

**UNDERSTANDING DECISION PROCESS IN THE TREATMENT
OF CANCER**

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UNDERSTANDING DECISION PROCESS IN THE TREATMENT OF CANCER

by

Department of Humanities and Social Sciences

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*Dedicated to my parents, Namita and Raj Kumar Jain,
whose unrelenting support and unconditional love has
filled my life with meaning and purpose.*

DECLARATION

I hereby declare that the work presented here in the thesis has been carried out by me towards the partial fulfillment of the requirement for the award of a PhD from the Department of Humanities and Social Sciences, Indian Institute of Technology Delhi. The work contained herein is my own and is a presentation of my original research work. Wherever quotations from others are involved, every effort has been made to indicate this clearly, with due reference to the literature. The content of this report, in full or in parts, have not been submitted to any other institute or university for the award of any degree.

Nishtha Jain

2017HUZ8589

CERTIFICATE

This is to certify that the thesis titled “**Understanding Decision Process in the Treatment of Cancer**” being submitted by Nishtha Jain to the Indian Institute of Technology Delhi, for the award of the degree of **Doctor of Philosophy**, is a record of original bona fide research work carried out by her under my supervision and guidance, and is in conformity with the rules and regulations of IIT Delhi.

She has fulfilled all the requirements for the submission of this thesis, which in my opinion, has reached the standard of fulfilling the requirements for the degree.

To the best of my knowledge, the materials contained in this thesis have not been submitted, in part or full, to any other Institute or University for the award of any other degree or diploma.

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Abstract

Health decisions, especially in the case of critical illnesses like cancer, are complex as they are often taken under time constraints and high stakes. Such decisions are further influenced by various social and structural factors, such as, healthcare infrastructure, availability of resources, economic status of the patients, among others and involve multiple agents, such as various medical experts, patients, and family caregivers. In the Indian scenario, these decisions are further complicated due to conditions of high patient load and limited resources and infrastructure, particularly in government hospitals. Further, research in India also suggests that the patients and family caregivers often rely on doctors to take critical decisions, particularly due to high trust in their expertise. The decision research literature is predominantly based on experiments with predefined alternatives and goals.

The major aim of the thesis is to investigate the decision process in cancer treatment in real-life setting from the perspective of the three main stakeholders, that is, patients, family caregivers, and doctors, as well as laypersons' perceptions. It investigated the critical decisions that arise during cancer treatment, the process of taking such decisions, and the subsequent emotional experiences of these decisions.

Using a mixed method approach, three studies were designed to explore these objectives. Study 1 and Study 2, both qualitative in nature, sought to understand these perspectives from the viewpoints of doctors and then cancer patients and family caregivers, respectively. Study 3 expanded upon some important findings of the preceding studies and explored the influence of decision-making style (paternalistic vs. shared) and the financial status of cancer patients on various aspects of the decision

process, including trust in doctors, patient agency, emotional distress, and attribution of responsibility.

It was found that the critical decisions that the doctors faced were treatment-modality related dilemmas, resource allocation dilemmas, and difficulties in communicating the illness to the patients and their family caregivers. Interestingly, for patients and caregivers, most critical decisions related to handling logistical and financial issues, rather than major treatment-related dilemmas. The doctor's decision process entailed two aspects: technical aspect consideration of evidence, literature, guidelines, and discussion with panel experts, and communicative aspect, sharing the decision with patients and families. Importantly, it was found that there are no single best or optimal decisions, but rather iterations of these two steps that helped the doctors to personalise or tailor the decisions according to the contextual realities of the patients and their family caregivers.

Further, both family caregivers and patients primarily relied on the doctors' advice for taking treatment decisions, to the extent that they were often unaware of crucial treatment details. Family caregivers often played a significant role while the patients were less proactive in the decision process. The three stakeholders also experienced a spectrum of negative emotions throughout the course of treatment. The thesis further highlights the complexities involved in the decision process, including, the role of trust on doctors, extent of patient's agency, involvement of multiple family caregivers, significance of effective communication among the stakeholders, the need for social support structures, reliance on cultural beliefs, and high financial burden of cancer. Moreover, it was found that a shift towards shared approaches does yield qualitatively superior outcomes in terms of increased trust in doctors and patients' agency along with reduced emotional distress.

Overall, the findings illustrate that the decision process isn't a linear trajectory from generating choice alternatives to reaching a final decision. Critical decisions are not made in isolation solely based on evidence. Instead, it reveals multiple layers, where experiences, new information, continuous communication with patients, family caregivers, medical expert, and existing information and research literature, all within a given social context, gradually amalgamate and culminate into the ultimate decision. The thesis makes significant theoretical, methodological, and practical contributions for the fields of healthcare, policy development, decision-making, and psycho-oncology.

Keywords: critical decisions, decision process, cancer, patients, family caregivers, doctors, social context

सार

स्वास्थ्य निर्णय, विशेष रूप से कैंसर जैसी गंभीर बीमारियों के मामले में, समय की बाधा और उच्च दांव के तहत लिए जाते हैं, इसलिए वे प्रयोजन और सामाजिक और संरचनात्मक कारकों द्वारा अधिक प्रभावित होते हैं, जैसे कि, स्वास्थ्य संरचना, संसाधनों की उपलब्धता, रोगियों की आर्थिक स्थिति, अन्यो के साथ और कई एजेंट्स के साथ, जैसे कि, विभिन्न चिकित्सा विशेषज्ञ, रोगियों, और परिवार के देखभालक। भारतीय परिदृश्य में, ये निर्णय अधिक जटिल होते हैं क्योंकि सरकारी अस्पतालों में उच्च रोगी भार और सीमित संसाधन और अधिकरण की स्थितियों के कारण उन्हें और जटिल बनाते हैं। भारत में किए गए अनुसंधान से यह भी पता चलता है कि मरीज और परिवार के देखभालकर्ता अक्सर महत्वपूर्ण निर्णय लेने के लिए डॉक्टरों पर निर्भर करते हैं, विशेष रूप से उनकी विशेषज्ञता में उच्च विश्वास के कारण। निर्णय शोध साहित्य मुख्य रूप से पूर्वनिर्धारित विकल्पों और लक्ष्यों के साथ किए गए प्रयोगों पर आधारित है।

इस शोध का मुख्य उद्देश्य वास्तविक जीवन में कैंसर उपचार के दौरान निर्णय प्रक्रिया की जांच करना है, तीन प्रमुख हितधारकों - मरीज, परिवार के देखभालकर्ता और डॉक्टरों के दृष्टिकोण से, साथ ही आम लोगों की धारणाओं को समझना। इस शोध में कैंसर उपचार के दौरान उत्पन्न होने वाले महत्वपूर्ण निर्णयों, इन निर्णयों को लेने की प्रक्रिया और इन निर्णयों से उत्पन्न होने वाले भावनात्मक अनुभवों की जांच की गई है।

इसे एक मिश्रित विधि प्रक्रिया का उपयोग करके तीन अध्ययनों को खोजने के उद्देश्य से डिज़ाइन किया गया था। अध्ययन 1 और अध्ययन 2, दोनों गुणात्मक प्रकृति के होते हुए, डॉक्टरों और फिर कैंसर रोगियों और परिवार के देखभालकों के दृष्टिकोण से इस दृष्टिकोण को समझने का प्रयास किया। अध्ययन 3 पिछले अध्ययनों की कुछ महत्वपूर्ण खोजों को विस्तारित करते हुए निर्धारित किया गया था और निर्णय-निर्माण शैली (पैटर्नलिस्टिक बनाम साझा) और कैंसर रोगियों की आर्थिक स्थिति के प्रभाव को समझने का अध्ययन किया था। इस प्रक्रिया के विभिन्न पहलुओं में, डॉक्टरों पर भरोसा, रोगियों की एजेंसी, भावनात्मक पीड़ा, और जिम्मेदारी का आरोप सहित निर्णय प्रक्रिया के विभिन्न पहलुओं पर कैंसर रोगियों की आर्थिक स्थिति पर निर्देशक प्रभाव की खोज की गई।

पाया गया कि डॉक्टरों को सामग्री-प्रकार संबंधित दिक्कतों, संसाधन आवंटन दिक्कतों, और रोगी और उनके परिवार कारेगिवर्स को बीमारी की संचार करने में कठिनाइयों का सामना करना पड़ता था। दिलचस्पी से, रोगी और कारेगिवर्स के लिए, अधिकांश महत्वपूर्ण निर्णय व्यावसायिक और आर्थिक समस्याओं को संभालने से संबंधित थे, बड़ी उपचार संबंधित दिक्कतों की बजाय। डॉक्टर के निर्णय प्रक्रिया में दो पहलुओं को शामिल किया गया: तकनीकी पहलू साक्ष्य, साहित्य, दिशानिर्देश, और पैनल विशेषज्ञों के साथ चर्चा का मूल्यांकन, और संचारात्मक पहलू रोगियों और परिवार के साथ निर्णय साझा करना। महत्वपूर्ण रूप से, यह पाया गया कि कोई एक बेस्ट या सर्वोत्तम निर्णय नहीं है, बल्कि इन दो पहलुओं के अनुरूप निर्णयों को व्यक्तिगत या अनुकूलित करने में डॉक्टरों की मदद के लिए यह दोहराव केकदम हैं।

और इसके अतिरिक्त, दोनों परिवार कारेगिवर्स और रोगी अधिकांशतः उपचार निर्णय लेने के लिए डॉक्टरों की सलाह पर निर्भर करते थे, इस हद तक कि वे अक्सर महत्वपूर्ण उपचार के विवरणों के अनजान रहते थे। परिवार कारेगिवर्स अक्सर निर्णय प्रक्रिया में महत्वपूर्ण भूमिका निभाते थे जबकि रोगी निर्णय प्रक्रिया में कम सक्रिय थे। तीनों हितधारकों ने उपचार के दौरान नकारात्मक भावनाओं का विविधता अनुभव किया। थीसिस और भी निर्णय प्रक्रिया में प्रासंगिक जटिलताओं को उजागर करती है, जिसमें, डॉक्टरों पर भरोसे की भूमिका, रोगी की क्रियाशीलता की सीमा, अनेक परिवार कारेगिवर्स की शामिलता, हितधारकों के बीच प्रभावी संचार का महत्व, सामाजिक समर्थन संरचनाओं की आवश्यकता, सांस्कृतिक विश्वासों पर निर्भरता, और कैंसर का उच्च आर्थिक बोझ शामिल है। इसके अतिरिक्त, यह पाया गया कि साझा उपायों की दिशा में एक बदलाव वास्तविक रूप से बेहतर परिणाम प्रदान करता है, जैसे डॉक्टरों पर अधिक विश्वास और रोगियों की क्रियाशीलता के साथ कम भावनात्मक तनाव।

सम्मतः, प्राप्त निष्कर्ष दिखाते हैं कि निर्माण प्रक्रिया विकल्पों का उत्पन्न करने से अंतिम निर्णय तक का एक सरल गतिक्रम नहीं है। महत्वपूर्ण निर्णय केवल प्रमाण पर आधारित अलगज किए जाते हैं। इसके बजाय, यह कई परतों को दिखाता है, जहाँ अनुभव, नई जानकारी, रोगियों, परिवार कारगर्मों, चिकित्सा विशेषज्ञों के साथ निरंतर संचार, और एक दिए गए सामाजिक संदर्भ में सभी मौजूदा जानकारी और अनुसंधान साहित्य को संग्रहित और अंतिम निर्णय में सम्मिलित होते हैं। थीसिस स्वास्थ्य, नीति विकास, निर्णय निर्माण, और मानसिक ऊतकीय के क्षेत्रों के लिए महत्वपूर्ण तात्त्विक, वैधानिक, और व्यावसायिक योगदान देती है।

कीवर्ड: महत्वपूर्ण निर्णय, निर्णय प्रक्रिया, कैंसर, रोगियों, परिवार कारगर्म, डॉक्टर, सामाजिक संदर्भ

Table of Contents

CERTIFICATE	I
ACKNOWLEDGMENTS	II
ABSTRACT	IV
संर.....	VII
LIST OF TABLES	XII
LIST OF FIGURES.....	XIII
CHAPTER 1.....	1
INTRODUCTION.....	1
THE CULTURAL CONTEXT OF DECISIONS	2
DECISION RESEARCH IN REAL LIFE SETTINGS.....	5
HEALTH SECTOR SCENARIO IN INDIA	7
THE PRESENT THESIS.....	8
CHAPTER 2.....	10
REVIEW OF LITERATURE	10
I. CRITICAL DECISIONS IN THE TREATMENT OF CANCER.....	10
II. SELECT THEORIES/PARADIGMS OF DECISION-MAKING	14
<i>Normative decision-making theories: The problem of Optimality</i>	14
Simon’s critique of rationality: ‘Bounded rationality’ and ‘Satisficing’	15
Prospect theory: Rational choice and framing of decisions	16
<i>Rise of Heuristics and Biases approach</i>	18
Fast and Frugal Reasoning	19
Nudge Theory	20
<i>Naturalistic Decision-making Paradigm</i>	21
Recognition-Primed Decision Model.....	23
III. DECISION-MAKING IN HEALTHCARE	24
<i>Basis of Decision-making: Eminence-based, Evidence-based, and Value-based</i>	
<i>Decisions</i>	24
Paternalistic decision-making	27
Shared decision-making	29
IV. THE STAKEHOLDERS IN THE DECISION PROCESS	32
<i>Doctors’ decision process in the treatment of critical illnesses</i>	32
<i>Patients’ decision process</i>	36
<i>Family caregivers’ decision process in critical illnesses</i>	38
V. EMOTIONAL CONSEQUENCES OF THE DECISION PROCESS	40
<i>Doctors’ emotional experiences</i>	40
<i>Cancer patients’ emotional experiences</i>	42
<i>Family caregivers’ emotional experiences</i>	44
VI. SALIENT FACTORS INFLUENCING DECISION PROCESS.....	45
<i>Doctor-patient communication</i>	47
<i>Trust in doctor-patient relationship</i>	49
<i>Cultural Beliefs and their role</i>	52
VII. GAPS IN THE LITERATURE	54
<i>Research Questions</i>	56
<i>Research Objectives</i>	57
CHAPTER 3.....	58
UNDERSTANDING THE COMPLEXITY OF THE DECISION PROCESS FOR DOCTORS IN	
CANCER TREATMENT	58

INTRODUCTION	58
METHOD	60
<i>Study Design</i>	60
<i>Sample</i>	61
<i>Interview Schedule</i>	61
<i>Procedure</i>	62
<i>Analysis</i>	63
RESULTS	64
DISCUSSION	107
CONCLUSION	121
CHAPTER 4	122
RELATIONSHIPS, RESPONSIBILITIES, AND EMOTIONAL CONSEQUENCES: EXPLORING THE DECISION PROCESS OF CANCER PATIENTS AND FAMILY CAREGIVERS.....	122
INTRODUCTION	122
METHOD	124
<i>Study Design</i>	124
I. Cancer Patients	127
Sample	127
Sampling Technique	127
Inclusion Criteria	127
Data Collection Tools	129
Procedure	130
Analysis	131
Results	134
Findings from the patients' narratives	134
II. Family Caregivers	164
Sample	164
Inclusion Criteria	164
Data Collection Tools	164
Procedure	166
Analysis	167
Results	169
Findings from the family caregivers' narratives	169
DISCUSSION	194
CONCLUSION	212
CHAPTER 5	213
EXPLORING THE INFLUENCE OF DECISION-MAKING STYLE AND FINANCIAL STATUS OF CANCER PATIENTS ON CRITICAL ASPECTS OF DECISION-PROCESS	213
INTRODUCTION	213
<i>Hypothesis</i>	220
METHOD	222
<i>Study Design</i>	222
<i>Sample</i>	223
<i>Inclusion/Exclusion Criteria</i>	224
<i>Measures</i>	224
<i>Analysis</i>	229
RESULTS	233
DISCUSSION	239
CONCLUSION	245
CHAPTER 6	246
GENERAL DISCUSSION	246
REAL LIFE CRITICAL DECISIONS IN THE TREATMENT OF CANCER	249
UNDERSTANDING THE COMPLEXITIES OF THE DECISION PROCESS	250

EMOTIONAL CONSEQUENCES OF TAKING CRITICAL DECISIONS	253
INFLUENCE OF DECISION-MAKING STYLE AND FINANCIAL STATUS ON DECISION PROCESS	254
IMPLICATIONS	256
LIMITATIONS.....	258
FUTURE DIRECTIONS.....	261
CONCLUSION	262
REFERENCES	263
APPENDICES	302
APPENDIX A: INTERVIEW SCHEDULE FOR STUDY 1	302
APPENDIX B: INTERVIEW SCHEDULE FOR STUDY 2: CANCER PATIENTS	305
APPENDIX C: INTERVIEW SCHEDULE FOR STUDY 2: FAMILY CAREGIVERS	307
APPENDIX D: SURVEY QUESTIONNAIRE FOR STUDY 3 (ENGLISH).....	309
APPENDIX E: SURVEY QUESTIONNAIRE FOR STUDY 3 (HINDI)	319
ACADEMIC RESUME.....	330

List of Tables

Table 3.1	<i>Demographic characteristics of participants</i>	61
Table 3.2	<i>Thematic analysis coding framework emanating from narratives of doctors</i>	65
Table 4.1	<i>Demographic characteristics of participants</i>	128
Table 4.2	<i>IPA themes emanating from narratives of cancer patients</i>	135
Table 4.3	<i>Demographic characteristics of participants</i>	165
Table 4.4	<i>IPA themes emanating from narratives of family caregivers</i>	168
Table 5.1	<i>Demographic characteristics of participants</i>	224
Table 5.2	<i>Descriptive statistics for the dependent variables across all four conditions</i>	231
Table 5.3	<i>Summary of Linear Mixed Model for Trust in Doctors, Patient's Agency, and Emotional Distress</i>	234
Table 5.4	<i>Summary of Linear Mixed Model for Attribution of Responsibility</i>	235

List of Figures

Figure 5.1	Mean scores of Trust in Doctors	236
Figure 5.2	Mean scores of Patient's Agency	236
Figure 5.3	Mean scores of Emotional Distress	237
Figure 5.4	Mean scores of Attribution of Responsibility	237