

**CONFRONTING CHRONICITY:
ILLNESS EXPERIENCES AND THE HEALTHCARE SYSTEM
AROUND TYPE-2 DIABETES AND OBESITY
MANAGEMENT IN INDIA**

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**DEPARTMENT OF HUMANITIES AND SOCIAL SCIENCES
INDIAN INSTITUTE OF TECHNOLOGY DELHI**

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ILLNESS EXPERIENCES AND THE HEALTHCARE SYSTEM AROUND
TYPE-2 DIABETES AND OBESITY MANAGEMENT IN INDIA**

AVILASHA GHOSH

Submitted in fulfillment of the requirements for the degree of
Doctor of Philosophy
to the



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CERTIFICATE

This is to certify that the thesis titled, **Confronting Chronicity: Illness Experiences and the Healthcare System around Type-2 Diabetes and Obesity Management in India**, submitted by **Avilasha Ghosh**, to the Indian Institute of Technology Delhi, for the award of the degree of **Doctor of Philosophy**, is a record of the original, bonafide research work done by her under my supervision and guidance. The thesis has reached the standards fulfilling the requirements of the regulations related to the award of the degree.

The contents of this thesis, in full or in parts, have not been submitted to any other Institute or University for the award of any degree or diploma to the best of my knowledge. I certify that she has pursued the prescribed course of research.

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Abstract

This thesis provides a situated understanding of chronic illness experiences and healthcare interventions by focusing on the public discourse that connects Type-2 diabetes and obesity in contemporary India. Based on an ethnographic study conducted between July 2021 to January 2023, the thesis examines how diabetes mellitus and obesity intersect with people's daily lives, health-seeking behaviours, care practices, and social relations across the inequalities of class, gender, region, and income. Additionally, the thesis provides an in-depth account of what chronic living entails for diagnosed persons and their families in the metropolitan cities of Delhi and Kolkata. Anchoring on the idea of 'chronic care,' I examine the various ways in which the prevailing healthcare infrastructure and policies, inequitable access to medical information and institutionalized care services, social suffering, and fragmented notions of chronic illness impact people's care practices and health-seeking behaviours around Type-2 diabetes and obesity management. The arguments in the thesis draw from a multi-sited fieldwork in local private clinics, public and corporate hospitals, and patients' homes in the high- and low-income settlements of Delhi and Kolkata, as well as in-depth qualitative interviews with diagnosed patients, informal caregivers, and healthcare professionals. The chapters address the social, economic, and personal challenges that persons suffering from chronic metabolic disorders confront with regard to institutionalized and non-institutionalized care in the everyday and highlights the existing tensions and gaps in the Indian healthcare system around chronic illness management. I further challenge the binary of the 'chronic' and the 'crisis' by postulating chronicity itself as a crisis of adequate care and healthcare provisions that disparately impacts people's illness, therapeutic decisions, access to care, and day-to-day life. In doing so, the thesis substantially contributes to existing debates on chronicity and care in medical anthropology, global health, and sociology of health and medicine.

सार

यह शोध समकालीन भारत में टाइप-2 मधुमेह और मोटापे से संबंधित सार्वजनिक संवादों को ध्यान में रखते हुए दीर्घकालिक बीमारी के अनुभवों और स्वास्थ्य देखभाल हस्तक्षेपों की स्थिति को समझने का प्रयास किया गया है। यह जुलाई 2021 से जनवरी 2023 तक किए गए एक एथ्नोग्राफिक अध्ययन पर आधारित है, जिसमें यह अध्ययन किया गया है कि टाइप-2 मधुमेह और मोटापा लोगों के रोजमर्रा के जीवन, स्वास्थ्य-संबंधी व्यवहार, देखभाल के तरीके, और सामाजिक रिश्तों के साथ कैसे जुड़ते हैं, विशेष रूप से वर्ग, लिंग, क्षेत्र और आय के असमानताओं के बीच। 'दीर्घकालिक देखभाल' के विचार पर आधारित होकर, मैं यह अध्ययन करती हूँ कि किस तरह से वर्तमान स्वास्थ्य देखभाल संरचना और नीतियाँ, चिकित्सा जानकारी और संस्थागत देखभाल सेवाओं तक असमान पहुँच, सामाजिक पीड़ा, और दीर्घकालिक बीमारियों के बारे में खंडित धारणाएँ लोगों के देखभाल के तरीकों और टाइप-2 मधुमेह और मोटापे के प्रबंधन में स्वास्थ्य-संबंधी व्यवहारों पर प्रभाव डालती हैं। यह तर्क शोधवृत्ति में दिल्ली और कोलकाता के उच्च और निम्न आय वाले इलाकों में स्थानीय निजी क्लिनिकों, सार्वजनिक और कॉर्पोरेट अस्पतालों, और मरीजों के घरों में किए गए बहु-स्थलीय फील्डवर्क के साथ-साथ निदान प्राप्त मरीजों, अनौपचारिक देखभाल करने वालों, और स्वास्थ्य देखभाल पेशेवरों के साथ गहरे गुणात्मक साक्षात्कारों से लिया गया है। अध्यायों में पुरानी मेटाबोलिक संबंधी विकारों से पीड़ित व्यक्तियों द्वारा संस्थागत और गैर-संस्थागत देखभाल से संबंधित सामाजिक, आर्थिक, और व्यक्तिगत चुनौतियों का सामना किया जाता है और भारतीय स्वास्थ्य देखभाल प्रणाली में दीर्घकालिक बीमारियों के प्रबंधन के संदर्भ में मौजूद प्रभावों और बाधाओं को उजागर किया गया है। मैं 'दीर्घकालिक और 'विपत्ति' के द्विभाजन को इस प्रकार चुनौती देती हूँ कि दीर्घकालिकता स्वयं ही पर्याप्त देखभाल और स्वास्थ्य सेवा प्रावधानों की एक आपदा है, जो लोगों के चिकित्सीय निर्णयों, देखभाल तक पहुँच, और दैनिक जीवन को असमान रूप से प्रभावित करता है। इस प्रकार, यह शोध चिकित्सा मानवविज्ञान, सार्वत्रिक स्वास्थ्य, और चिकित्सा समाजशास्त्र में पुरानी बीमारी और देखभाल पर विवेचन करने के लिए महत्वपूर्ण योगदान देती है।

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List of Abbreviations

1.	AIIMS	All India Institute of Medical Sciences
2.	ASSOCHAM	Associated Chambers of Commerce and Industry of India
3.	ASHA	Accredited Social Health Activists
4.	AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Sowa Rigpa, Siddha, and Homeopathy
5.	BJP	Bhartiya Janata Party
6.	BMI	Body Mass Index
7.	CGHS	Central Government Health Scheme
8.	EMI	Equated Monthly Installments.
9.	ESIS	Employees State Insurance Scheme
10.	EWS	Economically Weak Section
11.	GDP	Gross Domestic Product
12.	HLEG	High-Level Expert Group
13.	ICMR	Indian Council of Medical Research
14.	ICSSR	Indian Council of Social Science Research
15.	IMF	International Monetary Fund
16.	IRDAI	Insurance Regulation and Development Authority of India
17.	KMDA	Kolkata Metropolitan Development Authority
18.	MoHFW	Ministry of Health and Family Welfare
19.	NCD	Non-communicable Disease
20.	NCR	National Capital Region
21.	NFHS	National Family and Health Survey
22.	NHM	National Health Mission
23.	NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke

24.	NRHM	National Rural Health Mission
25.	NUHM	National Urban Health Mission
26.	OPD	Out-patient Department
27.	OTC	Over the Counter
28.	PCOS	Polycystic Ovarian Syndrome
29.	PHFI	Public Health Foundation of India
30.	PPP	Public Private Partnership
31.	SAP	Structural Adjustment Programme
32.	SJH	Safdarjung Hospital
33.	SSB	Super Speciality Block
34.	TMC	Trinamool Congress
35.	UHC	Universal Health Coverage
36.	VMMC	Vardhman Mahavir Medical College
37.	WHO	World Health Organization
38.	WHR	Waist to Hip Ratio