal period (Desk n.d.)[51]. One of the significant health inequalities between the developed and the developing countries is the gap in the risk of maternal deaths. Of the 140 million births that take place every year, the World Health Organization (WHO) estimates that ~810 women die every day globally from preventable causes related to pregnancy and childbirth (Desk n.d.)[51]. Of this, India contributes to about 27 million births per year and accounts for 20% of global maternal deaths. While India has made remarkable progress with declining maternal mortality rate in the last decade from 212 deaths in 2007-09 to 130 in 2014-16, significant socio-economic differences and inaccess to quality maternal healthcare continue to persist in India with unsafe abortion being the third leading cause of death. Lack of accountability as a part of governance in health service delivery (e.g., lack of grievance or redressal mechanisms, provider's negligence during delivery, irrational referral) could lead to poor health outcomes in terms of delays or even avoidable deaths (Mukesh Hamal 2018)[52].

It is quite ironic that an agrarian country like India witnesses appallingly high rates of anaemia. Despite government efforts to combat under-nutrition and anaemia, and that the country is self-independent to grow its own seasonal fresh fruits and vegetables, the problem of anaemia continues to persist and seep into every nook and corner of the country (MD 2020)[53]. According to NFHS-4 in 2015-16, over 67% of adult women in rural Jharkhand suffered from anaemia. The predominant symptoms of anaemia include fatigue, feeling cold, dizziness, irritability, and shortness of breath. A diet that lacks sufficient iron, folic acid, or vitamin B12 is a common cause of anaemia. Other plausible conditions that may lead to anaemia include pregnancy, heavy menstrual cycles, blood related ailments or cancer, hereditary disorders, and infectious diseases. The two common types of anaemia in India are iron-deficiency and vitamin B12-deficiency anaemia. Iron deficiency is more predominant among women than men owing to menstrual iron losses and the high iron demands of a growing foetus during pregnancies (Dhillon 2021)[54].

With about 26% of Indian population constituting women of reproductive age (15-49 years), it is estimated that six in 10 women in India face the risk of anaemia; about half of all global maternal deaths are due to anaemia and India contributes to about 80% of the maternal death due to anaemia in South Asia. According to the National Family Health Survey (NFHS) 2019-20, Indian women and children are overwhelmingly anaemic, with colder places witnessing much worse. In the union territory of Ladakh, a whopping 92.5% children, 92.8% women and around

76% men are anaemic in the given age groups, as per the NFHS-5 survey (Welfare 2020)[119]. Along with other South Asian countries, India is off track to meet the World Health Assembly target of a 50% reduction in anaemia among women of reproductive age between 2012 and 2025. The speculation of health representatives imply that the high prevalence of anaemia in the colder regions is due to lack of fresh green vegetation during the long winter each year owing to harsh weathers and restricted connectivity.

Another dimension to the maternal health issues are the deaths due to sepsis and obstructed labour that may be attributed to the high proportion of deliveries at home (University n.d.)[55]. Despite a liberal law on abortion in India, abortion-related complications cause an estimated 8% of all maternal deaths (Manning 2018)[56]. Owing to social stigma or misinformation that abortions are illegal even though India has a law allowing medical termination of pregnancies, they are often misclassified as suicides or murders, especially where the death is due to abortion by an unmarried pregnant woman.

The recent stigma and paranoia around the pandemic has also had a huge impact on pregnant mothers and infants; approximately 9,00,000 pregnant women (15% of the six million women giving birth) who needed critical care had to face enormous hurdles to obtain treatment at an appropriate hospital (Dasgupta 2020)[57]. Added to this were the women who have had miscarriages or sought abortions: that would be another 45,000 women every day. A 20-year-old in Telangana with anaemia and high blood pressure died after being turned away by six hospitals. Similarly, a 25-year-old woman in labour coming from a COVID-19 containment area in Delhi was turned away by at least six hospitals and clinics (Dasgupta 2020)[57].

4.2. Common Myths and Misconceptions

MYTH: 01 | **Consumption of saffron results in fairer skin of the child.**

FACT: While saffron has its own valuable medicinal benefits, high intake of saffron may increase the risk of miscarriage due to its uterotonic properties. At higher doses, saffron has also been shown to cause embryonic malformation in animal's models and is therefore suggested to be avoided by pregnant women (Norain Ahmad 2019)[58].

MYTH: 02 | **Pregnant women should not undertake any physical activity including exercises/lifting weights. Mothers should not climb stairs or uphill in the first trimester.**

FACT: USA's Centers for Disease Control and Prevention stated that physical activity is good for overall health of pregnant and postpartum women since it also improves mood in the postpartum period. It does not pose any safety risks or cause low birth weight babies, early delivery or miscarriage. In fact, the lack of physical activity would consequentially cause more problems during and post labour.

MYTH: 03 | **Pregnant women should eat for two people.**

FACT: Maternal obesity that may result from this myth are found to be associated with Gestational Diabetes Mellitus (GDM), gestational hypertension, pre-eclampsia, large for gestational age babies and childhood obesity.

MYTH: 04 | **Colostrum, the bright yellowish thick first milk, is impure.**

FACT: Colostrum is rich in proteins and has anti-infective properties.

MYTH: 05 | **Pain during labour is excruciating and completely unbearable.**

FACT: The right preparation done in a prenatal class – physical, emotional, and mental, will help cope with labour, and the breathing techniques will enable one to control pain.

MYTH: 06 | **Pregnant women develop perfect facial glow/facial glow implies a baby girl.**

FACT: Changes/fluctuations in hormonal levels can cause greasy hair, hyper pigmentation, oily skin, etc., and is independent of the baby's sex.

MYTH: 07 | **Pregnant women experiencing heartburns imply better hair growth of the baby.**

FACT: Heartburns occur due to the secretion of gastric juices more frequently by the pressure of a growing uterus over the oesophagus.

MYTH: 08 | **Babies born at night tend to stay awake at night.**

FACT: Birth time has no effect on the sleep/wake habits of the baby.

MYTH: 09 | **Turning on either side while lying down will result in the cord wrapping around the foetus' head and in suffocation.**

FACT: The baby is well protected by the umbilical cord and it does not cause strangulation.

MYTH: 10 | **Ghee intake acts as lubricant to make the delivery easy.**

FACT: While moderate quantities are harmless, excess ghee, which is a saturated fat will only add to unecessary weight

4.3. Case Study- Postnatal Isolation in Bundelkhand, Central India

In an agrarian country like India, over 90% of the tribal population continues to depend on agriculture and allied services. Given the challenging geographical terrain and the absence of the required medical infrastructure, it is no surprise that the needs of the tribal population are often excluded or overlooked. The livelihood and the food security of the marginalised groups, especially the women, continue to be prodded with high maternal and infant mortality rates despite the overall dip in MMR and IMR at the all-India level owing to certain social beliefs and customs. The problem is further compounded by poverty, lack of health facilities, people's ignorance and illiteracy. This combination of disadvantages threatens their very livelihoods. Case in point being, the peculiar belief of the tribal communities of Gonds, Kols and Mawasis residing in the forest regions of Bundelkhand in Central India owing to the lack of health support and education (Manjunatha B L 2017)[59].

> *The tribals believed that their goddess would watch the mother and baby during these three days and that it was against her wishes to attend to the mother and baby. Effectively, mother and child are left to starvation and eventual death. **(Manjunatha B L 2017)*** [59]

The social norms of the tribal populations are tightly knit, and certain practices have been continuing for generations together. In these tribal hamlets, illness or death is often associated with the curse of their goddess. Taking sick patients to the hospital or visiting doctors would imply disrespect to their goddess and is against their belief. Therefore, sickness is accepted as an act of God instead of seeking treatment. In this regard, a strange birth practice was followed by the tribal communities. Child marriages are still prevalent among the tribal populations. Whenever a tribal girl/woman delivers a baby, both the mother and the new-born infant were isolated from the family for at least three days following the delivery. The duo is not touched or attended to by anyone including the husband, family, or the midwife. In fact, even the mother is forbidden to attend to (touch, feed, care) the new-born baby and is made to lie on the floor while the baby is put in a bamboo basket. The tribals believed that the goddess would look after the new-born to the extent that the baby is denied the initial colostrum and even the milk/first feed from the mother. This brutal ordeal, rooted in superstition, would vary anywhere between three and seven days. It was believed that "if the mother and the baby are attended to, the Goddess would get angry and her curse can wipe off the entire family". Effectively, the mother and the child were left to starvation and eventual death owing to this practice. Even if they survived, the babies would inevitably suffer from malnutrition in the later stages of life and were often

susceptible to more diseases. The problem was solved only when the female functionary of Samaj Shilpi Dampatis (SSD) scheme took up the challenge and provided timely help to save the mother and child from starvation and death. The Samaj Shilpis are essentially social workers who lived and worked for the villagers on behalf of the Deendayal Research Institute (DRI), an NGO that has been relentlessly working for the uplift of the poor in the Bundelkhand region. From providing daily tuitions to their children to dismantling social evils, the work of the SSDs cannot be overstated in uplifting the lives of the tribal populations. The idea of such an intervention is to build rapport and trust to change the traditional practices and seek betterment. It is more so in case of reaching out to women and helping them with timely advice and medical treatment by breaking the shackles of the age-old life-threatening practices.

4.4. Experts Speak

DR ANUJA JAYARAMAN

She is the Director, Research at SNEHA, where she leads the research, M&E, and information management functions. She has an established track record of policy-oriented research in the areas of poverty and non-income dimensions of wellbeing, including maternal and child health outcomes in South Asia and Africa. Dr Anuja's scholarship has been published in national and international journals of repute.

PROF. M. SIVAKAMI

She is a Professor at the Centre for Health and Social Science, School of Health Systems Studies (SHSS), Tata Institute of Social Sciences (TISS), Mumbai. Prof. Sivakami broadly works in the areas of demography, gender, and health, and has been published in peer-reviewed national and international journals including the Lancet, BMJ Global Health, BMJ Open, Journal of Global Health, among others. She is also an academic editor at PLOS Global Public Health.

01 What kinds of misinformation (myths and misconceptions) prevail around maternal health in India?

Prof. Sivakami: Maternal and child health can be compartmentalised into the following three groups:

a. People's behaviour
b. Health system behaviour
c. Environmental factors

If you look at it from a people's behaviour perspective, there are many myths and misinformation on food habits, especially for expecting women. You will often hear people talking about these myths with no scientific proof whatsoever. With the health system too, there are rumours that C-sections will be prescribed for all or that pregnant women experience violence during labour. While we acknowledge such practices happen, we must not spread unnecessary rumours. This phenomenon will consequently affect women and restrict the number of such women seeking medical care, which implies they will resort to other means, like quacks. Usually, such misinformation spreads through word of mouth, with widespread consequences. Also, during the initial phase of COVID-19, health facilities denied maternal healthcare to women of the minority, especially Muslims, fearing the spread of COVID-19. However, they cannot deny healthcare, especially delivery care, to women from any background. The environment also adds to the misinformation regarding seeking and providing healthcare, i.e., the government's promises on maternal care. For example, there is a fear of the use/misuse of government schemes, like saying that if you go to the government drive in a clinic, they will perform a sterilisation or provide the wrong and same medicines for all health issues.

Dr Anuja: The challenges are in terms of not revealing their pregnancy in the first three months, which is not only the case in rural areas but is common in urban areas as well. Many are not open about it, so early registration of pregnancy becomes a challenge.

In the COVID-19 situation, many fear going to the hospital because they may be turned away or out of fear of contracting the disease during pregnancy, which can affect the child's health. This is a valid fear but there must be ways of circumventing this.

02 What are some of the biggest challenges in maternal health and how should these challenges be dealt with?

Prof. Sivakami:

a: Maternal Health

One of the existing challenges is to convince women of the significance of institutional deliveries. It also depends on the institutions to provide the proper care and respect for women. To me, not providing universal health coverage, especially to pregnant women, remains a huge challenge. More so now, while we are trying to push more institutional deliveries, we miss out on the demand side to equip the institutions in terms of infrastructure at all levels, resources, funding to deal with the voluminous intake, and provide care to the patients. Therefore, these have consequences on women for generations to access institutional deliveries.

b: Menstrual Health

There are many issues with menstrual health. There are myths and taboos with absolutely no scientific basis like not touching or eating things or participating in activities, to name a few. The measures and behaviours reflect on how society treats women, especially during menstruation. When our systems/governments talk about providing menstrual hygiene products, they only talk about supply, i.e., distribution of pads. But unfortunately, giving low-cost pads does not solve the problem of menstrual hygiene. It is a much larger issue with the following four parameters:

i. Creating knowledge
ii. Providing facilities
iii. Ensuring supplies
iv. Disposal and waste management: imagine the amount of waste generated and we have absolutely no sustainable mechanism for disposal. There are a couple of Policy documents here and there, but we do not have the clear behavioural change that we expect or the necessary structure in place for implementation.

For instance, in my village in Tamil Nadu, where there is no proper disposal mechanism, if there is a pad with a blood stain on it, there are rumours that ghosts will haunt the girls in the village; this can have long-term effects on young adolescent girls. While the states have progressed in terms of distributing supplies, the disposal mechanisms are still at the nascent stages.

Dr Anuja:

a: Contraceptive prevalence rates are low and unmet need is high among vulnerable communities residing in urban areas. Emphasis should be on promoting family planning methods for spacing and limiting number of children in a family.

b: Around 50% of women in India are likely to be anaemic, so working on anaemia is another challenge. Anaemia is not a disease like fever where it manifests openly. It results in tiredness and other such symptoms that people don't usually associate with any particular illness.

c: Once pregnant, taking care of themselves including intake of nutritious food, going for antenatal care (ANC) visits, and taking iron and folic tablets also is not consistent.

03

Behavioural change is one of the toughest goals to achieve. How do we address this problem in maternal health, considering that lack of awareness is the first hurdle here?

Prof. Sivakami:

Start early. Start awareness through the school curriculum. Our media has a huge role to play in shaping the mindsets of young boys, especially. Only recently, I have been told that Maharashtra school textbooks show women as police officers and men undertaking household work. Therefore, I am of the strong opinion that if there must be a behavioural change, it has to start early.

04

Given the low female literacy rates, what are the strategies to empower women to take decisions to use reproductive health services?

Dr Anuja:

Messaging and giving information to women regarding reproductive health services is the first step towards empowering women to take health-related decisions. At the same time, one needs to make sure that health services are indeed available when women try to avail them.

05 Considering the problem runs deep, what kind of strategies should the state/local governments adopt to tackle this important challenge?

Prof. Sivakami:

Health is a state subject and therefore, we need to increase the state budgets, equip the health delivery services, and improve infrastructure. All these are possible if all view health as a fundamental right. In states like Kerala and Tamil Nadu, people demand good health services. Similarly, other populations must demand good health services.

Dr Anuja:

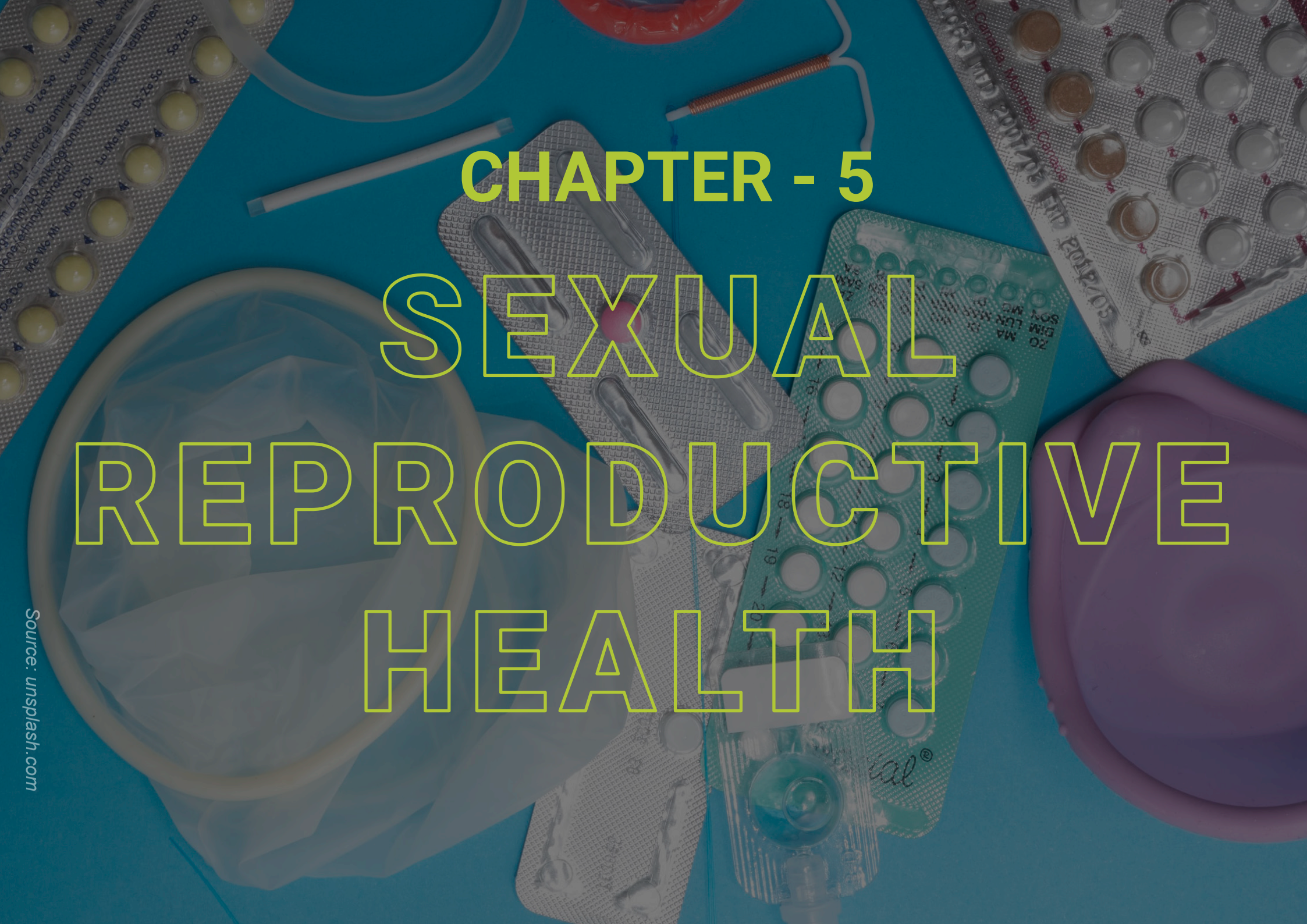
Role of government in healthcare is significant. Civil society can only play a supporting role in tackling health issues in India. There is an urgent need to invest in public health systems and facilities. From our experience, one can offer global solutions, but every corporation or every city or every state has its own context, and one has to look at that context and then design the solutions. What works for a rural community need not work in an urban set-up. The government could select poor performing indicators based on national surveys, understand the local context, and design strategies that address the specific constraints faced by the population.

4.5. Conclusion

In case of maternal health, misinformation manifests in more ways than one. Most times, pregnant women lack the adequate knowledge or withhold their reproductive and medical information, owing to family/societal pressures, and to evade private questions. Especially with something as gendered and sensitive as maternal health, there are social issues that combine with the medical issues, leading to a lot of confusion. And this confusion, fear and doubt, in turn become breeding grounds for misinformation, which only complicates things further. Traditional vertical health communication strategies are eroded by horizontal diffusion of conspiracy-like messages. The narratives of health especially maternal misinformation are often dominated by subjective biases including personal anecdotes, word of mouth, opinions on doctors, institutions & treatments, which in turn induce fear, panic, confusion, anxiety and mistrust in institutions. Therefore, one must be careful of the credibility of the agents who spread misinformation either through experience, or knowledge that is passed on from generations. Although traditional knowledge remains valuable, it must be taken with a pinch of salt, and given the access to modern knowledge (factual, scientific, and logical research),

it is essential for women to understand what their bodies are going through physiologically. Given that each pregnancy is unique, it is crucial that expecting mothers discuss their entire obstetric and reproductive health with their doctor so that right and customised guidance can be provided from the first trimester until the labour time.

These layers of stigma and misinformation are not going to disappear anytime soon. In fact, false information has significantly seeped into our households and have become the norm. However, However, specialized frameworks from subjects including Behavioral science, psychology and network science are being utilised to understand the patterns of misinformation and how to combat them. However, at an individual level, we can educate ourselves and talk about these issues more freely, so that with time, we learn to talk about maternal health with data instead of rumours and misinformation.



CHAPTER - 5

SEXUAL REPRODUCTIVE HEALTH

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5.1. Literature Review

As a demographic, unmarried women are completely invisible in the domain of sexual and reproductive health and rights in India. Due to societal biases and shame, such women de-prioritise their sexual health needs and refrain from accessing services. As a society, we do not acknowledge the fact that unmarried people have sex or are, in any way, sexually active, and that it is important to include them in the conversation on sexual health. Given that India has the second largest population and the largest adolescent population in the world, there are several reproductive health concerns in India including high unwanted fertility. According to the fourth round of the National Family Health Survey (NFHS IV), 9% of pregnancies were unwanted while 4% were mistimed (Welfare, National Family Health Survey (2015-16))[60]. As per the National AIDS Control Organisation's 2018-19 annual report, early diagnosis, appropriate and complete treatment of Sexually Transmitted Infections (STIs) and Reproductive Tract Infections (RTI) reduce the transmission rate of HIV infection by over 40% (Welfare, National AIDS Control Organization (NACO), 2020)[61]. According to an AIIMS report, 10-15% of all married couples in India face fertility issues and require external help (AIIMS, 2014)[62]. However, due to the stigma associated with the subject, people end up experimenting with quacks, tantriks and non-medical practitioners. It is estimated that 11.8 million adolescent pregnancies occurred in 2017 (Roy, 2017)[63]. The NFHS IV reports1 that one in every 10 women in rural areas in the age group of 15-19 years has begun childbearing (Welfare, National Family Health Survey (2015-16)),[64] while 20% of this age group with no formal schooling has also begun childbearing. This is also the age group with the highest percentage of non-live births. It is estimated that about 26% of the abortions were repeatedly performed by the women themselves at home (Welfare, National Family Health Survey (2015-16))[65]. Pregnancy-related complications are the number one cause of death among girls between 15 and 19 years (UNICEF, n.d.)[66]. Most of the unsuccessful abortions women experience can be traced to the purchase of non-prescriptive drugs that may be falsely advertised by chemists as an alternative and cheaper option to prescriptive abortifacients. According to a survey by NGO Haiyya, as low as 20% of the unmarried women knew about the abortion law in India, and 95% had never visited a gynaecologist to take consultation on sex, pleasure or contraception (Desk, n.d.)[67].

According to the National Health Survey 2015-16, the contraceptive prevalence rate among currently married women aged 15-49 decreased slightly, from 56% in 2005-06 to 54% in 2015-16, and the use of modern contraceptive methods stands at under 50% (Welfare, Contraceptive knowledge and use)[68]. Additionally, one in seven married women report that they no longer want to get pregnant but are not currently using any form of contraception. According to a Lancet study, 15.6 million abortions occurred in India. 11.5 million (73%) abortions were medication abortions done outside of health facilities, and 0.8 million (5%) abortions were done

outside health facilities using methods other than medication abortion, and only 2.2 million were surgical abortions, 0.8 million took place outside of legalised institutions in private clinics with variable costs and unsafe methods (Susheela Singh, 2018)[69]. On average, women with no schooling have an average 3.1 children, compared with 1.7 children for women with 12 or more years of schooling (Rattanani, 2019)[70]. In the socio-economic context, this translates to women in the lowest wealth quintile having an average of 1.6 more children than women in the highest wealth quintile. In relation to metrics relating to socioeconomic factors, namely levels of poverty and education, illiterate women are 48% more likely to have an unsafe abortion and women in households with minimal asset holdings are 45% more likely to undergo unsafe abortions.

High maternal mortality rate: Nearly 45,000 Indian women, accounting for almost 15% of estimated global maternal deaths, die every year due to causes related to pregnancy and childbirth (writer, 2016)[71]. The lifetime risk of maternal mortality is one in 70, i.e., one in every 70 pregnant women is at risk of death, even as she gives birth. Available data also indicates that a significant proportion of women suffer from obstetric morbidities. In fact, women in rural settings have a 26% higher chance of dying from complications than their counterparts in urban settings. The difference is wider in the case of indigenous women; 84% of indigenous women in Jharkhand do not have access to or do not use any form of contraception, whereas this is the case for 59% of non-indigenous women.

STIs/RTIs: In a nation-wide community-based study, prevalence was nearly 6% in the 15-50 years age group. The problem is further compounded by the predominant culture of shaming & silencing that discourages women from seeking the required medical treatment.

5.2. Common Myths and Misconceptions

MYTH: 01 | **The hymen is the definitive marker of virginity and, consequently, character.**

FACT: Virginity is a social construct. The hymen can break due to physical activities like gymnastics, cycling, using a tampon, intense exercise, etc.

MYTH: 02 | **You cannot contract an STI if you use a condom.**

FACT: While condoms are 98% effective, it is still possible to get an STI while using one.

MYTH: 03 | **Douching is necessary to keep the vagina clean.**

FACT: Douching can change the pH balance of vaginal flora (bacteria that live in the vagina) and natural acidity in a healthy vagina. A healthy vagina maintains both good and harmful bacteria. This balance of bacteria creates an acidic environment within the vagina that helps protect it from infections or irritations (Melissa Conrad Stöppler, 2020) [72].

MYTH: 04 | **Sex can increase the risk of cancer.**

FACT: Rather, it decreases the risk of cancer. Men who are in a healthy relationship are less likely to receive a prostate cancer diagnosis before age 70. It has also been observed that men who had frequent orgasms (defined as two or more a week) had a 50% lower mortality risk than those who had sex less often.

MYTH: 05 | **You cannot get pregnant on your period; sperm can only live a short while after it is released.**

FACT: While conception is most likely when intercourse occurs a few days before or during ovulation, it is still possible to get pregnant during your Menstrual Cycle. Sperm can live in the female body for up to 5 days after sexual intercourse under the right conditions. So, in some cases, sperm can fertilise an egg a few days after it has been released in ovulation.

MYTH: 06 | **The withdrawal method is effective in preventing pregnancy.**

FACT: A male's pre-ejaculation also contains sperm cells, which leads to the possibility of contraception despite the withdrawal method. So, it is preferrable to always use protection (like a condom) during intercourse if pregnancy is not desired.

MYTH: 07 | **Masturbation is harmful, especially to women, and it affects the relationship of a husband and wife.**

FACT: It is very safe; in fact, it increases mental wellbeing along with other advantages including enhanced sex between partners, understanding your own body, and increased ability for orgasms. Pleasure has a positive corelation with better mood and body image.

MYTH: 08 | **Doubling condoms means double protection.**

FACT: Using two condoms can, in fact, offer less protection than using just one. Incorrect use can cause too much friction, weakening the material and increasing the chance of the condom breaking during intercourse. (staff) [73]

MYTH: 09 | **STIs can only be transmitted when symptoms are present.**

FACT: Many STIs do not have symptoms but can be damaging to your body and spread to sexual partners.

MYTH: 10 | **STIs cannot be transmitted through oral or anal intercourse and only through multiple partners.**

FACT: Contracting an STI is a probability given one is sexually active, even if you only have one sexual partner. STIs can be contracted from any kind of intercourse or intimate contact with your partner(s).

5.3. Case Study- Mass Hysterectomies, a Way of Livelihood for Women in the Sugarcane Belt

In the drought-stricken interiors of Beed in Maharashtra, October to March are crucial months in the sugarcane belt. Given the good financial returns for the year, contractors employ migrants from nearby districts as sugarcane cutters during these months. However, the contractors faced a bizarre problem to cater to the needs of women on the fields. These cutters, both men and

women, spend up to 16 hours harvesting and loading the cane crop during these six months, with no toilets on the farms. Women, especially, would be penalised with a pay cut or, worse, a replacement if she requested leave during her menstrual cycle/first trimester of pregnancy. Owing to the high demand for work, the labour, especially women, are the most exploited. To counter the problem, the suggested solution was mass hysterectomy, i.e., the surgical removal of the uterus so that they can be gainfully employed on the sugarcane farms. In fact, it had became the norm to such an extent that the contractors refused to hire women who had two or three children and still had their ovaries and uteruses intact. The brazen inequality stands out as these vulnerable women are then made to pay for their own surgeries, which they never wanted in the first place. The exploitation begins when the contractors employ them and give them an advance for the hysterectomy but later recover the money from their wages. These women, who are sometimes as young as 25, undergo hysterectomy because the sugar industry is one of the few providers of employment in the region. The Hindu Business line reports, "you will hardly find women with wombs in these villages (Jadhav, 2019)[74]. These are villages of womb-less women." According to the report, "State figures say that in three years (2016-2019), as many as 4,605 women have had their uterus removed in Maharashtra. Civil rights organisations allege that the hysterectomy rate in Beed is 14 times more than that for the State or the country" (Shelar, 2019)[75]. In what is a definite labour exploitation, women are robbed of their sexual and reproductive rights over their bodies through systemic injustice. The hardships do not end with the hysterectomies because the removal of the uterus and the back-breaking work on the sugarcane fields give rise to other health problems including severe back and joint pains with no health safety net. Worse, according to the same Hindu report, "There could be a nexus between profit-driven doctors and the hysterectomies. This definitely needs to be investigated, among other things." When poor hygiene is coupled with gross exploitation and lack of information, the most vulnerable women of the region pay the highest price through unwanted hysterectomies. This is just one the many case studies that is witness to the blatant exploitation of the rights of the women living in the districts, who are uneducated and are, therefore, ill-equipped to make the right health choices.

> *You will hardly find women with wombs in these villages. These are villages of womb-less women owing to the high number of hysterectomies in Maharashtra's Beed district.* ***(Jadhav, 2019)***[74]

5.4. Experts Speak

MS AISHA LOVELY GEORGE

She is the Executive Coordinator of the Hidden Pockets Collective. She is an award-winning podcaster, and a speaker on reproductive health on various panels nationally and internationally. She is a trained Sexual and Reproductive Health educator and a counsellor.

MS KARISHMA SWARUP

She is a certified sexuality educator who actively busts myths about sex through social media, among other platforms.

DR NIVEDITHA MANOKARAN

She is a dermatologist and venereologist from India working as a clinician in sexual and reproductive medicine and HIV medicine in Sydney, Australia.

01 What kinds of misinformation (myths and misconceptions) prevail around sexual health in India?

Ms Aisha: I would say that the majority of women have no autonomy over their bodies. I mean, everything related to their sexual life and their bodies is decided by someone else. Most often, they are not given a choice as to what kind of contraception can be used or even given the quintessential sexual knowledge on safe and pleasurable intercourse. In case of married women, most often, the mother-in-law takes the decisions and in case she is not married, there is no question of discussion on sexual health. This is clearly because pre-marital sex is taboo in our country. So, the biggest challenge at hand is that women do not see their bodies as their own since it is always other people making decisions for them. Second, there is this stigma about the anatomy, their own body parts—most women do not know what or how their vagina and uterus look like or even the basic differences. It is a sad relationship that women have with their bodies. This is, in fact, not their fault. Owing to the lack of sexual education, these topics are not often discussed while growing up and even in schools, they brush up and skim through these chapters. On the other hand, the internet is full of information (right, mis and disinformation) and most times, women do not have access to the right information. So, most women do not know what to do when they have vaginal discharge or burning sensation and worse, Google search will always render a link to a site suggesting bacterial infection or cancer. Owing to the stigma around the issues, women do not talk about these things, thus worsening their own sexual and reproductive health. Therefore, the biggest challenge is to overcome the stigma and establish a healthy relationship with their bodies. And this is only possible though repeated guided conversations because each problem is unique and has to be dealt with subjectively instead of giving blanket answers. The first step is to understand your own body, listen to its needs and, if needed, seek help accordingly.

02 Given the Indian context and the patriarchal system, any conversation around young women's sexuality is limited and stigmatised. How should we attempt to break this barrier and educate people?

Ms Aisha: I would say that it is definitely not going to be that easy to overcome the system and conditioning of patriarchy overnight. Women have been taught to do certain things in their lives and it is not easy to bring about a behavioural change quickly. Therefore, it is important to involve the family members in the conversation because this is a collective societal change, so including the in-laws and parents in the conversation is crucial. Also, it is important to understand where they are coming from and one has to be extremely sensitive in addressing the topic. This is exactly what we do in our workshops. In our experience, I have noticed that sometimes, the men also want to help but were clueless as to where and how to begin. Given the cultural/social norms, most times, our workshops are conducted with men and women sitting in different rooms. Things have to change bottom-up. For that, first, it is important to have a conversation with both the sexes in the community to analyse the gaps in awareness, education and opinions. Sometimes, it is equally or more important to accept their beliefs and values in order to design an intervention and then slowly start building and moulding a conversation around it. It has to be a holistic approach especially targeting the decision-makers of the house including the men and the in-laws for any kind of constructive change to begin because only educating the woman is work half done and it is crucial to understand the dynamics at the grassroot level for any effective intervention.

03 In your research, have you come across any correlation (direct/indirect) between misinformation and miscarriages/abortions (safe and especially unsafe) in both married and unmarried women?

Ms Aisha: Yes, in my experience, misinformation plays a critical role, especially in unsafe abortions among adolescents/young women. There is limited understanding of the Medical Termination of Pregnancy Act, given that the language is not straightforward and has a list of criteria for women to be eligible for abortion.

Owing to the lack of understanding of the legal knowledge and their own bodies paired with misinformation on abortion, young women end up seeking help from outside medical institutions including quacks, thus resulting in unsafe abortions. Often, these quacks are not qualified or trained to handle 12-week or 20-week pregnancies, which end up in extreme loss of blood, incomplete abortion and complicated pregnancies. Therefore, there is a direct correlation between misinformation and abortion, but I have not seen any miscarriages till now given that we deal with a lot of unmarried young men and women, and most pregnancies are unintended.

Ms Swarup: It's hard because people under 18, if they are engaging in sexual activity, whether they're doing it with a young person or not, it's against the law. And I think that is what makes it really hard for young people to access abortion care or healthcare around their reproductive health because by law, a doctor would have to report if someone under 18 was pregnant, and I think that's a good law because the fact is the age of consent is 18. But it becomes a larger question of are we still creating space for those people to come forward safely and have these conversations and have trusted adults in their lives whom they can talk to about these things. So, there are some newer-age start-ups, for example, and there are crowdsourced lists of gynaecologists who will not be judgmental towards people. And I think that is the first step to help people connect with doctors who will not judge them and who will be able to provide them with care. The second thing is that sometimes, people think that abortion itself might be illegal, which is totally a myth because in India, we do not have that issue. And I think that is another reason why people feel inclined to go to quack doctors because there's just not enough knowledge around the fact that people can go to a legitimate doctor and ask for an abortion.

04 What has been the impact of alternative medicines (powders/pills), especially when it comes to infertility issues and abortions?

Ms Aisha: Again, this is extremely dangerous, given that young people seek alternatives instead of meeting with a doctor owing to the fear of judgment or getting caught. Therefore, they resort to the simplest alternatives and even if they consult a doctor for abortion, they do not go for follow-up check-ups or even find out if the uterus is clean, i.e., if the abortion is complete. Likewise, a lot of doctors are also not equipped to guide these youngsters or follow up with them and often times, the youngsters face condescending and judgmental behaviour from the doctors. In fact, we had a case where the patient was bleeding continuously for 14 days and it was critical to see a qualified doctor to deal with the complications. In reality, a lot of married/unmarried couples visit quacks, and one can never know what the composition of the medicine/pills is and what is the right dosage to consume. Often, these pills have a lot of side effects/bring about hormonal changes if consumed in higher doses, thus leading to further complications. Even in case of married women, there were a few cases where the women did not want to continue with the pregnancy but they did not wish to inform their husbands. In fact, one of the patients and her sister approached us to seek the easiest way to abort the pregnancy against the wishes of her family. We had to counsel them not to visit a quack and seek necessary medical expertise and connected to a doctor with the help of Hidden Pockets. And we often try to fill this gap of connecting the patients and a qualified doctor through our organisation.

05 What are the most affordable types of contraception available for people?

Dr Niveditha: Condoms are the safest, cheapest and most easily available form of contraception. There is probably a small percentage of people who could be allergic to latex and there are latex-free condoms available for such people. So, I think that is the most easy and safe thing that you can use, it is the only thing that protects you against STIs, and does fantastic contraception. So, condoms are a go-go for me and that is an easily sold contraception. I think where the problem arises is when a youngster has to walk through a supermarket to the condom aisle and pick a box of condoms or lubricant and go up to the front counter and get it billed standing in line with the other people who are probably giving them looks and talking about them, and I think that is where the problem arises and that is what is the barrier for people to be using condoms. And it's hard for us to change the attitude of the population of one billion. So, it's hard to say don't look at me like this, don't say this, don't see that. So, can we make condoms and lubricants more available in more common places? For example, a lot of our gynaecological clinics and sexual health clinics have bowls of condoms and lubes in the waiting room, in the sitting area, in the coffee area, etc. And we also place plenty of brown bags all over the place, so you don't have to flash your condoms. So, if contraception is easily available and not judged, people will probably use it much more than they use it these days, if they get the relevant education. On the other hand, there are IUDs or Copper-Ts that can be used for contraception for 5-10 years and the copper IUDs can also be used for emergency contraception.

06 Men have their challenges too when it comes to sexual health and living up to the stereotypes associated with them. What are some of the issues that they face?

Ms Swarup: I find that I get so many direct messages on social media from men, and a lot of them come from a place of insecurity, with questions like is my penis large enough? Am I lasting long in bed? Is my penis the right shape? These are questions that are very personal to them but also, in society, linked to masculinity itself. And these kinds of societal norms translate into the way that people feel about their bodies. And that is a big issue because it makes men feel ashamed of even asking for help when they need it. And they are often afraid to go to or approach a doctor. I have full-blown adults in my direct messages saying things like please help me, I need to speak with a doctor. And my response is always I'm not a doctor! You have to speak with a doctor to get you treatment for whatever issue you're facing. I think it becomes a culture of silence for them, which is ironic because society does afford them more agency and more power when it comes to sex—things like he's a man, so he's going to have sexual feelings; he's going to masturbate; he's going to be attracted to people. Those are stereotypes that exist. But at the same time, there is not as much open conversation around it.

07 Apart from unwanted pregnancies, the lack of knowledge on good contraception also results in STIs. How can people be more aware of STIs if they are sexually active?

Dr Niveditha: Most of the time, people approach a sexual health physician only when they start having symptoms, because symptoms tell them that something is wrong. However, I always keep telling people that STIs are mostly asymptomatic; they do not have any symptoms. 70-80% of the time, chlamydia, gonorrhoea and HIV do not show symptoms for a very long time. So, what we have to work and target towards is to get asymptomatic testing, which means that if you are sexually active, you need to get tested at least once or twice a year. If you are having unprotected sex, you probably have to do more STI screening. And if you are having sex with a member of the high-risk population, which includes gay men, sex workers, people who are having sex with sex workers, injecting drug users, people who have sex with trans men and women and then trans men and women themselves, the chances that you could acquire an STI are higher. So, go more frequently for STI testing and that is the only way you pick infections early, prevent complications and prevent life-threatening scenarios. This is something that I really want to encourage people to do but unfortunately, symptoms are the thing that usually make people rush to a doctor.

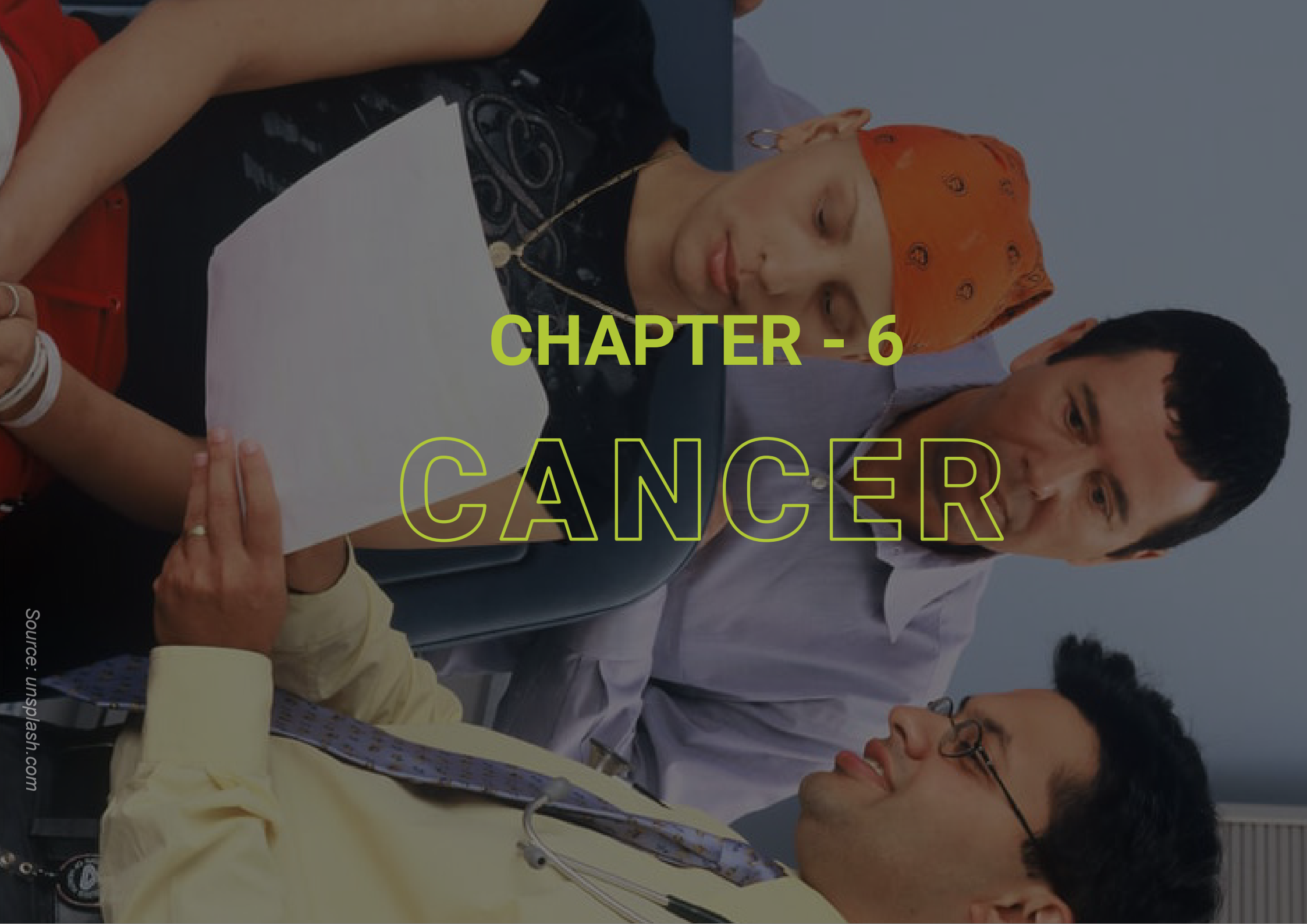
5.5. Conclusion

The stigma around sex leads to several undesirable consequences, from misinformation around the right contraception to people being afraid to seek help, which in turn leads to unsafe abortion and a spread in STIs. Access to information on the full range of acceptable and affordable contraceptives and the accurate methods is essential to both men and women's autonomy and health. The antidote to poor sexual and reproductive health is good sex education. The only weapon to combat misinformation and stigma is through right awareness, accessibility and affordability of sex education, products, and healthcare. Ms Swarup weighs in on the importance of sex education as the way forward:

Many multi-country studies have been done comparing different factors and one of the factors which correlates with a lower rate of misinformation is good sex education. In fact, one of the biggest misconceptions in India is that if you talk to teenagers about sex, they are going to venture out and have more sex but that is not necessarily true. It just means that they are going to be more aware and more informed and make better decisions about their sexual life, and that includes contraception and teenage pregnancy as well. I think there needs to be more awareness around contraceptives because the simple fact is that when someone is young, they are more likely to take risks and engage in risky behaviours without considering the consequences. Second, the lack of access to healthcare is a problem. Say, a young person who has a uterus wants to go and get birth-control pills, it is really difficult if they are under a certain age or I would say even if they're over 18, it is really hard to just go to a gynaecologist and ask for a birth-control prescription or even have a conversation about the appropriate methods of contraception because there's so much stigma around unmarried people having sex, while in reality, young people are sexually active. I think sex education needs to start from kindergarten and needs to go on throughout the entire school period, till class 12, and in college. Given that most of India's population does go through some type of schooling, if we make sex education a mandatory part of school curricula, everyone will have exposure and access to it. We want to also make it accessible in other avenues because if someone is not going to school or does not have access to sex education at school, they should be able to come home, Google it, and find reliable information but unfortunately, that's not the case at the moment. And 50% of the population has smartphones and a lot of young people will access pornography more easily than they'll ever find good sex ed. And that's why making it accessible online, making it accessible within school and college systems, and acknowledging the fact that young people have sexual agency and autonomy is really important. And I'm not saying that people under 18 should be having sex but just saying that they should have the knowledge and have the resources and have access to the education they need.

From the medical system to the education system to families and importantly, the individual—each one of us—there are many stakeholders involved in sexual healthcare. The problem must be approached from both the doctor's and the patient's sides. While attitudes and behaviours of the society are unlikely to change overnight, the primary focus must be to seek the right guidance—consult an expert/doctor to ensure credible information on the problem. One must refrain from consulting quacks or even diagnosing a sexual health problem by reading

about the symptoms online. Similarly, on the medical end, hospitals and medical practitioners must ensure that diagnosis and treatment are evidence-based, and actively bust myths and misconceptions for their patients. Listening attentively and empathising with the patient can go a long way in tackling the misinformation that is widespread in this stigmatised topic of sexual and reproductive health.



CHAPTER - 6

CANCER

Source: unsplash.com

6.1. Literature Review

While cancer remains a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020, the disease burden on India with a mammoth population is significantly high (W. H. Desk 2021)[76]. The International Agency for Research on Cancer (IARC) features that, "1 in 5 people develop cancer during their lifetime, and 1 in 8 men and 1 in 11 women die from the disease" (Cancer n.d.)[77]. Cancer is a generic term for a collection of related diseases which may develop in almost any organ or tissue in the body when there is an uncontrollable growth of abnormal cells formed due to alterations in DNA spread, and damage the surrounding tissues/ organs (Institute, NHI: Understanding Cancer n.d.)[78]. When these cells spread to other organs, the process is called metastasising, which is a major cause of death from cancer (Institute, NCI Dictionaries n.d.)[79]. Cancer is the second leading cause of death across the world among noncommunicable diseases after cardiovascular diseases (W. H. Desk 2021)[80]. According to The National Cancer Registry Programme (NCRP) 2020, released by the Indian Council of Medical Research (ICMR), it is estimated there will be 13.9 lakh cases of cancer in India in 2020, and that this number is likely to rise to 15.7 lakh by 2025—a 12% increase from current estimated cases—based on current trends, according to the report (NCDIR 2020)[81] (ICMR-NCDIR 2020)[82]. It further adds that breast cancer will be the most common cancer in women, affecting an estimated 2 lakh in India every year; with an increase of 30% over the past decade.

According to the World Health Organization (WHO), most cancer cases are detected only in the advanced stages, when they are untreatable (W. Desk n.d.)[83]. Cancer remains a life-threatening disease that is fuelled by hoax cancer cures and unproven therapies that pose a severe risk to patients' lives, rather than offering them any hope. Misleading information has often allowed it to be equated with sure death in people's minds, thereby bringing about changes in people's treatment-seeking behaviour. According to the NIH National Cancer Institute, "patients using complementary or alternative medicine are more than twice as likely to die as those treated with conventional medicine" (Staff 2017)[84]. The Lancet's paper on oncology, fake news, and legal liability too supports the fact that patients using complementary medicine are more likely to refuse surgery, radiotherapy, or chemotherapy which have minute probability of actually saving lives (Oncology 2018)[85]. The National Institute of Cancer Prevention and Research further underscores that of every two women diagnosed with the disease, one succumbs to it.

Cancer, unlike other diseases, is unique in nature, i.e., while the patient wonders why this is happening to them, the disease manifests itself in more ways than one. Every cancer is unique and depends on how severe it is and what stage it is at to seek the necessary treatment. Therefore, timely screening, treatment and prevention are requisite in understanding and approaching cancer. Globally, the most frequently diagnosed cancers include lung (1.8 million, 13.0% of the total), breast (1.7 million, 11.9%) and colorectal (1.4 million, 9.7%) (Biswas 2014)[86]. With over 1.5 lakh new breast cancer patients recorded in India in 2018, it accounts for 14% of all cancers among women. Today, one in every 28 women (one in 22 women in urban Indian, one in 60 women in rural India) is at risk of developing breast cancer in her lifetime (C. Desk n.d.)[87].

Given the complex and grievous nature of the diseases, broadly there are four obstacles in seeking proper treatment including:

1 *Misinformation obtained largely by accessing the internet:* When fact-checked, it was found that most of the videos propagating cancer treatment are mostly commerce-driven, intending to sell their products with no proven or scientific backing.

2 *Lack of information:* Most women are unaware about symptoms of breast cancer. Lack of adequate knowledge in common people with undeveloped personalities that has resulted in fear, confusion and inability to take logical decisions regarding their treatment options.

3 *Stigma of cancer:* Apart from myths, social taboos are also an obstacle in dealing with cancer. A diagnosis of cancer is a life-changing event commonly evoking feelings of shock, fear, anger, sadness, loneliness, and anxiety. The big C-word, as it is colloquially known, remains to be a taboo till date. Therefore, people who are diagnosed with cancer are often discriminated & stigmatized that in turn dissuades them from sharing their diagnosis and further seek treatment

4 *Fear of treatment and side effects:* The negative perception around cancer especially the misinformation surrounding treatment, side effects, and remission have certainly had an impact on treatment seeking behaviors. An early diagnosis of cancer and proper medical intervention would certainly lead to better prognosis and enhance the chances of disease-free survival.

Various factors such as the exorbitant price of the treatment and reluctance to deal with the side effects of standard treatment options such as chemotherapy force patients to choose unproven therapies and miracle cures that often result in deadly outcomes. It is indeed a great regret how years of scientific advancements that can result in remission and saving of lives can be easily undone by resorting to either inaction or reliance on unreliable and unscientific methods.

6.2. Common Myths and Misconceptions

MYTH: 01 | **Cancer is almost and always fatal.**

FACT: Not all cancers are fatal. While survival rates have been improving over the years, mortality depends on other factors like detection stage, type of cancer, parts of the body affected, etc. In fact, improved treatment options have made it possible for thousands of patients to be cured of the disease.

MYTH: 02 | **All cancers can be contagious.**

FACT: Apart from cervical cancer (caused by human papilloma virus) and liver cancer (caused by hepatitis B and C viruses), none of the other forms of cancer are contagious.

MYTH: 03 | **Lung cancer is prevalent only among smokers.**

FACT: Smoking undoubtedly increases the risk of lung cancer, but other pertinent factors like heavy exposure to asbestos, radon, uranium, arsenic, genetic pre-disposition, passive smoking and lung scarring from any prior illness can all lead to lung cancer.

MYTH: 04 | **Every abnormal growth is cancerous.**

FACT: Benign tumours do not possess the capability to metastasise. In case of any clinical problem, these can be surgically removed.

MYTH: 05 | **Cancer is predominantly a hereditary disease.**

FACT: Genetic predisposition is an important factor that contributes towards development of cancer, but all cancers are not hereditary. Only 5-10% of all cancers are attributed to genetic defects and the remaining 90-95% result from environment and lifestyle (Preetha Anand 1 2008)[88].

MYTH: 06 | **Sugars feed cancer.**

FACT: Sugar consumption does not directly imply the spread of cancer. Excess intake of sugar can lead to obesity and can, therefore, enhance the risk of cancer. (Biswas, 2014)[86].

MYTH: 07 | **Biopsies and surgery aggravate cancer.**

FACT: Bioposies are one of the most effective detection tools for cancer. It is a safe procedure that provides valuable information on the cancer diagnosis and also enable doctors to tailor the treatment. (Biswas, 2014)[86].

MYTH: 08 | **Drinking hot lemon water or three spoons of organic coconut oil daily in addition to not taking sugar can cure cancer.**

FACT: No research studies were found to substantiate the claims of curing cancer with a sugar-free diet, and drinking hot lemon water and organic coconut oil.

MYTH: 09 | **Supernatural factors and ill fate influence cancer.**

FACT: People often attribute an illness to supernatural factors, ill fate and witchcraft. These affect the wellbeing of patients due to delay in decision-making and seeking medical care.

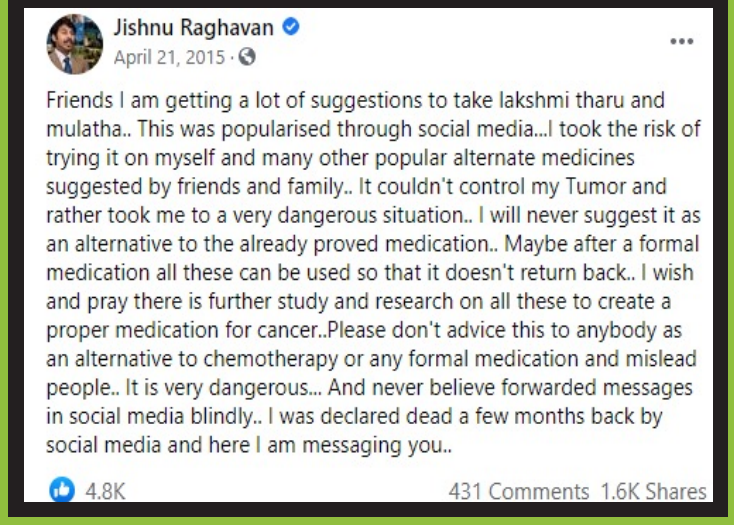
MYTH: 10 | **Cancer research is fruitless.**

FACT: Oncology, the study and management of cancer, is the fastest evolving branch of modern medicine today. Though the cause of cancer is still a mystery, the advanced interdisciplinary research has increased the scope of fighting the disease. Cancer research has brought in a number of new molecules that have helped to blend the targeted therapy, hormone therapy along with better surgical options, radiotherapy and chemotherapy to improve the disease-free survival of cancer patients (Biswas, 2014)[86].

6.3. Case Study- Tragic Demise of Malayalam Actor after Prolonged Battle with Cancer

In 2016, Malayalam actor Jishnu Raghavan passed away after battling cancer for two years. Having suffered from throat and lung cancer, the actor battled between hope and despair but unfortunately lost the battle to a vicious relapse. As in the case of famous personalities, actor Jishnu too was offered a lot of advice that included unscientific cures, personal anecdotes and wishful thinking that did not necessarily align with Western medicine.

Screenshot of the actor's message on social media



He attempted different remedies like local traditional plants including Lakshmi tharu (simarouba glauca) also known as the paradise tree and Mulathu/Mulethi (graviola). He took to Facebook to share his experience with his fans about how the belief-driven and not scientifically endorsed cures put him in a precarious spot. He left a note saying while altruistic suggestions of the loved ones are one thing, holding out any expectation of cure is another thing, especially when one is battling for life.

With its origins in Central & South America, Lakshmi tharu or the paradise tree found in parts of Kerala and Karnataka is believed to treat the side effects of chemotherapy, certain malignant cancers, dysentery, malaria, etc. Mulethi or liquorice root, on the other hand, is a sweetening agent used for medicinal purposes to cure various issues including sore throat, hair loss to now cancer, and is endorsed by Ayurveda and Chinese medicine. While these indigenous plants and roots do possess medicinal properties and consuming the concoctions can provide a certain relief to the effects of the aggressive treatments, there is no scientific evidence to prove that they will cure the disease, in this case, the cancer itself.

In fact, although most oncologists are on board with patients seeking traditional/alternate treatments to recuperate and boost their immunity, they have always cautioned that the traditional remedies must complement and not replace actual scientific treatment. As in the case of every cancer patient battling the disease, to quote journalist and cancer survivor Chitra Subramaniam, "Science matters in cancer treatment, so does faith and in that order" (Subramaniam 2016)[89].

Jishnu's cancer diagnosis was a misfortune and that is perhaps what incited his fans to prompt traditional medicine. However, Jishnu Raghavan advised caution to his fans against raising false hopes and expectations.

6.4. Experts Speak

DR GEETA KADAYAPRATH

She is a surgical oncologist with over two decades of experience, specialising in breast cancer surgery. Dr Geeta pioneered the establishment of sentinel lymph node biopsy and oncoplastic breast surgery as standard procedures in Max Hospital. She has spearheaded the formation of Breast Support Group, a forum that extends 'Care Beyond Cure' to breast cancer patients twice a month.

DR VINAY DESHMANE

He is a surgical oncologist and a specialist in breast cancer. He is the Medical Director of the Indian Cancer Society, and the editor of the Indian Journal of Cancer. He is amongst the first to have developed a specialised breast cancer treatment centre in the country. He has pioneered the development of breast endoscopy and oncoplastic breast surgery in the country. He is associated with the Breach Candy Hospital Trust, P. D. Hinduja Hospital and the Asian Cancer Institute, and has an experience of over 30 years in this field.

01 Of all the major ailments and diseases, cancer is often associated with immediate fear and imminent death. What are the things that people should know/be wary of?

Dr Deshmane: It is natural to be scared when you hear the word cancer, the big C as it is known. This is a natural phenomenon; you are scared of things you don't know. While everyone hears about cancer, it doesn't mean that every family has had or will have a patient with cancer. Cancer does not happen overnight. Cancer is basically an uncontrolled growth of cells similar to a software problem in your cells. Each cell has a normal lifespan; it grows, multiplies, divides. And when its function is completed, it dies. In cancer, the cell doesn't die. This is generally a very slow process, because our body has protective mechanisms. When things go wrong at the cellular level, they are corrected. It is when these mechanisms that protect us fail, that the cells start multiplying and become cancerous. This process takes many years. So, it is important to realise that cancer does not necessarily mean imminent death; there are so many treatments that are available. Detecting it early, and treating it effectively allows you to live a good, long life. And if caught early, one can lead a normal life doing practically everything that one wants.

Dr Geeta: Cancer has got these negative connotations, and this is something that has been handed over from generation to generation. But the fact is that the information that things have changed in these areas has not percolated down as quickly as this misinformation has that cancer means imminent death, which is untrue. And once you're diagnosed with cancer, what happens is there is a lot of panic and the panic essentially arises from the fact that most people go about with this notion that cancer is not curable; that whatever you do, it will come back and you just have a few months or a year or two years. And in many cancers, things have changed dramatically.

So, one thing I would suggest is that if someone is diagnosed with cancer, panic should go out because otherwise what happens is that any decision that you make in that state of panic is likely to be wrong, or incomplete, in the sense that the time that is spent to understand what is happening with this disease is very, very important. Broadly speaking, when you're diagnosed with cancer, there are three elements to it. The three stages of cancer treatment are diagnosis, followed by pathology and staging, and then treatment.

02

Misinformation about cancer in several local languages is far more accessible to common people than authentic information. As doctors, how do you address these myths and guide the patients or their loved ones in the right direction?

Dr Geeta: There is a lot of information online and patients usually come armed with some information. But as doctors, we have to put everything into perspective and tell them what the right way to move ahead is. So, the myths can start from the time of doing a biopsy or not doing a biopsy; patients think that a biopsy means that the disease is going to spread. But that is not true. For instance, in breast cancer, biopsy is the start point. You must have a diagnosis before you can decide how to deal with it. But there are other cancers where you should not do a biopsy, like in the cases with gallbladder or ovarian cancer, where you should not stick a needle. This common misconception about biopsy makes patients procrastinate, so they don't have a diagnosis, which in turn leads to delayed treatment. And obviously, the outcome also suffers in the bargain. Then there is also this myth that those without a family history of cancer

will not get the disease. But one should understand that family history and genetics contribute to only 5-10% of cancers and that the remaining 80-90% of cancers occur without a reason, what we call sporadic cancers. Therefore, the important thing is once you know that there is something wrong, you should visit your doctor and seek advice, which is where the balance is going to be. And that is where you're going to make your decision on how to go ahead with treating the disease. One thing that one should know about cancer is that your first chance is your best chance. And you should not whittle it away by spending time, energy and money on so-called magical cures and not getting anywhere and then finding yourself in a position where you will feel very disadvantaged and not able to get the kind of outcomes you could have had, had you gone to the right place at the right time.

03

What are your views on alternative medicine to counter cancer, especially when people are intimidated by surgery and chemotherapy? How should people go about seeking the right kind of treatment?

Dr Deshmane: In a place like India, where all of us grow up with alternative medicine and it is a way of life for many people, most of our patients will, at some point, take alternative medicine, because where there is hope, people tend to reach out for that hope, and alternative medicine offers that promise. There are patients who delay their treatment and take these treatments for a period of four to six months and only when they do not find an improvement, they return to allopathic treatment. But unfortunately, in some of these patients, the tumour advances, and what could have been treated more effectively has to be treated more aggressively. I'd like to say that if there is any truth that any of these treatments have been highly effective, then it will be a matter of practice all over the world. So, if there is any magical substance out there in alternative

medicine, the success of such a practice would have spread like wildfire. And in today's era of instant communication, no one can put a lid on it. So, yes, most patients will opt for alternative medicines. I personally don't have anything against people taking alternative medicines as long as they also follow what is accepted, proven medical treatment at the same time.

04

Breast cancer is the number one cancer that affects women of all age groups and across economic strata. How can women be wary or more aware of this given that there are home-based tests?

Dr Geeta: Even today, 70% of our breast cancers are picked up in advanced stages. So, our challenge is to reduce the number of stage fours that we see and bring them to a stage two and to convert the number of stage threes to stage ones. And that is possible only if women are aware of their own breasts. Therefore, breast self-examination, I would say, although very underrated in the West, is of prime importance for a population like ours, where access to screening mammograms is poor. So, you should be doing a breast self-examination every month.

The trouble is that our women are so loath to touching themselves, and it is only when the disease is so big and visible that they come to the doctor. So, getting into the habit of examining yourself once a month, three days after your periods are over in those women who are having their periods is very important. Familiarising yourself with your breasts essentially means that you will be able to pick up an abnormality if it were to happen. And for those women who have stopped having their periods, they can possibly start examining themselves on the first of every month or a day that coincides with their birthday or anniversary. The essential idea is that you do it diligently and regularly every month. So, this is a weapon that you have in your hand, and this is what can bring about early diagnosis as far as breast cancer is concerned.

Dr Deshmane: As you rightly said, it affects women across economic strata. And what's really been happening in the last two to three decades is that because of rapid urbanisation, we are seeing a larger number of breast cancers. However, the good news is that it can be treated extremely effectively, without removal of the breast, and it is possible to live a long life if you detect this cancer early. The easiest way is to do something called breast self-examination, which simply means that you get used to the feeling of your own breasts by palpating it once a month. The best time is that after your periods, and if you feel any lump in the breast, which persists despite having one or two periods, then you should seek a doctor's attention. The other way is by undergoing mammography. Mammography is an effective tool for diagnosing early cancers. There is something called a breast MRI, which may be used in women who have a significant family history and in young women with dense breasts. Only 7-10% of breast cancers are related to transmitted breast cancer genes. These genes are transmitted through families and cause the basis for these cancers. So, most cancers in the community are sporadic.

05 As someone who treats cancer patients, how should patients go about seeking treatment from the starting to the end and eventually get better and overcome this disease?

Dr Geeta: Being in a positive frame of mind is a huge plus; I am a witness to that because I run this breast support group in my hospital. And I've seen my patients thrive on the kind of positivity that emanates out of that group. This feeling of isolation and loneliness and feeling singled out as that one person who's got cancer goes when they interact with so many other women who've had cancer and see how they bounce back and live life much better than what they used to before cancer. The tips that they share, the positive vibes that they share, the kinds of modifications that they have brought to the lifestyle that they share, the kind of things that they do to fill themselves with positivity that they share it's a kind of hand-holding that not even a clinician can do. Because it makes more sense for a patient to hear from people who've been through the experience. I always tell my patients that they have to take one step at a time. So don't think that it's going to be eight-and-a-half months of torture, or one year of torture. Don't plan too much into the future; just focus on doing one thing at a time. It is important to focus on the treatment because you must realise that your goal and my goal at the end of it is the same and that is to get past this disease and cure you of the disease. And whatever it takes to get there, we have to commit ourselves to doing it.

06 What do you think is the way forward in debunking cancer-related misinformation? How should we sift the facts from the myths that are widely available both online and offline?

Dr Deshmane: I think the most important aspect is for patients to start understanding what cancer is. They are bound to read like everybody now reads on the internet, or tend to ask family and friends, but when they hear things, they must run these past their doctor. Only experts can help you sift the fact from the myths. They must also realise that common sense will always tell us that if there is something which is working, or highly effective, this sort of a truth especially related to cancer cannot be hidden anywhere in the world today. Everyone would get to know of it; it would have been in the newspapers and mass media by now. In fact, every few months, you will hear something about a magical drug coming up and then you don't hear too much of it later. So, there's always a new treatment on the block but again, most of these therapies, treatments, and alternative medications have not stood the test of time. So, it is very important to be logical in your thought process. Have belief in your doctor and trust in them. Finally, it is most important to realise that cancer can be cured or treated very effectively if detected early. So, listen to your body, and if there is something which worries you, seek medical advice.

6.5. Conclusion

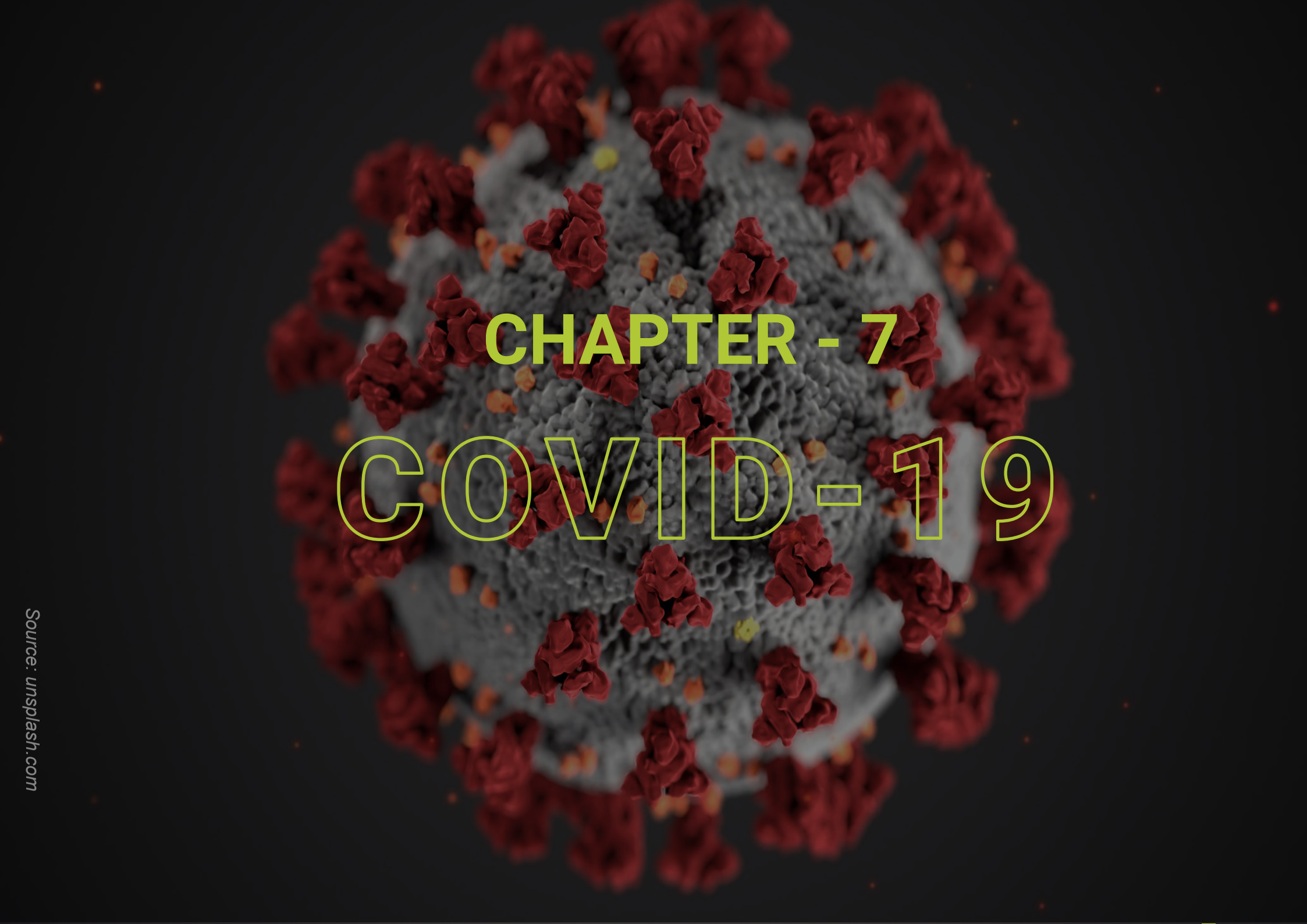
Cancer research has made a lot of progress over the past few decades and continues to do so today. Yet, cancer-related misinformation percolates to people through both online and offline vectors. Given how simple the images read or the videos play to convey the inaccuracies, especially to people who are looking for that one ray of hope, misinformation has proved to be influential in patients seeking treatment and their behaviour. Therefore, there is a massive need to be tuned in to this conversation as cancer can happen to anyone, and so, having the right information becomes crucial in the fight against it. As such, believing false information has many harmful effects, especially given the fatal nature of the disease. The complexity and diffusion of misinformation ranges from word-of-mouth to magical cures or herbal remedies to science journals based on a germ of truth or possess a minute anti-cancer characteristic. However, one must be careful to not fall for these unscientific treatments and lose time by replacing a more established and scientific treatment. As Dr Geeta Kadayaprath says,

> Your first chance is your best chance. And you should not whittle it away by spending time energy and money on the so-called magical cures and not getting anywhere and then finding yourself in a position where you will feel very disadvantaged and not be able to get the kind of outcomes you could have had had you got to the right place at the right time.

The antidote to uncertainty is awareness. Dr Vinay Deshmane pitches in,

> Awareness is the first step to tackle the challenges of cancer. Being aware of the body and symptoms would mean early detection which in turn implies effective and less aggressive treatment. The last block of this chain would only suggest the inverse relationship of effective treatment and death rates, i.e., more effective the treatment, fewer will be the deaths due to cancer.

Added to this would be the role of the medical fraternity, governments, fact-checkers and social media giants to ensure and promote the visibility of public-health campaigns related to cancer, especially preventive measures and risk factors. While it is true that misinformation enjoys broader coverage than fact, the public must be educated to verify online and offline cancer misinformation by pushing the accurate content through relevant public-health communication.



CHAPTER - 7

COVID-19

Source: unsplash.com

7.1. Literature Review

Coronavirus refers to a large family of viruses known to affect birds and mammals, including humans (Desk, Home: WHO | Coronavirus (COVID-19) Disease, n.d.)[90]. The recent disease, COVID-19, that first appeared in China in December 2019, is caused by a type of coronavirus. There are hundreds of coronaviruses but only seven are known to affect human beings. Four out of the seven (229E, NL63, OC43, HKU1) are known to only cause mild cold or flu-like symptoms. The remaining three coronaviruses pose serious risks to humans.

Currently, SARS-CoV-2 has caused a global pandemic affecting most countries in the world. The transmission occurs predominantly from human contact, or one who has contracted the virus through small droplets from the infected person's nose or mouth. In this context, it has been recommended to maintain at least one-metre distance between individuals. The most common symptoms include fever, dry cough, and tiredness[90]. Less common symptoms include pains, nasal congestion, headache, conjunctivitis, sore throat, diarrhoea, loss of taste or smell, or a rash on skin or discolouration of fingers or toes. Most people (about 80%) recover from the disease without needing hospital treatment. Around one of five people who gets COVID-19 becomes seriously ill and develops difficulty breathing. Older people and those with inherent medical problems like high blood pressure, heart and lung problems, diabetes, or cancer are at higher risk of developing serious illness.

While pandemics are not a novel phenomenon, COVID-19 is the first pandemic in history where social media and technology have been leveraged to connect, inform, and engage people. The simultaneous spread of the pandemic along with the infodemic has caused an unprecedented outbreak across the world and India is no exception to this. Like the virus mutations, misinformation has also manifested over time since the beginning of the pandemic. In the Indian context, the misinformation can be categorised into six broad themes including:

1 *Symptoms and causes of the virus:* Several symptoms (mild and serious) were labelled as COVID-19. For instance, common flu symptoms such as headache or runny nose were not labelled as COVID-19, making people either anxious or very lenient about the symptoms.

2 The internet has seen the dawn of several COVID-19 cures including drinking hot garlic or lemon water and even alcohol. This also led to a section of people relying on these magical cures instead of seeking proper and timely medical treatment (Reddy, 2020)[91] (Mandadi, 2021)[92].

3 There has been a significant share of misinformation on the origin and the spread of the virus. Shocking images and videos were shared linking them to the COVID-19 burden in different countries, which were untrue.

4 Medical authorities and governments were also not immune to misinformation given that official logos were misused to propagate false information including fake government orders on lockdowns, timings, cures, etc. (Sripada, 2021)[93].

5 Conspiracy theories on how COVID-19 is a human-made pandemic to depopulate the world or that the virus will make minority communities impotent and thereby regulate their population, Chinese military scam, 5G technology caused the second wave in India, and other bizarre theories have floated around (Kalidoss, 2021)[94].

6 The final theme includes vaccine hesitancy since the beginning of the vaccine rollout. While in the beginning, people including frontline workers were sceptical of the vaccine timelines and its efficacy, several states in India struggled with low turnouts. Over the last four months, owing to the misinformation circulating on social media, people have either moved to a wait-and-watch approach or have rejected the vaccine. The reasons for hesitancy/refusal include social media content (unscientific cures, conspiracy theories, rumours, fake news), anecdotal (word-of-mouth, past experiences), rumours in case of digital divide in rural India, sense of invincibility, lack of safety around vaccination centres, serious consequences post inoculation including impotence and death, religious reasons, choice of vaccines, changing guidelines of the gap between the doses, etc.

Health authorities including the World Health Organization (WHO) and the Ministry of Health & Family Welfare of India have developed timely information, education and communication material on handling the COVID-19 crisis including strategies adopted from the international framework. These include wearing masks and practising social distancing, among other things. However, there lacked a robust risk communication plan excluding vulnerable communities, migrant labour, sex workers, and others. This chapter focuses on the importance of a robust risk communication plan and the role of stakeholders in communicating and navigating the misinformation crisis.

7.2. Common Myths and Misconceptions

MYTH: 01 **Camphor, hot boiled garlic, lemon and baking soda mixture, rinsing nose with saline water, etc. can cure COVID-19.**

FACT: There is no scientific evidence to prove that any of these mixtures or ingredients can kill SARS-CoV-2. As of today, there is no mixture/medicine to prevent or cure COVID-19 (Kalidoss, Factly, 2021)[95].

MYTH: 02 | **Non-human DNA will be introduced into our bodies which will, in turn, enable humans to pick up certain animal traits.**

FACT: There is no scientific evidence that the mRNA vaccine will introduce non-human/animal-like traits in human bodies.

MYTH: 03 | **COVID-19 vaccine contains pig fat/pork gelatine, thus dissuading Muslim population from taking the vaccine since they consider it haram.**

FACT: Gelatine derived from pigs is used in some live vaccines as a stabiliser to protect live viruses against the extreme temperatures, but the COVID-19 vaccines developed and approved in India do not contain any pig fat.

MYTH: 04 | **Women should avoid COVID-19 vaccination during their menstrual cycle.**

FACT: Ministry of Health & Family welfare did not say anything regarding the vaccination of women during their menstrual cycle under the contraindications (conditions that suggest one should not take the vaccine) section, which implies women can get vaccinated during their periods. International health agencies like WHO have also not suggested that menstruating women should not take the COVID-19 vaccine.

MYTH: 05 | **WHO has accepted an Indian student's home remedy as COVID-19 cure.**

FACT: There is no authentic information that an Indian student from Pondicherry University has found a cure for COVID-19. The WHO website clearly states that, to date, there are no medicines that can prevent or treat COVID-19.

MYTH: 06 | **One can check for COVID-19 by holding their breath for 10 seconds or longer without coughing or feeling discomfort.**

FACT: According to the CDC, you can have the coronavirus and have no symptoms and can also transmit the virus before showing any symptoms. As per the WHO, "the most common symptoms of COVID-19 are dry cough, tiredness and fever". (Desk, WHO: Advice for the public, n.d.)[96]

MYTH: 07 | **COVID-19 vaccine causes infertility in men and women.**

FACT: The vaccine trials are also being tracked by the WHO and it has found that none of the COVID-19 vaccines differentiate between males and females.

MYTH: 08 | **Hand dryers and UV disinfection lamps are effective in killing the coronavirus.**

FACT: According to the WHO, "hand dryers are not effective in killing the coronavirus. UV lamps should not be used to sterilize hands or other areas of skin as UV radiation can cause skin irritation. To protect yourself against the new coronavirus, you should frequently clean your hands with soap and water or an alcohol-based hand rub." (Desk, WHO: Advice for the public, n.d.)[96]

MYTH: 09 | **Extreme hot showers or baths prevent COVID-19.**

FACT: According to the WHO, "your normal body temperature remains around 36.5°C to 37°C, regardless of the temperature of your bath or shower. In fact, taking a hot bath with extremely hot water can be harmful, as it can burn you." (Desk, WHO: Advice for the public, n.d.)[96]

MYTH: 10 | **Drinking alcohol can prevent COVID-19.**

FACT: According to the WHO, "drinking alcohol does not protect you against COVID-19 and can be dangerous. Frequent or excessive alcohol consumption can increase your risk of health problems." (Desk, WHO: Advice for the public, n.d.)[96]

7.3. Case Study- Vaccine Hesitancy in Rural India

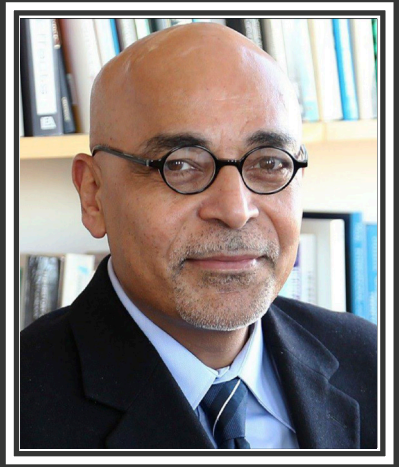
A video from Uttar Pradesh's Etawah district surfaced where an old woman was seen hiding behind a drum fearing COVID-19 vaccination, showing how real vaccine hesitancy is in the rural belts of the country. The elderly woman in the video is seen ducking and hiding behind the drum while healthcare workers and family members try to persuade her. The saga continued until the healthcare workers convinced her to come out from her hiding place under the premise that she will not be injected with the COVID-19 vaccine.

Similar stories were heard from other villages in Uttar Pradesh where villagers fell prey to misinformation that healthcare workers would inject people with poison instead of the COVID-19 vaccine. In May 2021, residents of Barbanki village in Uttar Pradesh fled their homes and jumped into the Sarayu river when healthcare workers and officials went to vaccinate the village.

> *The residents of Barbanki village in Uttar Pradesh fled their homes and jumped into the Sarayu river when healthcare workers and officials went to vaccinate the village. (**Live Mint**)*

Owing to the misinformation about COVID-19 vaccines being poisonous, villagers jumped into the river to avoid the vaccination campaign. Owing to poor and unclear communication, the ripple effects of vaccine hesitancy are especially seen in the rural and tribal-dominant regions and among the minority communities. Analogous resistant stories were observed across the country. Abuses were hurled at doctors and healthcare workers in the states of Bihar and Madhya Pradesh. In Indore in MP, stones were pelted at doctors while in Bihar, residents shut the doors to their houses to resist vaccination. The reluctance to vaccines includes believing unfounded rumours of vaccination inducing infertility, impotence or death. This is a classic instance of how fears, myths and rumours have translated into real-time and large-scale hesitancy and a dip in the vaccination uptake.

7.4. Expert Speaks



PROF. K. VISWANATH

He is Lee Kum Kee Professor of Health Communication in the Department of Social and Behavioural Sciences at the Harvard T. H. Chan School of Public Health (HSPH). He is also the Director of Harvard Chan India Research Center and the founding Director of DF/HCC's Enhancing Communications for Health Outcomes (ECHO) Laboratory. Dr Viswanath's work, drawing from literature in communication science, social epidemiology, and social and health behaviour sciences, focuses on translational communication science to influence public health policy and practice.

01 India does not have an anti-vaccine movement like the kind seen in the United States or Europe. However, there is a lot of vaccine hesitancy manifesting now. And this is mostly due to the uncertainties around COVID-19. So, as an expert who has worked with vaccine hesitancy issues in the United States, how do you suggest we address this uncertainty and hesitancy, and how do we build trust and confidence in the public?

Prof. Viswanath: Let us disentangle that notion. If you can look at it, there are roughly three groups. There is one group of people about whom we don't have to worry; they are what we call vaccine compliant, they are the first to go out and get it. We just have to reinforce what they have done, encourage them, and get them into a clinic. Then there is the anti-vaccine group, that does not accept any convincing. I think this is a group that is determined not to get vaccination. The third group is what we call fence sitters. This is the group with doubts and can lean on to either side. Therefore, what I suggest is, let us figure out what are the underlying bases for those who are hesitating even when they get a chance. Is it just complacency? If it is complacency, we should make it easy for them to get it so that they run out of excuses. Let me give you an example, once adequate number of doses are available in India, we can say, I will give it to you in your workplace. So, you don't have an excuse to say I have to go to a clinic and get it. I will give it to you in your place, I may have a mobile van, I will come to your neighbourhood, your apartment complex, and administer to everybody. We can do that; India has done it. The complacency part can be addressed. And then the misinformation part could be of two types. One type is it doesn't really matter, because you get it anyway. And for that, the message is that it matters. Because even the number of people who end up getting it is much smaller than people who are not vaccinated. Even if you get it, vaccination will reduce hospitalisation and severity. It will help you. And then there is the hesistant group, which trusts rumours, myths and folklore, and that's a group we must observe very carefully, and see what these rumours and myths are, and then provide adequate information to continuously promote conscious thinking. You can't force them, but you can promote conscious thinking about how baseless the rumours and myths are. And we need to find out whom they trust as sources. Is it the doctors? Is it actors and other celebrities? In our case, I would argue that it is our neighbours and friends and family. Because that's where the most powerful persuasion is. Family members, neighbours and colleagues, and doctors (who are always trusted) can push them towards vaccination. That's the strategy.

02

As of today, there is ample literature and, in fact, there's information overload around COVID-19. And the research continues to evolve by the day as we speak. So, how can this evolving research be effectively communicated to people?

Prof. Viswanath: This is possibly one of the most difficult questions to answer and the reason is, we always communicate and when you talk about communication of risk, it is always about communication of uncertainty. And you are talking in terms of probability, if you don't do it, you are likely to get it. That is a term we use, and people have difficulty understanding or internalising probability. I always give my favourite example, which is very simple. If I see dark clouds in the sky, I'll take my umbrella with me. I calculate the probability by my prior experience, which is that dark clouds means it might rain. Why don't I play safe? It may not rain, but I played safe, right? So that's how you calculate your uncertainty and we have always done that. But I think with COVID-19, it's been tough because, number one, the knowledge is changing every day, every week. Take the delta variant: we were getting very comfortable here in the United States, and we were looking at India and wondering what's happening in India? Why is it spreading so fast? Is it because they have opened too soon? Is it because they are complacent? And then when it has spread across the world, we are realising that this is a completely different strain, much more viral and much more serious. So, we are learning, that's one challenge. The second challenge with COVID-19 is, if you remember, we did not know anything in January of 2020. Seventeen months later, we know a lot. In every other scientific topic, you take two years, 10 years, 15 years, 20 years, to learn about those topics. All of this has been happening in 17 months, and there have been, I think, something like 150,000 publications, right? Millions of posts, and that's the information overload. And so, people are having trouble coping with it.

So, how do you communicate uncertainty? This is my recommendation. One, we know something we know. We stick to those facts we know for sure. We take credible sources, like healthcare professionals, politicians and decision makers, and journalists are extremely important here too. Two, we have to be transparent in saying what we don't know. It's very important to tell people what we don't know. That's when people start trusting you because you're being honest with them. You're saying this is what we know, this is what we don't know, this is what we recommend, and we will update you, complete transparency, that is not hiding anything. Also, providing information about what we know and don't know through credible sources such as healthcare professionals, journalists, and other decision makers including politicians will go a long way in reducing misinformation. Now, it's extremely important to do that, and journalists have a critical role to play in this.

03

Vernacular media journalists are important stakeholders in effective public communication. But there is a lot of contradictory information also available on the internet. So how should they sift the facts and and report the unknown, all while remaining a credible source?

Prof. Viswanath: When 10 studies are published over 10 months, six of them agree with findings and four of them may not agree because that's the way science works. Science is a self-correcting mechanism. I can go to the Journal of American Medical Association and say there is a new article that has come out, which says drug x seems to be effective. That's great. Okay, so what is the lay person or the non-technical person's understanding of the drug? What is the trial? Who is funding the trial? What are the data saying? You don't have to know sophisticated statistics, what you need to know is something about the design of that study. Is it just one study? Is it two studies? Is it 10 studies? Just because one study is reporting something, doesn't mean those findings are durable. Tomorrow there will be another study which will disprove that. So, you might want to wait for four or five studies. Even on WhatsApp, I see lay people spreading information on some drug that has proven to be effective. No, don't rely on one study alone. To know something about the design principles of research, go to these reliable sources, and look at what is the consensus in the sources, so they might contradict each other, but if there is an overall consensus, you report on that.

04

How should the stakeholders in health communication come together and adopt strategies/best practices?

Prof. Viswanath: One of the best practices is information surveillance systems. Unfortunately, the governments have not been doing a good job. I want a communication system around risk and disease. Our communication systems are built for the 20th century environment but what we have is a 21st century problem. Therefore, the first thing we need to do is bring our communication systems in the government into the 21st century media ecosystem. And number two, I think we really need to train reporters: we must invest in reporters on science, communications, communication of science and health. It is easy to blame the journalists for getting one story wrong, one fact wrong, but the question you have to ask is, how have you helped the journalist to get it right, especially if they are running around, writing three or four stories a day? So, we have to have a system in place, and the skills in place. The government has to have a communication system that is suitable for 21st century, to build systems with

the media, capabilities and capacities. And then we have systems that we have to provide to healthcare providers. Most of them don't know how to communicate, they're not expected to communicate. You need to provide the healthcare providers the systems and support to enable proper engagement with the public/patients. Then we must work with NGOs; NGOs are very critical, because they are working in the trenches. How do you provide help to them so that they can communicate risk in a reliable way? So, it is imperative that we work with all stakeholders; it is not one group's problem.

05

We are often influenced by the people around us, but misinformation has seeped into our households and our daily lives in the online and offline worlds. What is the way forward to combat this misinformation?

Prof. Viswanath: We have published a few papers in which we found that in every group, there is one person, or at least two people whom we call health information mavens. What we mean by that is this is a group of people who are somehow anxious, who feel like they should share information with everybody around them. Every family has one, every networker group has these mavens. The more interesting part of this is that these mavens are no more knowledgeable than the information you see and that is the problem. Therefore, the first thing is to ask questions: Who is the source? Where did they get this information? Who has funded the trial? etc. If you're buying a product, you do a lot of research, especially if it's an expensive product. If you're buying a car in India, a scooter or a washing machine or refrigerator, you ask around. You don't just go by ads. You ask friends, you go to the showroom, you ask a ton of questions, you bargain with them. If you're going to do that for a for a product, don't you want to do that for health information that affects you? Also, media organisations, communication and public information departments in the government, hospitals, healthcare providers, NGOs are all part of the system that must work together for communication to be effective.

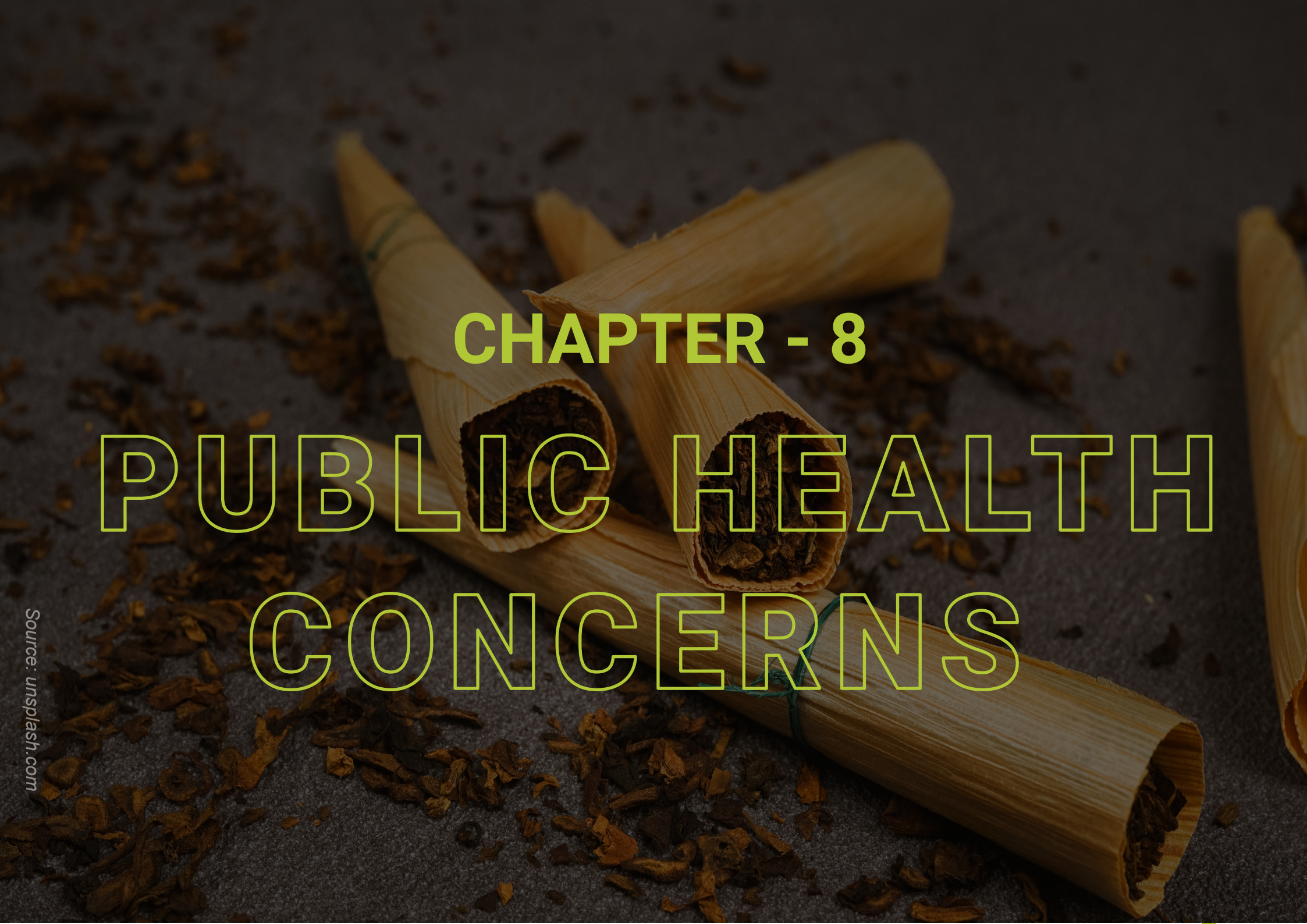
7.5. Conclusion

Like the novel coronavirus, there is no cure for misinformation yet, since we are more reactive in sharing it than proactive in curbing its spread by nipping it in the bud. As seen above, the rampant misinformation including false cures, rumours, and conspiracy theories has the potential to adversely affect the efficacy of containment strategies; in this case, for example, it has manifested as vaccine hesitancy. Also, a widespread attitude observed in India is a sense of invincibility, i.e., one would not be affected by COVID-19, thus distorting their risk perception towards the disease. Misinformation coupled with the delta variant resulted in a deadly second wave that included severe cases requiring hospitalisation, higher mortality rates, disease burden, and eventual economic fallout. With the information overload on COVID-19, especially with contradicting information and misinformation, a recent study by Uscinski et al reinstates the proclivity to reject information from experts and also due to psychological predisposition (Dr Meghan McGinty, 2020)[97].

For instance, given the diversity and distinct topography of the country and the varied reasons behind vaccine hesitancy, there is no one-size-fits-all solution. It is imperative to curate and adopt local solutions through the concerted efforts of community stakeholders including the local government from District Collectors to the Panchayats, civil society organisations, teachers, healthcare workers (doctors, nurses, ASHA workers), local influencers, etc. However, one must be careful in devising local strategies, especially in the case of vaccine hesitancy, which has behavioural and psychological aspects to it. For instance, while incentivisation or compulsion of vaccines appear to be feasible, it will only further erode the trust in the efficacy of vaccines and institutions. Similarly, social media giants like Facebook, Twitter and Instagram have been at the forefront, especially in curbing COVID-19 misinformation through: collaborating with fact-checkers to identify contextual and regional misinformation; identify some of the 'famous' fake experts and take the necessary action to halt the spread of misinformation; and direct official authorities towards COVID-19 and vaccine-related news on these platforms. As discussed above, it is not the role of one stakeholder but many such as the individual, family, local government, state and national governments, media, expert authorities, and health officials, all of whom have a huge role to play in strategising health messaging and combating misinformation.

While there is no one-stop solution to the deep-rooted problem, a starting point for an individual is to be more educated: not believing a piece of information that is too good to be true and identifying the fact instead of an emotion in any given information. It is important

to believe only in science since it is evidence-based but believe it with a pinch of salt. As Prof. Vishwanth says, "science is a self-correcting mechanism", especially since information is evolving in nature on a subject like COVID-19. When in doubt, seek the help of fact-checking agencies and engage with them to know more about credible sources, authenticity and understanding the methodology to sift the fact from the information overload. An effective practice is to pause before sharing, an added layer of responsibility before sharing and consuming information to build resistance against misinformation. It is highly suggested to seek information only from credible health authorities and, in the case of COVID-19, continue to wear masks, practise social distancing, and get inoculated against both COVID-19 and the prevalent misinformation.



CHAPTER - 8

PUBLIC HEALTH CONCERNS

Source: unsplash.com

8.1. Literature Review

According to the National Centre for Biotechnology Information (NCBI), public health is concerned with disease prevention and control at the population level, through organised efforts and informed choices of society, organisations, public and private communities, and individuals (Lakshminarayanan, 2011)[98]. However, the role of the government is crucial in addressing these challenges and achieving health equity. These include alcohol and tobacco consumption, addiction and rehabilitation, HIV, TB, malaria, eating disorders and obesity, teenage pregnancies and unwanted abortions, air pollution, etc. While India has made a significant transition both in terms of its economy and healthcare in better life expectancy, and decreased infant and maternal mortality rates, it continues to suffer from the triple burden of diseases, including infectious/communicable diseases, non-communicable/lifestyle diseases, and the emergence of new microbes causing pandemics and epidemics (Narain, 2016)[99]. Tobacco consumption, for instance, is the most easily preventable risk factor for premature death in the world, and yet, in developing countries like India, the consumption of cigarettes continues to increase. Owing to its easy accessibility, availability and affordability, tobacco is one of the biggest public health threats both in India and globally. Thus, this chapter aims to cover misinformation around tobacco consumptions under public health concerns, given the extent of social, environmental, and economic costs.

Tobacco Consumption

Tobacco contains over 4,000 chemicals including carcinogenic compounds and 400 other toxins. India is the second largest consumer of tobacco in the world, after China, with 266.8 million adults consuming different tobacco products (Desk, n.d.)[100]. The prevalence of tobacco use among males is 42.4% and that among females is 14.2%, according to the Global Adults Tobacco Survey 2016-17 (WHO)[101]. The survey also presented that about 55% of the current smokers in India are planning to quit, while 48.8% of smokers have been medically advised to quit smoking. According to a report by the Ministry of Health and Family Welfare, the total economic costs attributable to tobacco usage-related diseases in India in 2011 for people aged 35-69 was Rs 1,04,500 crore (around USD 22.4 billion) (PHFI)[102]. India is home to roughly 11.2% of the smokers in the world and 1.35 million people in the country die every year due to tobacco-related illnesses, while 27% of the cancer cases in India are due to tobacco usage. In the context of the environment too, the millions of cigarette butts dumped in the world's beaches leach lots of toxic chemicals into the oceans. Therefore, given the intent and the necessity for tobacco cessation, tackling misinformation becomes quintessential in addressing this public health problem.

8.2. Common Myths and Misconceptions

MYTH: 01 | **Nicotine is the only harmful substance in cigarettes.**

FACT: While nicotine is the addictive substance, cigarettes have thousands of chemicals including lead, arsenic, ammonia, radioactive elements, etc., and at least 70 of them are carcinogenic.

MYTH: 02 | **Smoking relieves stress.**

FACT: While smokers justify the act of smoking as relieving stress, in reality, it increases tension and anxiety in the body, while nicotine creates a sense of relaxation and this perceived relaxation in turn creates a sense of craving.

MYTH: 03 | **Rolling your own tobacco is more natural than factory-made.**

FACT: No matter how 'natural' the rolling is, tobacco is harmful in all forms and has thousands of chemicals and gases.

MYTH: 04 | **Quitting after years of smoking is futile as the smoker's systems are permanently damaged.**

FACT: Multiple studies have shown the positive effects of quitting smoking including the repair of lungs, reduced levels of carbon monoxide, normalised blood pressure, and reduced risk of heart diseases and other tobacco-related diseases.

MYTH: 05 | **E-cigarettes, hookah, and cigars are safer alternatives.**

FACT: It is a myth that there is no nicotine (a highly addictive substance) in hookah or e-cigarettes. These are equally harmful. In fact, the coal used in hookah releases a higher amount of carbon monoxide than traditional cigarettes.

MYTH: 06 | **A lot of smokers live into old age and so, smoking is perhaps not that harmful.**

FACT: Most people buying into this argument are not informed of the risks and probability of tobacco-related diseases and cancers. Only quitting smoking can improve life expectancy and quality of life.

MYTH: 07 | **Social smokers are not at the risk of addiction.**

FACT: Owing to the addictive nature of nicotine, according to American Cancer Society, anyone who starts smoking can become addicted to nicotine and have a tough time quitting it.

MYTH: 08 | **Chewing tobacco is safer than smoking tobacco since there is no inhalation of smoke.**

FACT: Chewing tobacco is as harmful as smoking given that chewing likely develops oral cancers on the tongue, cheek, lips and gums.

MYTH: 09 | **Cutting back on cigarettes is good enough, if not quitting.**

FACT: Often, it is not the number of cigarettes but taking more puffs or inhaling the tobacco more deeply and harder to over-compensate that is the issue. This also gives them a false sense of security and further delays cessation.

MYTH: 10 | **Medications do not aid in quitting smoking/one should wait for the 'right time' to quit.**

FACT: Several medications can lower nicotine withdrawal and thereby help overcome addiction. Medication paired with therapy and will power will aid the withdrawal process.

MYTH: 11 | **Menthol cigarettes are harmless.**

FACT: Menthol cigarettes have added flavours in addition to the same nicotine and the flavour can, in fact, make it more addictive than traditional cigarettes.

MYTH: 12 | **Non-smokers are safe from lung and other cancers**

FACT: From air pollution to second-hand smoking, non-smokers are also exposed to/at risk of lung cancer through inhaling carcinogens.

8.3. Case Study- Tradition vs Science among Hookah Users in Rajasthan

About the Cigarettes and Other Tobacco Products Act

The Cigarettes and Other Tobacco Products (Prohibition of Advertisement and Regulation of Trade and Commerce, Production, Supply and Distribution) Act (COTPA), 2003 is applicable to all products containing tobacco in any form, i.e., cigarettes, cigars, bidis, gutka, pan masala (containing tobacco), mavva, khaini, snuff, etc., across the country. The recent amendment to the Act in 2018 prohibits any person from 'owning or opening and running on behalf of someone else, a hookah parlour at any place in the state, including at eating houses'. The rationale behind the amendment was both safety concerns of hookah parlours and to discourage youngsters (minors and college students) from consuming hookah that contains tobacco.

A new University of California, Los Angeles study finally busted the myth that smoking hookah is safer than smoking a cigarette (Mary Rezk-Hanna, 2018)[103]. It finds that smoking hookah for 30 minutes has a similar probability of developing cardiovascular risk factors (stiffening of arteries) as smoking a cigarette and, therefore, concludes that hookah is hazardous. In fact, flavoured hookah does have tobacco as against the usual belief that is not a tobacco product. The coal that is used is also harmful to the user.

> *Traditionally, hookah consumption is a deep-rooted cultural norm and a social event in most of the rural areas, so much so that it is an everyday gathering after work in the fields (gram chaupals), weddings, and all social gatherings including funerals.* ***(Times Of India)***

However, the COTPA amendment is a challenge to the cultural norms followed in the villages of Rajasthan. Traditionally, hookah consumption is a deep-rooted cultural norm and a social event in most of the rural areas, so much so that it is an everyday gathering after work in the fields (gram chaupals), weddings, and all social gatherings including funerals. This has made it difficult for health authorities to implement the amended COTPA in the rural areas, where the elders especially refuse to comply with the ban. Unlike in the urban setting, hookah in these villages is not recreational but a part of social norms that binds people together. The villagers explain that unlike in the urban areas, they make their hookah with jaggery and tobacco and believe it to be safe, if not less harmful, than the chemical hookah and liquor. However, there is enough evidence that tobacco is harmful in any form and the goodness of jaggery does not overcompensate for the harmful chemicals in the tobacco. Health officials and activists continue to disseminate awareness both about the law and the harmful impact of tobacco that will disrupt their social fabric at the community and individual levels. Therefore, consumption of tobacco in any form including hookah in unhealthy and is a grave public health concern for which appropriate laws are in place.

8.4. Experts Speak

DR PREETI KUMAR

She is Vice President, Public Health System Support at the Public Health Foundation of India. She is an ophthalmologist and a public health specialist, working in the area of health systems, in the domain of infectious diseases She has over 25 years experience of working with the Government of Uttar Pradesh, Ministry of Health, Government of India, World Health Organization (WHO) and the Global Fund to fight AIDS, Tuberculosis and Malaria.

DR SONU GOEL

He is working as Professor in the Department of Community Medicine and School of Public Health, Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh with over 18 years of experience in the field of public health. He has written over 140 papers, authored 35 chapters, produced 12 films on national health programmes, and edited many books on public health. He is also Vice-Chair of Tobacco Control section of International Union against TB and Lung Diseases.

01 What are some of the biggest challenges in public health concerns (HIV, TB, alcohol and tobacco consumption, addiction, eating disorders, etc.) and how should these challenges be dealt with?

Dr Kumar:

1. The lack of a universal healthcare approach results in siloed investments in planning, financing, and implementation of all disease prevention and control programmes.

2. The health system response is reactive rather than anticipatory or proactive: the priorities are still infectious diseases, while the Global Burden of Diseases study clearly demonstrates the higher impact of noncommunicable diseases on morbidity and mortality across the country.

3. Priorities and investments continue to be influenced by global agendas, where infectious diseases in LMIC (low- and middle-income countries) have a large potential impact globally rather than nationally. Similarly, the effect of global strategies on national strategies. An example of HIV: despite the prevention programme of HIV in India demonstrating great success, funding is increasingly diverted to testing and treatment, while time-tested strategies on prevention are not a priority.

4. Structural investments in the public health system strengthening continue to be limited, with the public and private sectors siloed: public systems continue to focus on emergency and priorities while the entire spectrum of healthcare provision lies in the private sector.

02 What are some of the biggest challenges in tobacco control? And how should we deal with these challenges?

Dr Goel:

Tobacco is one of the problems where we have excellent laws, not only globally, but also in our country, and most people are aware of these laws. However, the challenge arises in the proper implementation of these laws. Although we know that smoking in public is an offence, people continue to do so without any consequences like fines. Bystanders do not report these smokers either. Number two, the tobacco industry, which is the organisation, or the people who are involved in the tobacco trade, from production to consumption, usually try and find loopholes in the law, delay or dilute the implementation through lobbying. That is why the tobacco industry is the biggest challenge for tobacco control advocacy in the country. Although we must abide by the WHO's 5.3 framework convention on tobacco control, like every other country in the world, we still have several challenges. The third issue is the question of banning tobacco. The problem with this is that it is not just the decision of

the Health Ministry; 13 ministries are involved in tobacco control, right from the agriculture ministry, to taxation, to customs, to education, to excise and taxation, finance ministry, and so on. Therefore, we must advocate and appeal to each of these ministries for tobacco control as the health ministry is just a minuscule stakeholder in tobacco control.

03

Behavioural change is one of the toughest things to achieve, especially with something like addiction. How do we address this public health concern?

Dr Goel: I think tobacco or smoking is a graver addiction than something like heroin. According to statistics, 5% of the people, say 5 in 100 people, quit smoking without any intervention; with counselling, about 15-20% people quit smoking. Further, using pharmacotherapy (medication) along with counselling, they don't go beyond 25-30%. Therefore, despite the best of the counselling, we may not be achieving the target of 100% people quitting smoking or tobacco use. So, that means that that stopping initiation is more important than cessation. And again, that means that we need to focus more on school children and the youth, so that they don't initiate smoking till they reach 25 years, after which there is very little chance of initiation. Second is to focus on sustainable cessation techniques, like the simple ABC technique which includes: A - ask about tobacco use whenever we see them in the clinics, whether it is cardiology, or neurology, or any other clinical discipline. We always ask the question whether s/he is/ was a tobacco user. Then B - brief advice: we give them brief, tailored advice based on their condition. This is followed by C - counselling to quit tobacco and suggest them psychiatric OPDs to ensure they get all the support they need.

Dr Kumar: Behavioural Change Communication (BCC) is a continuous, unceasing process. Unfortunately, BCC is largely programme-driven and one of the first to be axed in prioritisation of budget exercises. Therefore, advocacy for BCC budgets is essential. However, embedding communication in implementation science research is needed to build a case for its importance and potential for creating an impact. BCC strategies rarely undergo a scientific development process. There is a need to understand context, use mixed method approaches to broaden our understanding of population behaviour, and use the huge amounts of data generated for informing strategies and demonstrating impact.

04

Unlike liquor, tobacco products have easier and wider accessibility and availability in public spaces. Given the extensive sale of tobacco products, what kind of interventions must be adopted to educate people, especially the youth?

Dr Goel: There are a few things that are in the pipeline with the Government of India, for example, to increase the age limit for purchasing tobacco from the current 18 years. At present, any person who is 18 years and above can buy it from tobacco shops, but we are propagating that the age should be extended to 21 or 25 years (on lines with alcohol), preferably, which

will thereby decrease accessibility. We are also propagating tobacco vendor licensing, another concept on the lines of alcohol license. We have exclusive alcohol shops, but we don't have specific tobacco shops. Instead, there are tobacco vendors in every nook and corner. Some states like West Bengal, Uttar Pradesh, Uttarakhand, Himachal Pradesh have introduced this tobacco vendor licensing and have allotted tenders only to a few shops. And for example, they have selected an area, like within 500 metres or one kilometre, there shall only be one shop, and that one shop should abide by all the guidelines. Besides propagating for a ban, we need to realise that spreading continuous awareness is the most sustainable and effective way to reduce tobacco use.

05

We have all seen advertisements in the theatres, such as the famous Mukesh ad, and the graphic illustrations on cigarette boxes with a disclaimer that smoking kills or causes cancer and yet, people don't take it seriously. Has the visual communication been effective? What other effective methods should be adopted to educate the public better?

Dr Goel: About the graphic images on the cigarette packs, I must compliment the Government of India, because initially, the graphic covered only 20% of the package and was not that strict. But now, 85% of both sides have the graphic material. So, that means whenever a person opens the pack, he repeatedly sees that body. And various technical literature has shown that it has caused a reduction in tobacco use when they repeatedly see the graphic body, and this is a kind of education for the smokers. Theatre advertisements have also proven to be effective. However, it is imperative to look for innovative techniques to especially appeal to the youth. As per the latest global adult tobacco survey, the mean age for smoking is 19 years as opposed to 18 years, five years ago. This is important because studies show that if the age limit is increased to at least 24 years, there is only 5-10% chance that the person will pick up smoking thereafter. We should use social media for innovative IEC (information, education, and communication) to reach out to the youth. While tobacco companies continue to promote catchy headlines on the safety of 'organic' cigarettes, thereby downplaying the harm on the public health, especially with addiction, efforts must be channelised to inform, engage with, and continuously spread the awareness on tobacco consumption in terms of cardio and neurological problems, and oral and lung cancers it causes.

06

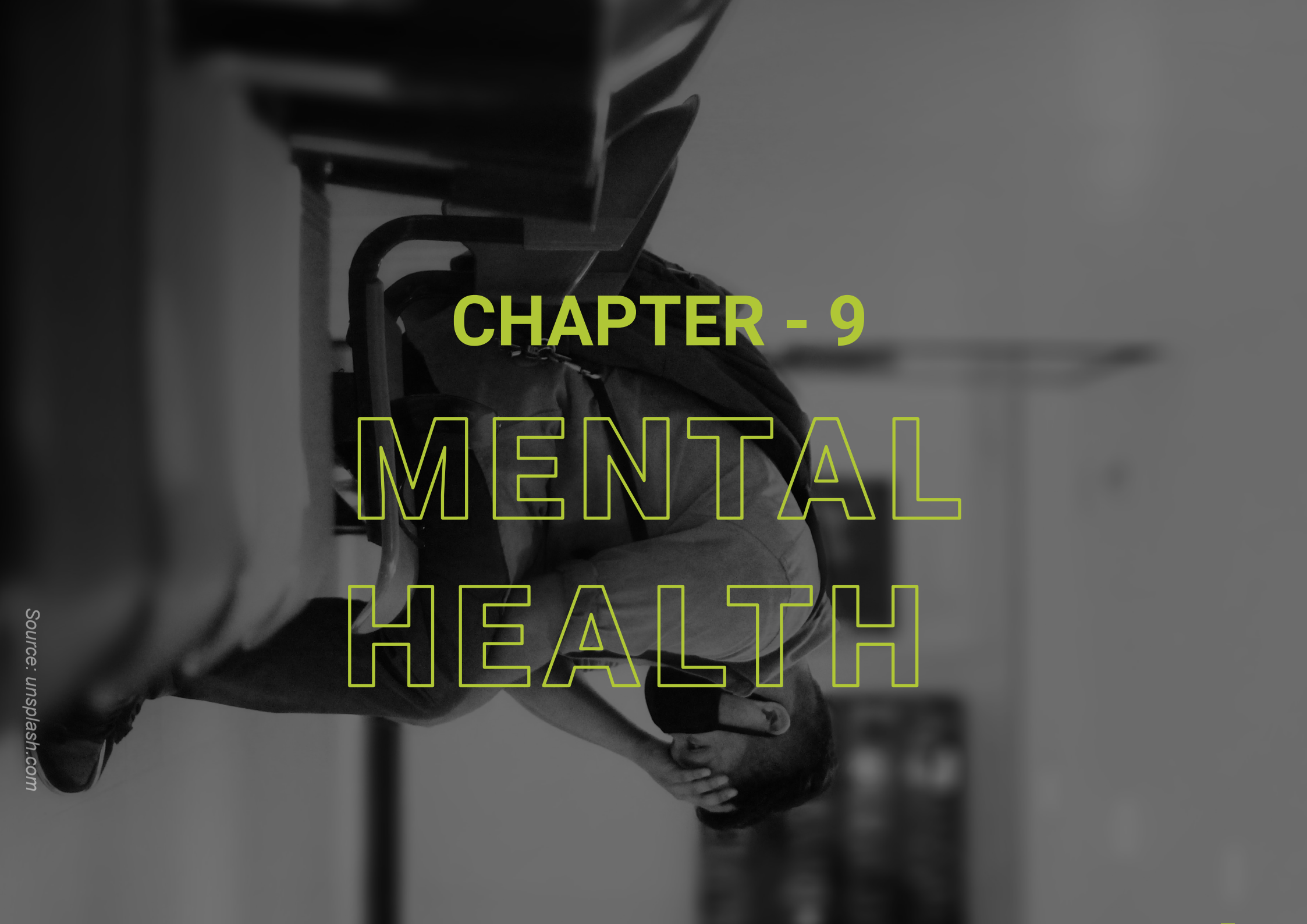
What has been the impact of COVID-19 on public health in India?

Dr Kumar: COVID-19 has brought health emergencies to public attention. It has increased a political prioritisation of funding for strengthening extremely neglected public health areas, such as surveillance, outbreak response, and management. Within the health system, it has

highlighted the need for strengthening primary healthcare and the lack of continuity between primary healthcare and hospital-based care. On the upside, COVID-19 has been a field laboratory for scale-up of technology/ICT in improving access to services through different models, for surveillance, testing, diagnosis, and care and treatment. It has also highlighted the need for strengthening community engagement. Last, it has shown the need for strengthening the public sector on healthcare delivery, to reduce the financial burden on households in pandemics.

8.5. Conclusion

Given the significant prevalence of misinformation on vaccines, public health is no exception in the percolation of misinformation. Under the spotlight of tobacco consumption, there is significant misinformation in terms of not providing warnings on mass media such as YouTube, Facebook, and Twitter on tobacco products. The other major stakeholder involved in misinformation is the tobacco industry that has, time and again, misled the public through explicit denial that there is no causal relationship between smoking and cancers or addiction. With catchy taglines and advertisements, the public has been led to believe that the 'organic/herbal' nature of some of the tobacco products and e-cigarettes is sustainable. Other misinformation includes non-filtered cigarettes being more harmful or e-cigarettes not having an impact on children; and hookah or menthol cigarettes being a 'healthier' option. Both misleading and non-factual claims made in the media by pro-tobacco stakeholders must be actively debunked given how incorrect beliefs continue to persist. Misinformation, especially in the context of addiction of tobacco products, can easily manipulate and mislead the public of all age groups into undermining the dangers of tobacco in the coming years. This, in turn, implies that misinformation is a major threat to public health, especially to the vulnerable who are in the grip of addiction. Such false/undermining messages on social media will only further the damage. Addiction is a grave public health concern that requires hours of therapy, will power, support (physical, mental and financial), rehab in some cases, and many other things. Although the first step is to retract and provide corrective statements, their recall value is limited in the minds of the public (Joseph N. Cappella, 2016)[104]. Also, misinformation and disinformation percolate faster than corrective statements do. Therefore, once the corrective statements are in place, it becomes imperative to address the root cause of the problem—fighting the addiction and helping the public to overcome the same. Both the state and national governments must work on anti-tobacco campaigns including providing necessary infrastructure in primary healthcare centres, IEC material propagated by healthcare workers and local stakeholders, and proper implementation of COTPA. Effective strategies must be in place to handle the burden of addiction by consulting the relevant stakeholders to address this grave public health concern.



CHAPTER - 9

MENTAL HEALTH

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9.1. Literature Review

Mental health is "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to his or her community" (Organization 2004)[105]. Every 40 seconds, someone in the world takes their life. 75% of these deaths are from low- and middle-income countries and mental health has a significant role to play in such extreme steps (Release 2019)[106]. In the era of booming social media and an ongoing pandemic, the importance of mental health cannot be overstated. 50% of mental health conditions begin by age 14 and 75% of mental health conditions develop by age 24. Statistics in India show that 1 in every 5 individuals suffers from some form of mental illness symptoms (Deepika Padukone 2018)[107]. The World Health Organization (WHO) estimates that in India, the burden of mental health problems is 2,443 DALY (disability-adjusted life years) per 100,000 population (Desk n.d.)[108]. This is only reflective of the growing burden of mental illnesses resulting from behavioural and psychiatric disorders and the problems worsen in the context of rapid urbanisation. When examined from the social, economic and psychological lenses, there are still knowledge gaps owing to the stigma and lack of awareness. In the gaps of this vicious cycle is where most of the misinformation is bred in terms of myths and misconceptions.

Mental health literature and data is a fairly new concept compared to the literature of physical illnesses. This also implies that there are issues both on the supply and demand sides. For instance, while patients are not aware of/recognise the symptoms of mental illnesses, those who do recognise the problem face obstacles like availability, affordability, and accessibility of mental health in terms of skewed doctor-patient ratio, expensive medication and continued support of therapy or medication. The National Mental Health Survey of India, 2015-16 study reveals that due to the stigma associated with mental disorders, nearly 80% of those with mental disorders had not received any treatment despite being ill for over 12 months (Gururaj G 2016)[109]. India's number of mental health beds was found to be well below average with only 2.15 beds per 100,000 compared to the global figure of 6.5. Treatment gaps greater than 70% exist due to insufficient funding of mental, neurological, and substance use disorders.

According to Lancet, one in seven Indians was affected by mental disorders of varying severity in 2017 (Prof Lalit Dandona 2020)[110]. An infodemic of the kind seen in the case of the pandemic is not new to mental health. The mental health crisis has especially been exacerbated during the COVID-19 pandemic. Especially with lockdowns and the never-ending scrolling of the COVID-19 feed related to infections and deaths, the risk of mental health illnesses is on a rise. Mental health has always been that grey area where there has been a dearth of true/factual

information. Even traditionally, the media has always portrayed mental illnesses as something enigmatic, 'abnormal', and often associated with paranormal activities. This has translated into the continued practice of faith healing and ritualistic practices that vary in different socio-cultural traditions. The National Mental Health Survey of India, 2015-16 study reveals that 10% of the population has common mental disorders and 1.9% of the population suffers from severe mental disorders (Gururaj G 2016)[109]. It is observed that almost one in 20 suffers from depression, being higher in females in the age-group 40-49 years. 22.4% of the population above 18 years suffers from substance use disorder, with the highest contributed by tobacco and alcohol use disorder and detected more among males. With the extensive penetration of fake news (misinformation) in our daily lives, especially in a sensitive issue like COVID-19, there has been a severe impact on mental health. While it is pertinent to clear mental health misconceptions through robust awareness/communication campaigns, this chapter does not dwell on the scientific details of various kinds of mental illnesses but gives an overview of the nature of misinformation that is prevalent in this subject. Owing to the vastness of the subject, this chapter will focus on the generic understanding of mental health and the impact of misinformation in our approach and understanding of mental health.

9.2. Common Myths and Misconceptions

MYTH: 01 **Mental illnesses are not real illnesses; they are just a phase and go way on their own.**

FACT: Mental illnesses are equally if not more real than physical illnesses. From change in lifestyle behaviour to coping with things in life, people face real challenges, and these problems require effective treatments from mental health professionals.

MYTH: 02 **The treatments for mental illnesses are often brutal and involve electric shocks.**

FACT: Such brutal methods are a thing of the past. Today, with the discovery of effective drugs and evolved methods of therapy, the treatment is more humane.

MYTH: 03 **Mental illnesses last for life and often, one cannot recover from them.**

FACT: With timely medical help, the right treatment plan and supportive friends and family, there is a recovery out of the issues.

MYTH: 04 | **People with mental illnesses cannot handle work or academics.**

FACT: While mental health concerns do have an impact, there are a lot of professionals/ students who cope with it, and seeking professional help at the right time can result in rather successful careers. Many celebrities and well-known people with successful careers too have experienced mental health issues.

MYTH: 05 | **Mental health issues won't affect me and is only a thing prevalent in extreme socio-economic strata.**

FACT: Mental health issues are not a choice and can happen to any one of us at any point. While the best we can do is to limit stress and remain healthy, a lot of other factors such as genes, function of our environment, past experiences, incidents/ circumstances can affect our mental health or our loved ones. Just like physical illnesses, it can happen to anyone and is not restricted to a particular stratum of the society.

MYTH: 06 | **Children do not experience mental health problems.**

FACT: Very young children can also show signs of mental health concerns, and they need to be identified at an early age and seek early interventions to help the child to not let these issues interfere with their growth and development.

MYTH: 07 | **Mental illnesses can be cured through prayers, willpower and determination.**

FACT: Like how willpower cannot heal a headache or a fracture, mental health too is not a thing of grit. Mental health requires equal efforts/approach to identify symptoms such as appetite changes, sleep changes, mood changes and cure the illness in the likes of physical health.

MYTH: 08 | **Psychiatric medicines are harmful and addictive.**

FACT: Not all psychiatric medicines are addictive or toxic when used under medical supervision and must only be taken in the recommended dosage and duration suggested by a qualified and professional psychiatrist after a correct diagnosis. This will assist in balancing the chemicals in the brain and help the patient feel better.

MYTH: 09 | **The odd behaviour is often because the patient is possessed by supernatural phenomena.**

FACT: Unlike the symptoms of physical health, symptoms of mental health are manifested in thought and behaviour. Therefore, it is difficult for people to comprehend what exactly is transpiring and this odd behaviour must not be attributed to supernatural possession.

MYTH: 10 | **Mental illnesses are hereditary.**

FACT: While genes are a factor to be considered, experts are not yet sure how significant genetics are in determining one's risk of mental illness. While it is wise to remain aware, one should not worry too much about the risk factors they cannot control.

MYTH: 11 | **Depression is not an illness and is a weakness of character.**

FACT: Depression is a complex mental illness that has social, biological, and psychological origins. It is often characterised by anxiety, stress, sleep concerns, impacted decision making, laziness, appetite changes, etc. If not treated in time, depression can end one's life.

9.3. Case Study- Religious Healing Practices in Mehendipur Balaji Temple in Rajasthan

When it comes to understanding or treating mental health issues, supernatural attribution to the symptoms/behaviour is not a novel concept in India. The folklore of almost every religion including Hindu, Buddhist healing temples, the Sufi dargahs, church healings, etc. have existed for a long time now and includes a range of religious practices and mortification rituals. These include long periods of fasting, tying up in chains, exorcism, etc. in what essentially is a dissociative state of the patient. One such case study in India is the Mehendipur Balaji temple located in Rajasthan's Dausa district that has a reputation for treating psychological ailments through ritualistic healing and exorcism of evil spirits (Sood 2016)[111]. Generally, people with inappropriate social behaviour, people having incomprehensible fears or symptoms that cannot be medically explained, and other such cases visit the temple for recourse treatments. Usually, these symptoms are akin to psychosomatic and dissociative disorders. The treatment process in Balaji, involving extreme acts that subject the body to pain, does not align with global

mental health definitions of humane or evidence-based care. The temple follows the harshest punishments to the 'spirits' that have 'possessed' the devotees. There are numerous rules to enter, stay and leave the temple for visitors.

Millions of people visit this temple from far and wide and it is believed that the devotees will be cured of negative energies and find salvation at the temple. Owing to the skewed doctor-patient ratio in psychiatry and the unavailability of trained medical health professionals, especially in the rural and interior regions, people from these regions often resort to magico-religious alternatives mainly associating mental health issues with such harsh customs and treatments. This, in turn, exacerbates the stigma and misconceptions about psychiatric problems. While the debate on Western vs folk medicine continues, the global mental health framework is at the intersection of biology, beliefs, and human rights of mentally ill people. For instance, in this temple, the people believe that the magical powers of the temple will exorcise evil spirits and give them relief from their possessions/black magic. The affected people are often subjected to inhumane methods and their loved ones are not supposed to intervene. In the battle between belief and science, often the former takes precedence, especially in the case of mental health.

However, the ultimate blow to the traditional mental health sector was delivered in early 2002, when the Supreme Court of India passed the following ruling in the conclusive stage of the Writ Petition hearings in the order dated 5 February 2002:

> Both the Central and State Governments shall undertake a comprehensive awareness campaign with a special rural focus to educate people as to provisions of law relating to mental health, rights of mentally challenged persons, the fact that chaining of mentally challenged persons is illegal and the mental patients should be sent to doctors and not to religious places such as temples or dargahs. (Supreme Court of India 2002)[112]

> *The Mehendipur Balaji temple in Rajasthan is known to treat psychological ailments through ritualistic healing and exorcism of evil spirits through the harshest punishments. (Sood 2016)*[111]

This ruling became a milestone in guiding the future mental health policy formulations in India and affected the functioning of traditional healing sites across the country in many ways. However, till date, owing to the lack of mental health infrastructure, personnel and communication material, people—especially in the rural areas—continue to visit such local religious places for relief from the alleged spirits instead of seeking proper mental health care.

9.4. Expert Speaks

DR DEBANJAN BANERJEE

He completed his post-graduation (M.D.) and post-doctoral (D.M.) in Geriatric Psychiatry from the esteemed National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore. He was attached with the Geriatric unit of NIMHANS for over five years and specialises in ageing and old age-related mental health problems. Dr Debanjan is presently a Consultant Old Age Psychiatrist in Kolkata and a member of the Advocacy Committee, International Psychogeriatric Association (IPA).

01 Misinformation and disinformation can affect us by creating anxiety, fear, depression, or stress and this was especially exacerbated during the pandemic. What is the impact of misinformation on mental health?

Dr Banerjee: : I think this is a very pertinent question, considering the present times of the COVID-19 pandemic. As you rightly said, misinformation is considered one of the very serious public health hazards. And in the digital world, there is no limit to the amount of information that we can consume. The same is the case with misinformation too. And partially because we have an inherent need to know; that is the very basis of our psychology or human psyche at times of crisis. So, when there is any public health disaster like COVID-19, there is, in general, a lot of perceived need for information. And I think in that case, any form of misinformation or disinformation will lead to panic, uncertainty and fear. And there is also something called panic activities. To give you a very common example, there was a lot of panic buying during both waves of COVID-19. So, people went after toilet paper, tissues, sanitisers, soap, and sprays. Such social chaos and public health risk behaviours increase when there is uncontrolled misinformation. And pandemic or not, I think related to any aspects of health, including mental health, we do see the spread of misinformation on social media. It also leads to harm in certain ways. For example, if there is a lot of anti-vaccine campaigning, people will refrain from vaccination. If there is stigma propagated against mental health, people will not seek professional advice. And finally, the way sometimes certain health issues are portrayed, especially in terms of cancer and mental health, people develop unreasonable fears that prevent them from seeking timely help. So, these are all the ways in which misinformation can cause health hazards propagating stigma and false beliefs.

02 The conversation around mental health has only picked up in recent times. What is the impact of the rise of social media influencers on the mental health space?

Dr Banerjee: As a psychiatrist, it is really good to see that there is a lot of discussion, discourse and debate—both academic and unacademic—on mental health; a lot of people have come forward to share their experiences. The pandemic has, in fact, shown us the crevices, the social inequalities, the need to place our minds equally beside our bodies. Given all that, it is also very ironic to me that we needed such a global wide-scale infection to serve as an eye-opener to the importance of mental health. And that brings the further concern that considering the stigma and the societal attitudes that we have here towards psychological wellbeing and mental health, when the pandemic eventually ends, will the resultant awareness related to mental health concerns also cease? I am a little sceptical about that. But I'd like to hope and believe that whatever lessons we have learned, the importance of mental health as an integral part of public health and the importance of mental health during disasters, and the need to seek professional help, I really hope that these lessons are carried forward. Consideration for mental wellbeing needs to transcend the pandemic.

03 What has been the impact of COVID-19 on mental health across age groups and various sections of the society?

Dr Banerjee: This is a never-ending saga—the effects that the pandemic has on the mind has many angles to it. One, what the virus does to the brain directly. When we talk about the mind, it is an abstract entity. But with regard to how certain parts of the brain are affected, which deals with our emotions and thinking, there can be psychiatric side effects. So, the virus has shown to have a certain affinity towards the nerve tissue and over the last two years, there has been a lot of research on this. Especially, early this year, there have been two large studies published in The Lancet psychiatry that show that a lot of people affected with COVID-19 are suffering from confusion, strokes and memory problems that persist for quite some time, including new-onset epileptic attacks. People who have severe infections are even more prone to having long-term effects—the neurological and psychiatric effects of the virus.

Coming to the wider and the larger picture, what are the effects of the pandemic as such? The public has had a lot of fear and uncertainty as their schedule has been disrupted, lives and living have been disrupted. The earlier structure has gone. Online education and work from home have emerged as the new normal challenges. It's been a paradigm shift in the way we used to live, especially when it first started and then when many countries were hit by the second wave.

Now, besides that, I think there are certain sectors that have been affected more. We talk about COVID-19 being the great equaliser, but no, it isn't. In fact, people on the margins—children, older people, migrants, people who are on the front line, gender and sexual minorities—have taken a larger hit due to the pandemic. So, in general, those who had pre-existing psychiatric problems like depression, psychosis, dementia, sleep disturbances and anxiety have seen an increase in these problems. The availability of medicines and accessibility to care have decreased owing to the risk of COVID-19. A lot of people are afraid to visit the doctors, so many of them had the symptoms that resulted from stress and lack of medicines. So, I think it is still the tip of the iceberg that we are seeing. And over the next few months to two years, we are going to see an even larger picture, especially with posttraumatic stress, because this is a kind of trauma that continues in a prolonged and fluctuating fashion.

04 Given that there is skewed doctor-patient ratio and other supply-end issues like accessibility and affordability, how should people navigate through mental health challenges?

Dr Banerjee: There have always been resource constraints in our country. In fact, latest National Mental Health Survey data tells us that there is one psychiatrist for roughly every 10 lakh people, and the number of clinical psychologists is even lower. Also, only 15% of those with mental health issues receive the help that they need. Having said that, I think it's also important that we have our awareness straight because mental health, as I keep saying, is not something exotic, that you have to discuss on one fine day. It is something that is involved in our day-to-day lives, the way we work and live, how we interact with people, it's involved in everything. So, there has been an attempt to train lay counsellors, the grassroot health workers, district physicians, general physicians, to be equipped with basic mental health care, what we call Mental Health First Aid, and also involve the media, local resources, community resources, in having a primary and tertiary healthcare tie up, so that patients do not really need to go everywhere. Certain common mental health issues can even be dealt with by general physicians or by any specialties, especially with Indian tele psychiatry guidelines, which were very aptly released in 2020. During COVID-19, I think there is an immense scope, because people can actually access tele psychiatry care from many regions and we can also train a lot of doctors and handhold them to provide better psychiatry care in communities. So, resource limitation was there and will be there but if we raise our awareness and fight the stigma associated with mental illness, I'm sure that the proportion of people who will seek professional care will be much higher.

05 What are some of the urgent public mental health problems that require immediate attention and how do we address these issues?

Dr Banerjee: I think the first thing will be to understand and acknowledge mental health issues as an integral public health problem. To give you a very basic example, when you visit a hospital, before or after COVID-19, you are advised about hand hygiene and sanitation, right? You wear a mask if you are going to an infectious disease unit. But do we talk about mental hygiene? We normally don't discuss it, but mental hygiene means giving yourself space, taking care of your happiness, having hope, doing something that you like.

These things may seem philosophical; they might appear generic. But basic things like spending 15-20 minutes a day for what you like, what makes you happy, like humming your favourite tune, reading a few lines of your favourite book, writing, talking to friends—these things are missing. And the last two years have taught us the real importance of social touch, no matter how much you were connected digitally—a friendly hug, a pat on the back, a handshake or playing with friends or children. There is no substitute for these. So, in our venture to become more civilised, we are getting separated from our roots of being social animals. Public mental health priority starts at an individual level. So, individuals need to be more aware, and develop knowledge, the right attitude and practice about mental health.

Mental health literacy is a public health top priority, involving people in the community, or using community resources like health workers, the district mental health team, panchayats in villages, the municipal corporation's key stakeholders and leaders locally, the media and trying to build a good community network. Integration of primary and tertiary care is also important, because there are very few qualified mental health professionals. So, they can help train the more general physicians in giving very basic mental health care. And if you really talk in terms of illness, I think three things need to be put right in the front. One is major depression and another is dementia. We are talking in the month of September, which is considered World Alzheimer's Month. The population above 60 years is rapidly increasing in India, and along with that, the burden of Alzheimer's disease or dementia is also increasing significantly. So, that is definitely a public health priority. Suicide prevention must also be a top priority and it is important that we discuss the national suicide prevention strategy. I'm sure that the government is already working on it, and we can hope that ultimately, it materialises, and there is some blueprint for suicide prevention in such a huge and populous country like ours. But if we really talk about public mental health priorities, the first thing is to fight social stigma and increase awareness at all levels so that people can seek professional help, especially in the rural areas.

9.5. Conclusion

While the discourse on mental health has been picking up, the pandemic has exacerbated mental health issues across age groups and economic strata. Having said that, it has also led to a robust and comprehensive response from mental health professionals (psychiatrists, therapists, and allied workforce) to tackle the gravity of the situation on ground. Even workplaces have taken cognisance of mental health and have taken multiple steps to make the situation easier for employees. However, this is restricted to large companies in the organised sector. Misinformation and mental health issues continue to affect the unorganised sector workforce and vulnerable populations equally if not more than others, and especially so after the onset of the COVID-19 pandemic. There is need for evidence-based research to fully gauge the impact of COVID-19 on varied stakeholders including children, adolescents, migrants, LGBTQIA+ communities, specially abled people, new mothers and other vulnerable populations, and accordingly plan interventions.

It is pertinent to note that there two types of misinformation in mental health: 1. Misinformation that triggers mental health; for instance, COVID-19 misinformation has not only led to hindrance of mental wellbeing, but has caused real-time and large-scale paranoia across the world. 2. Existing misinformation (myths and misconceptions) as discussed above in the mental health space; for instance, owing to multiple traditional beliefs or fear of 'addiction', people are generally reluctant towards accepting and seeking treatment for mental health unlike with physical health. Therefore, the most effective antidote to misinformation is increased awareness, and especially in a subject like mental health, this is all the more true. While it is necessary to be sceptical and question things, people are often sceptical of life-saving medications and fall prey to misinformation which ideally should have been the other way around.

Misinformation in the already stigmatised mental health has only added another significant barrier to seeking proper treatment. Unlike physical health where there are definite and tangible parameters, mental health is about how one feels and is, therefore, abstract. However, one must be careful in analysing whether their feelings are contextual/circumstantial or if they continue for long periods of time. Therefore, it is important to discuss mental health and make it a part of our daily conversation like how we discuss diabetes or blood pressure, and not treat it like a new, exotic subject. There must be more focus on disseminating mental health literature through various media. The outdated information on treatments and medication has to be replaced with factual literature and the same must be disseminated effectively. It is important to understand the psychological and behavioural aspects of misinformation and its impact on mental health and, therefore, the root cause of the problem must be addressed. The onus of this

lies on multiple stakeholders including mental health professionals, healthcare professionals, the media, and the government. Even at the individual level, efforts must be put into educating oneself and loved ones on the issues of mental health and guide them accordingly. This is especially true in the case of the ongoing pandemic.

CHAPTER - 10

NON-COMMUNICABLE DISEASES

Source: unsplash.com

10.1. Literature Review

Non-communicable diseases (NCDs) are defined as diseases that are not contagious/easily transmissible from one person to another and for which a complete cure is rarely achieved (McKenna 1998)[113]. As per the World Health Organization (WHO), these are usually chronic, i.e., last lifelong and are often a result of genetic, environmental, lifestyle and behavioural factors. The types of NCDs include diabetes, cardiovascular diseases, respiratory diseases including chronic obstructive pulmonary disorders (COPD) and asthma, hypertension, kidney ailments, liver diseases, and thyroid. One major facet of NCDs, especially in the Indian context, is causes of concern including early-age onset of diseases, undiagnosed diseases till later stages and the high rates of mortality. Owing to the current lifestyle choices including smoking, alcohol consumption, unhealthy diets, sedentary lifestyle, and unplanned urbanisation and globalisation, people of all age groups including children, adolescents, adults and the elderly are at an increased risk of and vulnerable to NCDs. As per the WHO, NCDs are the reason behind the deaths of 41 million people, i.e., the equivalent to 71% of all global deaths (Desk 2021)[114]. NCDs are often known as silent diseases given that a lot of people are not aware of these conditions until symptoms becomes apparent. Cardiovascular diseases have now become the leading cause of mortality in India. Low- and middle-income countries account for a higher burden of non-communicable diseases while India factors for about 60% of the fatalities owing to NCDs (Suzanne Nethan 2017)[115]. India, therefore, is dealing with a double burden of diseases, both communicable and non-communicable diseases, today.

In fact, diabetes is the ninth leading cause of deaths globally (Desk, 2020)[116]. India represents one out of six individuals in the world with diabetes and is home to over 77 million diabetics, only second to China, according to the International Diabetes Federation's Diabetes Atlas 2017 (I. D. Desk 2020)[117]. According to a 2019 study titled 'Variation in health system performance for managing diabetes among states in India: a cross-sectional study of individuals aged 15 to 49 years', about 47% of the population, i.e., one in every two Indians living with diabetes, is unaware of their condition and is evidence that there is a diabetes epidemic in India (Jonas Prenissl 2019)[118]. According to Dr Viswanathan Mohan, Chief of Diabetology at Dr Mohan's Diabetes Specialities Centre and a co-author of the same 2019 study, India may surpass its neighbour in the next five years to become the diabetes capital of the world. This is in tandem with the findings of the International Diabetes Federation that India will likely touch 134.3 million people living with diabetes by 2045. Speaking of epidemics in the healthcare ecosystem, the impact of the COVID-19 pandemic cannot be understated given how NCDs have exacerbated the impact of COVID-19. While there were speculations of the potential effects of NCDs on COVID-19, misinformation had already fuelled panic in the public and the lockdowns have only exacerbated the panic, especially with the disruption of essential public

health services. Another added layer of the problem is that half of the diabetic population struggles to manage/control their condition because people often resort to alternate/traditional therapies instead of proven scientific methods and often delay the right treatment. Given the gravity of the diabetes epidemic and the fact that we all know at least a friend, parent or an elderly person who is diagnosed with diabetes and living through the ongoing pandemic, this chapter highlights the need to combat misinformation to tackle the diabetes epidemic within the pandemic.

10.2. Common Myths and Misconceptions

MYTH: 01 **Diabetes is merely a lifestyle disease and not very serious.**

FACT: Diabetes is a chronic health condition and can often turn serious/life threatening if not managed properly through diet and lifestyle changes.

MYTH: 02 **Diabetes is caused by high sugar consumption.**

FACT: Sugar alone does not cause diabetes. It is caused by a blend of genetic, environmental and lifestyle factors. In fact, high sugar content implies being overweight and that is a potential risk factor for diabetes.

MYTH: 03 **Diabetes can be cured with insulin.**

FACT: As of today, there is no cure for diabetes. It can, however, only be treated and controlled through a healthy diet and increased activity.

MYTH: 04 **Diabetes can be cured with insulin.**

FACT: Although the risk of heart disease is greater in men, there is no evidence that women are immune to it and vice-versa in case of diabetes. Post 65 years, men and women are at equal risk of the diseases and need to get regular body check-ups done.

MYTH: 05 | **People with heart diseases or diabetes must take it slow in terms of physical activities.**

FACT: In fact, it is the opposite—an active lifestyle can reduce the risks of obesity and other complications. People with heart diseases and diabetes must not have a sedentary lifestyle but are encouraged to exercise/undertake physical activities to stay healthy.

MYTH: 06 | **Fat intake must be completely cut off for people suffering with NCDs.**

FACT: While intake of saturated fats must be lowered and trans-fats should be avoided, not all fats are bad for the body. In fact, the good fats from lean meat, salmon and nuts are essential for the functioning of the body, especially the heart.

MYTH: 07 | **Only obese people are definitely prone to diabetes, especially type 2 diabetes.**

FACT: While obesity is a probable risk factor of diabetes and heart diseases, not every obese person suffers from these. In fact, a lot of people in the older generation who are not obese suffer from these conditions. However, a healthier diet with sugar in moderation and activity goes a long way in keeping these lifelong diseases at bay.

MYTH: 08 | **Diabetes is contagious and more so if it runs in the family.**

FACT: Diabetes is a chronic disease that is caused by reduced amount of insulin (hormone that regulates blood sugar) or resistance to the action of insulin, or even a combination of the two. It is based on the individual, and lifestyle and environment factors. While family history implies higher risk, it is not necessary that those with one develop diabetes or that people without a family history are secure.

MYTH: 09 | **Type 2 diabetes is mild and reversible.**

FACT: Type 2 diabetes cannot be cured, at best the glucose levels can return to normal range. In fact, poor management of type 2 diabetes can lead to severe, life-threatening conditions. So, it is vital to manage and control as most diabetes are not reversible.

MYTH: 10 | **Diabetes implies eventual loss of sight/blindness.**

FACT: While poorly controlled diabetes is a risk factor for loss of eyesight, not everyone with diabetes is blind. Early symptoms/mild cases can even be treated with rigorous diabetes management.

10.3. Case Study- A Social Media 'Doctor' who can Cure Diabetes

In the context of NCDs, misinformation often appears in captivating messaging that 'there is no such thing as bad cholesterol' or 'diabetes will be cured in two days', often giving people hope that their chronic disease might finally have a cure. The spectrum of misinformation ranges from the prescription of insulin in India as a scam to help pharmaceutical companies make profits to fad diets to two-day homeopathy cures for diabetes and eating a dozen bananas to cure diabetes. A lot of such fake news has been circulating on social media platforms for years now.

While there is no allopathic cure to diabetes or obesity, precautionary and preventive care for NCDs is often long-term lifestyle changes including changed diets and physical activity. Therefore, when a social media post or advertisement claims that there is an 'immediate' and short-cut cure, people often become optimistic and experiment with alternate medication. While information dissemination continues on social media, one 'doctor' who has owned the misinformation space on diets and COVID-19 is Dr Bishwaroop Roy Chowdhury. He is a self-proclaimed doctor who claims to hold an honorary PhD in diabetes studies from Alliance International University, Zambia, which is headquartered in the Caribbean and not in Africa. Before spreading misinformation on the COVID-19 pandemic, his forte was to curate special DIP (Disciplined and Intelligent People) diets to reverse diabetes within 72 hours. His antidote to curing diabetes is to eat 'sweet fruits' so blood sugar comes down. He has hosted several online and offline events and people have flocked to watch his magic 'scientific' cures. His YouTube videos have over a million views. The sycophancy can be seen in the comments to his videos, where people heap praise on him for his misleading messages. The engineer-turned-doctor's DIP diet promises to cure diabetes, thyroid, PCOS and even cancer, among many other chronic problems.

> *Dr Bishwarooy Roy Chowdhury's infamous DIP diet plan can fix any kind of disorder including weight loss, PCOS or thyroid and can reverse diabetes in 72 hours. (**YouTube**)*

Although social media giants like Facebook, Twitter and YouTube have banned most of his channels, the internet doctor's videos and messages continue to be circulated on social media, garnering thousands to millions of views. There are many more quacks like him who claim to 'cure' chronic diseases through diets, pills and natural fruit concoctions. However, it must be remembered that doctors and medical professionals across the world would have been following such breakthrough cures, if at all they existed. Since there is no magic formula that will cure most NCDs, the only scientific and proven solution is to have an overall lifestyle change including diet control and physical activity that can prevent, control and manage severe diabetes and plausibly reverse prediabetes or extremely mild diabetes, cholesterol and other chronic health issues. Digital literacy, therefore, becomes a crucial tool to combat health misinformation. While one can explore alternate treatments, one should be careful to distinguish between credible alternate treatment and the quacks whose advice can, in fact, make these health issues worse.

10.4. Expert Speaks

DR ISHU KATARIA

She is a Senior Public Health Researcher with RTI International's Center for Global Noncommunicable Diseases. Dr Kataria works on NCD prevention and control both in India and globally. She has experience in conceptualising and developing training interventions, and designing and implementing programmes on cancer prevention, adolescent NCDs, maternal and child health, and behaviour change communication.

01 What are some of the biggest challenges in NCDs and how should these be dealt with?

Dr Kataria: India has traditionally seen a lot of focus on communicable diseases, and it continues to do so. However, 60% of all the deaths are due to NCDs and the situation is similar at the global level as well. While the debate of non-communicable diseases vs communicable diseases continues, it is important to note that NCDs need to be prioritised given that they are chronic in nature. Long-lasting diseases require complicated treatments for life and more so in the case of the combination of NCDs a person has. There is a lot of interplay including unhealthy diets, air pollution, alcohol consumption, physical inactivity, etc. To prevent and control major NCDs, the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) was developed to have a multi-sectoral approach through National Monitoring and Action Plan (NMAP) for prevention and control of common NCDs. The idea was that the onus is not on one ministry or one set of stakeholders but rather how there is a need for different players in the ecosystem to prevent and combat NCDs through this blueprint. For instance, different stakeholders like civil society organisations, academia, stakeholders for monitoring and surveillance, among other stakeholders, are required to be embedded in talks about health promotion and preventions. Therefore, there are strategies and plans in place that the government has initiated recognising the problem and state governments are following suit, but I think there still needs to be a lot of prioritisation for NCDs, specially with regards to funding, which remains a challenge, even globally.

02 According to you, what is the impact of alternative medicine on people, especially those with NCDs?

Dr Kataria: In a lot of places in India and even if you look at the other systems, you have a good majority of what you call these quacks, and there is a lot of belief in them. In fact, people would rather consult the quacks over trained medical professionals owing to community pressure or peer pressure, which is in terms of people living in the neighbourhood, or you have elders in the communities where you see such things happening. This can have a serious negative impact given that they take the medication or treatment for progress but instead it leads to worsening of the diseases. There is a vast difference between how a professional would approach the problem, diagnose it and treat is as per the protocol versus how the quacks do it. In my experience, this can have severe consequences, sometimes even prove to be fatal for certain diseases and disorders. On the other hand are the people who seek alternative treatment in different stages—some at an early stage or some resort to these treatments when

there is no effect of allopathic medicines. Therefore, it is on both sides of the spectrum, and it does have an impact because you are not following the correct protocols for treating the condition and this can, therefore, impact the health of people who resort to alternative medicine providers.

03 Misinformation around nutrition is an under-debated topic. How should we start an effective conversation around it and inform people to consume the right diet?

Dr Kataria: I think change should come at the policy level; it must be communicated from the national or state perspectives. If you see a piece of information from the government, you assume it is correct and credible, and it has a wider reach among the masses. Take food labelling, for instance; the issue with it is that the regulation of the guidelines pertaining to labelling in the country is not strong enough. This, in turn, provides manufacturers with loopholes, who then add false claims to their labels. Therefore, if these things are modified at the policy level, there are better chances of streamlining it and reducing the false claims through right messaging from top-down. That said, there are many players spread out within the nutrition sector right now that are picking it up. Some of them are trained and credible. On the other hand, there are people and organisations who are not trained yet they claim to know the rules of the game. Therefore, change must be brought at a policy level, i.e., strengthen the policies and provide the right information even within specific sections of the Ministry that deal with the topic. Once the policies are formulated in a way that they are more consumer-friendly, then comes the enforcement of the policies and the manufacturers would find minimal loopholes.

04 You have significant experience in capacity building from conceptualisation to implementation and monitoring. How have the outcomes been so far?

Dr Kataria: Capacity building happens at different levels. In my experience, I predominantly engage in capacity building with young people who work on the ground, either implementation or in liaison with implementation organisations on NCDs, engaging their communities and different stakeholders. I think the impact of monitoring and evaluation comes right from the start and not in the middle or at the end. The point is that you will be monitoring at different time points and evaluating at different time points starting from conceptualisation and planning, and this gives you a better chance of learning as you go along. You will see that if you have made mistakes, there are chances of course correction, and that is how you get the maximum impact; that is what we call embedded learning. This is what we try to do in all the capacity building work that happens, where you not only capacitate people on how and what to do based on what they tell you is the need of their context but also build monitoring and evaluation right from conceptualisation.

05 What has been the impact of COVID-19 on NCDs in India?

Dr Kataria: I'd suggest a different framing for it, and say that both NCDs and COVID-19 are very closely interlinked, and it has now also been documented very well that NCDs exacerbate COVID-19. For instance, if you have risk factors like tobacco consumption or obesity, you see linkages that make you more vulnerable to COVID-19. We have been seeing a lot of literature coming up about obesity, diabetes, heart conditions, etc. as an underlying risk factor for exacerbating it. It is critical to observe and understand the impact of COVID-19 on morbidity and mortality, and NCDs are definitely playing a huge role as risk factors for contraction and recovery of COVID-19.

10.5. Conclusion

The evidence from the current literature shows that there is a reciprocal relationship between COVID-19 and NCDs; NCDs imply vulnerability to COVID-19 while COVID-19 increases NCD-related risk factors. The need to prioritise NCDs has never been more significant. While low- and middle-income countries like India are already struggling for monetary and infrastructure needs, the pandemic has added an insurmountable burden to the existing NCD problems. Added to this are the layers of misinformation that not only disrupt the ecosystem but also make course correction a herculean task. While certain preventive measures are already in place, the challenge of tackling misinformation involves more than one stakeholder. Misinformation coupled with industry leaders promoting false or misleading food labelling to boost their product sales and revenue is a disaster recipe for NCDs. The proposed way forward includes understanding the impact of misinformation on NCDs, especially during the pandemic, which has been exacerbated manifold. For instance, the lockdowns witnessed the suspension of out-patient services in hospitals while on the other hand, people feared seeking medical care owing to the fear of contracting COVID-19. Therefore, data-driven research is key to understand the extent of the problem. Followed by this is the need to gather the relevant stakeholders including the governments (state and national), civil society organisations, healthcare experts, researchers, on-ground partner/implementation organisations, funding partners, media and others to identify the challenges and barriers, and ways to fight misinformation. Pertinent research on best practices and success stories from around the world and innovative practices must be collated and contextualised to fit in at the state, region and community levels.

Misinformation is a complex problem that requires deep behavioural and psychological understanding of people. Digital literacy must involve modules to specifically address the negative impact of misinformation on NCDs, and provide credible and course-corrective messages to the people on NCDs.

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About the Global Health Fellowship

As part of their fact-checking programme, social media giant Facebook has launched a Global Fellowship to combat health misinformation. Factly Media & Research was shortlisted among the 10 fact-checking organisations across the globe to be offered this fellowship. Other fact-checking organisations are based in Indonesia, Philippines, Colombia, South Africa, Turkey, Italy, and the United Kingdom. The Health Fellowship announcement was made at a time when the world was reeling under the repercussions of misinformation owing to the ongoing COVID-19 pandemic.

Each of the 10 organisations that is part of Facebook's fact-checking programme brought in a new team member (Health Fellow) to help them approach the complex and important topic of health misinformation. The Fellows were to help the host organisations map out a plan for integrating health misinformation into their fact-checking work. For this, Factly inducted Nanditha Kalidoss to help shape the health misinformation vertical through authoring The Health Misinformation Report, hosting a podcast (*Un-Viral*), and launching a microsite (health.factly.in) dedicated to health misinformation. During the fellowship, Nanditha was also a part of virtual training sessions conducted by third-party experts and CrowdTangle, a social analytics tool. On account of being Facebook's credible fact-checking partner, Factly aims to map the health misinformation landscape in India and accordingly develop methodologies and strategies to combat health-related misinformation in the country.

About Factly (www.factly.in)

Factly Media & Research is an organisation striving to make public data and information more accessible to citizens. Factly was established in 2016 and is based out of Hyderabad, India. The following are the major activities that Factly undertakes.

Data Journalism/Fact Check: Factly's written and visual stories lay out facts with evidence and help separate the wheat from the chaff in times of hyper-connectivity and constant information bombardment. The content aims to simplify public data and information that might otherwise be in complex forms. Fact-checking viral misinformation is another of Factly's major activities. Misinformation on varied issues such as viral social media claims on policy, data, politics, society, medical, financial, and government schemes are fact-checked. A verified signatory of the International Fact Checking Network's (IFCN) Code of Principles, Factly is also a third-party fact-checking partner with Facebook. The content is published as stories on the Factly portal and converted to short videos published on Factly's YouTube channel and other social media handles.

Building Information/Data Tools: Creating and developing information/data tools that increase access to public data and information by making it easy, interactive, and intuitive is another of Factly's verticals. 'Counting India' is Factly's first tool in its beta version that focuses on accessibility and data visualisation of Census 2011 data. Factly Dashboards is another initiative where rich and intuitive dashboards are built on important issues using data.

Advocating Open Data: Factly believes that for better public engagement with government data, the supply side must also be strengthened. Factly actively advocates an 'Open Data' policy to governments and agencies that house large amounts of public information.

A soft copy of this report can be accessed at *health.factly.in*