

**DETERMINANTS OF TREATMENT NON-ADHERENCE AMONG PATIENTS  
WITH CHRONIC CONDITIONS**

A Thesis submitted to Goa University for the award of the Degree of

DOCTOR OF PHILOSOPHY

IN

MANAGEMENT

By

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RESEARCH GUIDE

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GOA UNIVERSITY

TALEIGAO-GOA

2015

## DEDICATION

This thesis is dedicated to my father, **(Late) Shri. Keshav B. Pawar**, who had always encouraged me towards higher academic pursuits and to my mother, **Smt. Lalita K. Pawar**, for her concern and good wishes.

## DECLARATION

I, Mrs. Vidya R. Dalvi, do hereby declare that this dissertation entitled “**Determinants of Treatment Non-adherence among Patients with Chronic Conditions**” is a record of original research work done by me under the guidance of Dr. Nandakumar Mekoth, Professor, Department of Management Studies, Goa University.

I also declare that this dissertation or any part thereof has not been previously submitted by me for the award of any Degree, Diploma, Fellowship or other similar titles.

Vidya R. Dalvi

Place: Goa University

Date:

## CERTIFICATE

This is to certify that the Ph.D. thesis titled “**Determinants of Treatment Non-adherence among Patients with Chronic Conditions**” is a record of original research work carried out by Mrs. Vidya R. Dalvi under my guidance, at the Department of Management studies, Goa University.

This dissertation or any part thereof has not previously formed the basis for the award of any Degree, Diploma, Fellowship or other similar titles.

Prof. Nandakumar Mekoth

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Date:

## **ACKNOWLEDGEMENTS**

First and foremost I thank the Almighty God for granting me the patience and strength to complete this research work. The completion of this doctoral dissertation was only possible due to the support of several people. I would like to express my gratitude to all of them.

I am deeply indebted to my research guide Professor Nandakumar Mekoth, for his continuous support and guidance during my Ph. D. study and research. He has always been available, even on holidays, to clarify my doubts, despite his busy schedules and I have learnt a lot from his research expertise, knowledge, patience, and enthusiasm. My sincere thanks to the member of Faculty Research Committee, Professor C.M. Ramesh, Goa Institute of Management, for his motivation, invaluable comments and suggestions. I appreciate the contribution of Dr. M. S. Dayanand, Dr. Purva Hegde Desai, Dr. Nirmala Rajnala and Dr. Nilesh Borde, Department of Management Studies, to my work by way of comments and suggestions during the Ph. D. presentations held every Thursday at the Department.

My special thanks to Dr. Gopakumar, Librarian, Goa University, for his timely assistance. I am grateful to Dr. Aruna Mesquita e Noronha, Micheal Sony and Fatima Sousa for their co-operation and help. I place on record my gratitude to all the doctors who gave time, shared their views on the area of research and gave permission to conduct the surveys. My special thanks to Dr Siona Gomes, Medical Superintendent, and Dr. Doreen Dias, Hospicio Hospital, Margao; Dr. Rajeshwar Naik, Royal Hospital, Margao, Dr. Gopal Vaidya , Margao, Dr. Rupa Valaulikar, Margao, Dr. Manoj Togle, Belgaum, Dr. P.

Sivarama, AIDS Counseling and Treatment Center, Belgaum, Dr. A.Y. Ambekar PHC, Kankumbi, Khanapur, Belgaum, and Dr. Kulkarni, ESI, Hospital, Belgaum for their co-operation.

I am obliged to Shri. Bhaskar G. Naik, Principal, and Dr. Ashok Mangutkar, Vice-Principal, Government College of Arts, Science and Commerce, Quepem, for their encouragement. My special thanks to Dr. Pradeep Salgaonkar, Dr. Seema Salgaonkar, and Smt. Asha Mangutkar, for their motivation to register for Ph.D. I am particularly grateful to Smt. Florence Rebello for making the time to proof read my thesis. I am also thankful to my wonderful and generous friends and colleagues: Dr. Elizabeth Henriques, for training me with use of SPSS package, and for constantly extending her research expertise throughout my research work. I owe a lot to her for this achievement; Smt. P.S.Deepa for editing a research paper and volunteering to help me in spite of her family and professional responsibilities; Shri. Onkar Ainapur for helping and relieving me from all college administrative work and computer related work. I deeply miss my friend (Late) Smt. Bharati Parab, who was one of my motivators but sadly is not here to share my joy.

I acknowledge wholeheartedly the kindness and service of the administrative staff of Department of Management Studies, Goa University and of Government College of Arts, Science and Commerce, Quepem.

I appreciate the efforts of my husband Mr. Raghunath Dalvi, my son Mr.Mandar Dalvi and my daughter Ms. Sailee Dalvi for always boosting my morale and being pillars of strength. My field study was made easier because of the help by my husband, my brothers Mr. Anant Pawar, Mr. Rajesh Pawar, my nephew Mr.Rajesh Dalvi, and my friend Mrs.Sujata Kadam. I extend my gratitude to all of them. My sincere thanks to all the respondents for their co-operation and help.

Vidya R. Dalvi

# **DETERMINANTS OF TREATMENT NON-ADHERENCE AMONG PATIENTS WITH CHRONIC CONDITIONS**

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## **ABSTRACT**

This research focuses on identifying the nature and structure of ‘treatment non-adherence’ among patients with chronic conditions. In-depth interviews were conducted among 18 patients with chronic conditions to get deep insights into the experiences of patients about their treatment and to assess their non-adherent behavior and to explore the themes for the development of hypotheses and for the development of scales. Two scales: Determinants of Chronic Disease Treatment Non-adherence Scale (DOCDTNAS) and Chronic Disease Treatment Non-adherence Scale (CDTNAS) were developed to identify the dimensions of the determinants of ‘treatment non-adherence’ and to measure non-adherence among patients with chronic conditions. The scales were pre-tested by administering them to 107 patients seeking health care services from facilities across the states of Goa, Karnataka and Maharashtra. A cross-sectional study was conducted among 479 outpatients with chronic conditions seeking treatment across health care facilities in Goa and Karnataka.

Exploratory Factor Analyses were performed to identify the dimensions of determinants of ‘treatment non-adherence’ and dimensions of treatment non-adherence. Multiple Regression Analyses were performed to find the predictors of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence. SPSS version 16.0 was used for data analysis. For testing interaction effects, Multiple Regression Analyses

were performed to test the interaction effects on the relationships between the determinants of ‘treatment non-adherence’ and treatment non-adherence, medication non-adherence and lifestyle modification non-adherence. The statistical outputs and the interaction graphs were achieved with the help of Interaction Version 1.7.2211 by Daniel Soper.

Analysis of data revealed that:

1. Eight independent variables: work compulsions, unaffordability, dissatisfaction with staff quality, lack of external support, frustration, inconvenience, social stigma and regimen difficulty and three dependent variables: treatment non-adherence, medication non-adherence and lifestyle modification non-adherence and 70 items to measure these dimensions were explored from the qualitative study results.
2. The cross sectional study has identified ‘treatment non-adherence’ as a multi-dimensional construct comprising of medication and lifestyle modification non-adherence. Non-adherence is predicted by eight dimensions of determinants which influence treatment, medication and lifestyle modification non-adherence in varied combinations.
3. The cross-sectional study results have revealed that the variances explained in non-adherence ranged from 8.3% to 24.2% which is moderate.
4. The most significant determinants of ‘treatment non-adherence’ are identified as: regimen difficulty, social stigma, lack of external support, dissatisfaction with staff quality, frustration, work compulsions and unaffordability.
5. The most significant determinants of medication non-adherence are identified as: dissatisfaction with staff quality, regimen difficulty, lack of external support, and inconvenience.



6. The most significant determinants of lifestyle modification non-adherence are identified as: work compulsions, lack of external support, frustration and regimen difficulty.
7. Gender, state, type of health care facility, age, monthly income of the family and monthly expenditure for the treatment have interaction effects on treatment non-adherence, medication non-adherence and lifestyle modification non-adherence.

The content of the thesis may be summarized as follows:

1. In-depth interviews among patients and use of Interpretative Phenomenological Analysis for qualitative research analysis.
2. Development and validation of Scales (DOCDTNAS and CDTNAS) to identify the dimensions of the determinants of 'treatment non-adherence' and to measure non-adherence among patients with chronic conditions.
3. Testing construct validity and testing hypothesized relationships.
4. Testing the interaction effects of moderating variables on the relationship between independent variables and the dependent variables.

Key Words: Determinants, Treatment non-adherence, Medication non-adherence, Lifestyle Non-adherence, Interaction effects

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## **Abbreviations**

IPA- Interpretative Phenomenological Analysis

I-CVI- Individual Content Validity Index

S-CVI- Scale Content Validity Index

DOCDTNAS-Determinants of Chronic Disease Treatment Non-adherence Scale

CDTNAS- Chronic Disease Treatment Non-adherence Scale

ESI- Employees State Insurance

HIV/AIDS-Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome

HAART-Highly Active Antiretroviral Therapy

## CHAPTER 1

### INTRODUCTION

In recent times a major challenge to the healthcare system the world over is the growing prevalence and deaths on account of chronic diseases. The fact is corroborated by studies carried out by the World Health Organization and other researchers. This worrisome phenomenon can be attributed to several factors, the gravest among them being '*treatment non-adherence*'.

During the last decade (2005-2014), researchers (Kondryn, Edmondson, Jonathan, & Tim OB, 2011; Evans, Eurich, Remillard, Shevchuk, & Blackburn, 2012; Banerjee & Varma, 2013; Naidoo, Peltzer, Louw, Matseke, Mchunu, & Tutshana, 2013; Al-Ramahi, 2014; Lemstra & Alsabbagh, 2014; Syed, Rog, Parkes, & Shepherd, 2014) have reported the rates of non-adherence ranging from 24% to 84% among patients with chronic conditions. Various descriptions given to non-adherence such as, "*a hidden problem*" (National Institute for Health and Clinical Excellence, 2009), America's "*other drug problem*" (National Council on Patient Information and Education, 2007); and "*worldwide problem of striking magnitude*" (World Health Organization, 2003) indicate the seriousness of this health issue. Complications resulted from non-adherence are more expensive than medicines (Murray & Valkova, 2013). The consequences of non-adherence to the patients include sub-optimal health outcomes, additional health care cost (NICE, 2009; WHO, 2003; World Health Organization, 2005), disease progression, low quality of life and even death (NCPIE, 2007; WHO, 2003; American Pharmacist Association, 2013) whereas for the healthcare providers, pharmaceutical manufacturers, insurance companies, employers and the government, non-adherence signifies additional financial burden. Any step

towards the diagnosis and treatment of non-adherence will have substantial benefits to all the stakeholders of the healthcare industry.

Efforts to combat non-adherence should begin with an exploration of patient's perspectives on non-adherence and unearthing its root causes (NICE, 2009). There is no particular single factor attributable to non-adherence, but a combination of many factors. During the last decade, the determinants of 'treatment non-adherence' among patients with chronic conditions identified by the researchers are varied and inconsistent across the studies. Sewith, et al., (2004) found that therapeutic relationships influence non-adherence to medication. Sarna, Pujari, Sengar, Garg, Gupta, & Van Dam, (2008) found that severe depression impacts on low adherence. Tibaldi, Clatworthy, Torchio, Argentero, Munizza, & Horne, (2009) have considered necessity-concern related constructs to explain treatment non-adherence. Bhattacharya, Easthall, Willoughby, Small, & Watson, (2012), in their study in UK teaching hospital, found forgetfulness as a barrier to adherence. Ujjinappa, Gowda, Kumaraswamy, & Ujjinappa, (2013) in their study in India found poverty is the significant reason for non-adherence. Nirojini, Bollu, & Nadendla, (2014) in their study in India found medical costs as a predictor of non-adherence. There is limited literature identifying determinants of 'treatment non-adherence' among patients with chronic conditions based in Asian countries especially India. It was the lacunae of research in this specific area that motivated this researcher to undertake the present study with the explicit objective of exploring the experiences of patients with chronic conditions. Such a study will facilitate the description of the nature and structure of 'treatment non-adherence' and also the identification of the determinants of 'treatment non-adherence' further enabling the designing and the formulation of appropriate interventions to enhance adherence among patients with chronic conditions.

## **1.1 BACKGROUND OF THE STUDY**

### **1.1a .Theoretical background**

During the last four decades (1974-2014), various theoretical models are in use to predict non-adherent behavior. Till date, researchers are using, the Health Belief Model, the Theory of Reasoned Action, the Theory of Planned Behavior and the Trans-theoretical Model etc. to predict health behavior. These models are general and not specific to predict non-adherent behavior. Researchers, (Leventhal and Cameron 1987; Taylor, et al. 2006; Mensberger, et al. 2013), have emphasized the need for more comprehensive models to predict health behavior. The present study aims to adopt an indirect method to measure ‘treatment non-adherence’ by applying comprehensive model comprising of economic, social, psychological, demographic, geographical factors to predict non-adherent behavior.

Despite the availability of numerous questionnaires, there is no standard scale to measure non-adherence. Most of the scales measure adherence and have been disease specific. No study has developed and empirically tested a generic tool to measure ‘treatment non-adherence’ among patients with chronic conditions. Therefore, there was a need to develop and validate new scales of generic use to measure non-adherence and determinants of ‘treatment non-adherence’ among patients with chronic conditions. Further, the study is also aimed at finding the associations between determinants of ‘treatment non-adherence’ and dependent variables to identify the most significant predictors of non-adherence. Finally, variables moderating the relationship between determinants of ‘treatment non-adherence’ and dependent variables will also be identified to explain the additional variance in non-adherence.

### **1.1b. Practical background**

The prevalence of high rates of non-adherence (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001; WHO, 2003; Schmid, Hartmann, & Schiffli, 2009), indirectly points to the seriousness of non-adherence throughout the world. The health care systems face serious challenges of managing chronic diseases and non-adherence to chronic diseases. At present, measurement of non-adherence does not feature in public health policy. The new scales will help the health care managers to measure non-adherence among patients with chronic conditions. This study is aimed at exploring not only medication non-adherence but also lifestyle modification non-adherence and identifying moderating variables which will help the healthcare professionals, managers of healthcare facilities and policy makers in designing and implementing interventional strategies for the reduction of treatment non-adherence.

### **1.2SIGNIFICANCE OF THE STUDY**

Chronic diseases are considered to be a major future healthcare challenge (World Health Organization, 2002). A few studies from India (Juvekar, et al. 1995; Sharma, et al. 2012; Hinchagery, Patil, Khavane, Bhandra, & Swarnakamala, 2012; Sathvik, Karibasappa and Nagavi 2013) have assessed the determinants of non-adherence and the impact of interventions on adherence. Since non-adherence is a critical issue, the scales developed should add to the existing knowledge in the area of non-adherence and should help the health care professionals to simultaneously measure treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions. Given the prevalence and incidence of chronic diseases and the dangers of non-adherence to chronic disease treatment, there is a need for diverting the attention to

these issues. The findings of this study are likely to have policy implications and will help to improve health and reduce the cost of non-adherence to stakeholders.

## **1.2 SCOPE OF THE STUDY**

The scope of the study is restricted to patients with chronic conditions. The geographic area of study is limited to the states of Goa, Karnataka and Maharashtra. The study covers exploration of nature and structure of treatment non-adherence in patients with chronic conditions and the determinants thereof.

## **1.3 RESEARCH PROBLEM**

If non-adherence issue is addressed effectively, it will be advantageous to the society at large (WHO, 2003; Pharma 2011). There is an extensive literature focusing on non-adherence to medication across chronic diseases. To mention a few: Mental illness (Shuler 2014; Sharma, et al. 2012; American Pharmacist Association 2013); Diabetes (Mann, et al. 2009; Ciechanowski, Katon, Russo, & Walker, 2001; Becker & Janz, 1985; Shobhana, Rama Rao and Paul 1998; Mumu, Saleh, Ara, Afnan, & Ali, 2014); HIV/AIDS (Horne, Buick, Fisher, Leake, Cooper, & Weinman, 2004; Mbuagbaw, et al., 2012); Hypertension (Lemstra and Alsabbagh 2014; Iloh, Amadi, Okafor, Ikwudinma, Odu, & Godswill-Uko, 2014). Researchers have focused more on quantifying the rates of non-adherence among patients with certain medical conditions in particular and not specific determinants of chronic disease treatment in general. Very few studies have documented the determinants of non-adherence to lifestyle modifications. Mumu, et al. (2014), and Bisiriyu (2009) have documented factors associated with lifestyle modification non-adherence among diabetic patients. Arias-Lioyente, Garcia, & Diaz Martin (2012) have documented non-adherence to medication and non-adherence to physiotherapy among patients with cystic fibrosis. No study has documented chronic disease treatment non-adherence, medication non-adherence



and lifestyle modification non-adherence simultaneously in a sample representing many chronic diseases. Treatment non-adherence is a multidimensional construct, which is predicted by the combination of various determinants; hence, a deeper understanding of the construct can be achieved by exploring it further.

This research is aimed at answering the following questions:

1. What is the concept of chronic disease treatment non-adherence and what are its dimensions?
2. What are the factors that lead to treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions?
3. Are the relationships between determinants of non-adherence and treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions affected by any moderating variables? Which are these variables? And what is the strength of the relationship?

## **1.5 OBJECTIVES OF THE STUDY**

The objectives of the study are:

1. To identify the nature and structure of chronic disease treatment non-adherence.
2. To identify the determinants of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions.
3. To test the interaction effects of moderating variables on the relationships between the determinants of 'treatment non-adherence' and treatment non-adherence, medication non-adherence and lifestyle modification non-adherence.

## **1.6 RESEARCH PLAN**

Reviewing the literature on services marketing and consumer behavior in various service industries, the broader issue selected for the study was ‘consumer behavior’ in the healthcare sector. It was observed that, consumer behavior in healthcare service is different from the other service sectors. Hence ‘healthcare sector’ and ‘the outpatient with chronic conditions’ as a unit of analysis were selected for study. The research area ‘determinants of treatment non-adherence’ from the patients’ perspectives was selected.

The next step was to know as to why the patients are non-adherent to chronic disease treatment. Keeping this in mind, in-depth interviews were conducted at Goa and Karnataka, among 18 patients, to explore the underlying determinants of ‘treatment non-adherence’. The Interpretative Phenomenological Analysis (IPA) was adopted to generate the broad and subordinate themes from the patients’ transcripts. The themes and other items, so generated were considered in the development of hypotheses and the development of the scales.

The next step was to review literature to know the theoretical background to predict patient non-adherent behavior, the existing non-adherence measurement scales, and the already documented determinants of ‘treatment non-adherence’. Determinants of Chronic Disease Treatment Non-adherence Scale (DOCDTNAS) and Chronic Disease Treatment Non-Adherence Scale (CDTNAS) were developed. The inter-rater reliability, validity and readability of each scale were tested and final drafts of the scales were prepared. The scales were pre-tested by administering them to 107 patients seeking health care service from facilities across the states from Goa, Karnataka and Maharashtra.

The next step was the quantitative study among 479 patients from Goa and Karnataka. The scales (DOCDTNAS, CDTNAS) were used to collect the data. Data were analyzed using

SPSS 16.0 version. Factor Analyses were performed to identify the dimensions of determinants of ‘treatment non-adherence’ and the dimensions of treatment non-adherence. Multiple Regression Analyses were performed to identify significant predictors of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence and to test the interaction effects of the moderating variables on the relationships between determinants of ‘treatment non-adherence’ and treatment non-adherence; and on the relationships between determinants of ‘treatment non-adherence’ and dimensions of treatment non-adherence. The statistical outputs and the interaction graphs were achieved with the help of Interaction Version 1.7.2211 by Daniel Soper.

## **1.7 ORGANIZATION OF THESIS**

The thesis consists of seven chapters.

### **Chapter 1 Introduction**

This chapter includes an introduction, background of the research, the significance of the study, the scope of the study, research problem, objectives of the study, research plan, and the organization of the thesis.

### **Chapter 2 Literature review**

This chapter presents a review of literature in the areas on determinants of non-adherence, the theoretical frameworks, and measurement of chronic disease treatment non-adherence, medication non-adherence and lifestyle modification non-adherence.

### **Chapter 3 Research Methodology**

This chapter provides an outline of the research methodology adopted in the study, giving the details about the underlying philosophy behind the selection of the research designs, unit of analysis, data collection methods and data analysis methods.

### **Chapter 4 Development of hypotheses and scales**

This chapter gives details about the qualitative study, development of hypotheses, development of scales, inter-rater reliability, content validity, face validity and readability test of the scales.

### **Chapter 5 Pilot study and quantitative study**

This chapter gives details about the pilot study, and quantitative study and interaction effects. This chapter indicates the methods used for conducting the pilot study which was undertaken to pre-test the scales. Further the details of quantitative study conducted to test the hypotheses are included in this chapter. Finally the method adopted for testing interaction effects are provided.

### **Chapter 6 Analysis and results**

This chapter presents the results of the analyses of qualitative study, quantitative study and interaction effects. This chapter is divided into three parts: Part I, Part II and Part III. Part I provides the details about analyses and results of qualitative study. Part II provides the details about analyses and results of pilot study. Part III provides the details about analysis and results of quantitative study, interaction effects and results.

## **Chapter 7 Discussions and conclusions**

This chapter presents the details about the key findings and discussions. It also includes conclusions of the qualitative and quantitative study. Further the details of testing the hypotheses, interaction effects, theoretical contribution and managerial implications of the study are provided. Finally the areas for future research and limitations of the study are provided thereof.

## **CHAPTER 2**

### **LITERATURE REVIEW**

Despite the knowledge and awareness of the dangers of non-adherence, patients are non-adherent. It is essential to explore the underlying determinants of ‘treatment non-adherence’, if a patient decides not to follow prescribed regimen. There is no particular single reason attributable for non-adherence, but a combination of many factors. Therefore, comprehensive literature review was performed. This chapter provides the detailed account of the extent of literature available on the measurement of non-adherence, theoretical background to predict health behavior and the determinants of ‘treatment non-adherence’.

#### **2.1 DEFINITIONS**

Chronic conditions are the health problems that require ongoing treatment and self-care management for a longer period of time (WHO, 2002). In 2002, mental disorder and physical impairment were included in the list of chronic conditions.

Early research focused on medication compliance, later the focus was shifted to adherence and concordance. In 1976, terms ‘compliance’; in 1993, ‘adherence’ and in 2005, ‘medication adherence’ were introduced to medicine research (Vrijens, et al., 2012) Compliance is the patient’s passive follow up of doctor’s recommendations, whereas adherence is more focused on discussion of the treatment regimen and decision making by the patient to follow the prescribed treatment. ‘Treatment Non-adherence’ is patient non-conformity to prescribed treatment.

There is no formal definition of non-adherence (Vrijens, et al. 2012). In the literature, the terms, ‘low adherence’ and ‘poor adherence’ are also used. In research, medication non-

adherence and lifestyle modification non-adherence have been defined in different ways based on the purpose of the study.

### **Medication non-adherence**

Horne, Weinman, Nick, Elliott, & Morgan (2005) have divided the medication taking behavior into two types viz. intentional and unintentional non-adherence.

Hirth, Greer, Albert, Young, & Piette (2008) in their study of out-of-pocket spending and medication adherence among dialysis patients in twelve countries studied 'primary medication non-adherence'.

Bagchi, Ambe, & Sathiakumar (2010) in their study of determinants of poor adherence to anti-tuberculosis treatment studied non-persistence aspect of treatment.

Mbuagbaw, et al. (2012) in their study of factors associated with adherence to antiretroviral therapy measured non-adherence in the form of degree of non-optimal adherence.

Braithwaite, Shirkorshidian, Jones, & Johnsrud (2013) in their study reported the role of medication adherence in the US healthcare system focusing on non-adherence to prescribed therapies.

### **Lifestyle modification non-adherence**

The recent research studies by Mandal, et al., 2012; Mumu et al. 2014; and Iloh et al. 2014, have specified the methods used to measure lifestyle non-adherence.

Mandal, et al. (2012) in their study with diabetic patients measured adherence and non-adherence in terms of diet and exercise activities performed by the patient during the previous month.

Mumu et al. (2014) in their study of non-adherence to lifestyle modifications among diabetic patients, considered the patients as non-adherent if they did not follow diet,

exercises, foot care, blood glucose testing, and quit smoking and betel quid chewing habits as per healthcare provider's recommendations.

Iloh et al. (2014), in their study, defined adherence to lifestyle modifications by hypertensive patients, in terms of the extent to which the patient's diet and other lifestyle change behavior coincided with the prescribed regimen. They have also calculated the prevalence of non-adherence among hypertensive patients.

Although these definitions were successful in attaining the specific objectives of the studies, they are too diverse and inconsistent to explain all components of treatment non-adherence. The definition of adherence given by WHO (2003) is comprehensive, as it explains medication as well as lifestyle change adherence by patients with chronic conditions. It recognizes the partial autonomy of the patient with regard to follow-up of the treatment. It is a commonly used definition in adherence/non-adherence research.

## **2.2 THE DOUBLE BURDEN OF CHRONIC DISEASES AND NON-ADHERENCE**

### **Burden of chronic diseases**

The World Health Organization and other researchers have done an estimation of the rise in chronic disease throughout the world, especially in low and middle income countries. Nugent (2008) found that, the middle and low income population in developing countries is more vulnerable to chronic diseases. As per WHO (2003), chronic disease will account for two third of the burden of all diseases worldwide in 2020. Stuckler (2008) has estimated that till 2030, the economic development in low and middle income countries will be affected due to the rise in mortality rates of chronic diseases. These estimates indicate that the prevalence of chronic diseases is rising and these diseases are the leading cause of death.



## **Burden of Non-adherence**

Non-adherence is a serious health issue affecting all the stakeholders of the healthcare industry. The consequences of non-adherence to the patients include sub-optimal health outcomes, additional health care cost (NICE, 2009; WHO, 2003; WHO, 2005), disease progression, low quality of life and even death (NCPIE, 2007; WHO, 2003; American Pharmacist Association, 2013) whereas for the healthcare providers, pharmaceutical manufacturers, insurance companies, employers and the government, non-adherence signifies additional financial burden. Drugs trend report (2011), states that elimination of non-adherence related cost can cover the health care cost for millions of Americans. In a nationwide survey of diabetes patients, it was found that the improvement in adherence leads to the saving of billions of dollars annually (Jha, Aubert, Yao, Teagarden, & Epstein, 2012).

### **2.3 TREATMENT NON-ADHERENCE**

Chronic diseases are long term diseases, and demand systematic approach to treatment (WHO, 2005; WHO, 2003). As per ABC Report (2012), non-adherence can occur at the *initiation stage, implementation stage* or *non-persistent stage* of the treatment. There is a substantial evidence of treatment non-adherence. In a review of three decades of compliance research, Vermeire et al. (2001) found that the rates of non-compliance range from 30% to 50%. A Meta analysis of 569 research studies indicated an average non adherence rate was 24.8% (DiMatteo M. R., 2004). Research has documented various rates of non-adherence to treatment across diseases: 25% (HIV) (Horne, Buick, Fisher, Leake, Cooper, & Weinman, 2004); 63% (cancer) (Kondryn et al. 2011); 50% (hypertension) (Evans et al. 2012); 66.9% (unipolar depression) (Banerjee & Varma, 2013); 83.8% (Tuberculosis and HIV) (Naidoo et al. 2013); 48.5% (hypertension) (Lemstra

&Alsabbagh, 2014); 54.2% (hypertension) (Al-Ramahi, 2014) and 24% (multiple sclerosis) (Syed et al. 2014).

The available evidence indicates that during the last decade (2004-2014), the prevalence of non-adherence has been reported across diseases and the rates of non-adherence varying between 24%-84% were explained by various predictors. The determinants of treatment non-adherence identified in the studies are: doctor-patient communication (Ciechanowski et al. 2001); depression (Sarna, Pujari, Sengar, Garg, Gupta, & Van Dam, 2008); cultural factors (Wasti et al. 2011); lack of information and negative outcome (Syed, Rog, Parkes, & Shepherd, 2014); awareness of illness, cognition issues, economic and social factors, insurance status (Shuler, 2014); and age, forgetfulness, medication beliefs and dissatisfaction with treatment (Al-Ramahi, 2014).

#### **2.4 MEDICATION NON-ADHERENCE**

A large body of literature has focused on medication non-adherence among patients with a chronic condition. In a review, DiMatteo (2004) found that the level of adherence differed across diseases. Research has documented various rates of non-adherence to medication across diseases: 33% (fibromyalgia) (Sewith, et al., 2004); 28% (diabetes) (Mann et al. 2009); 70.2% (diabetes) (Adisa, Alutundu, & Fakeye, 2009); 25.2% (AIDS/HIV) (Tran et al. 2013); 23.3% (cancer) (Bhattacharya et al. 2012); 15% (diabetes) (Ujjinappa et al. 2013); 38% (mental disorders) (Sharma et al., 2012); 56.5% (unipolar depression) (Banerjee and Varma, 2013); and 18%-84% (psychiatry) (Nirojini, Bollu and Nadendla (2014). The findings of Winkler, Teuscher, Mueller, & Diem (2002), are dissimilar to other studies. In a small sample of 19 diabetic elderly patients, they found that 42.1% of the patients were 100% adherent.

The available evidence, points out that during the last decade (2004-2014) reported rates of chronic disease medication non-adherence varying from 15% to 84% across studies were explained by various predictors. The determinants of medication non-adherence identified in the studies were: patient- doctor relationship (Sewith, et al., 2004); disease and medication beliefs (Mann et al. 2009); lack of knowledge and awareness of illness and treatment (Sharma et al. 2012); cost, number of medicines, adverse effects, cognition, vision and depression (Doggrell, 2010); and forgetfulness, inconvenience, and concern (Mbuagbaw, et al., 2012).

## **2.5 LIFESTYLE MODIFICATION NON-ADHERENCE**

Lifestyle non-adherence is a less often dimension of non-adherence. The studies by Bisiriyu (2009) and Mumu, Saleh, Ara, Afnan, & Ali (2014) exclusively measured lifestyle non-adherence among diabetes patients. Bisiriyu (2009) found that 37.4% and 52%, of the patients were non-adherent to diet and to exercise respectively. In a study by Mandal, et al. (2012) among diabetic patients, 53% of the patients were non-adherent to lifestyle medication to diet, physical activity and addiction. Mumu, et al. (2014) found that the rates of non-adherence varied from 25% to 88%, across the components of lifestyle modification non-adherence. The study by Iloh et al. (2014), found that 83.6% patients were non-adherent to lifestyle modification.

The available evidence, from 2009- 2014 points out that the reported rates of lifestyle modification non-adherence vary from 25% to 88% across studies and were explained by various predictors. The determinants of lifestyle modification non-adherence identified in the studies were: old age, unemployment, not feeling necessity, being busy and multiple diseases (Mumu et al. 2014); lack of self efficacy, eating out, lack of information, financial

constraints, lack of exercise partner, winter season, distance (Bisiriyu, 2009) and inconvenience (Banerjee & Varma, 2013).

## **2.6 MEASUREMENT OF NON- ADHERENCE**

### **Approaches followed in qualitative research**

When the research topic is complex, the qualitative approaches such as; phenomenology, grounded theory, discourse analysis, conversation analysis, ethnography and interpretative phenomenological analysis are useful. The literature review of the qualitative approaches to research indicated that, Interpretative Phenomenological Analysis has been successfully employed in health psychology related studies. Researchers Smith & Osborn (2007), Griffiths, (2009), Gambling & Long, (2012) and Harris, (2012) have employed IPA to study the experiences of patients' with chronic conditions.

### **Theoretical models employed in health behavior research**

The theoretical models give the direction to the research and can also help in designing intervention strategies (Redding, Rossi, Rossi, Velicer, & Prochaska, 2000). The theoretical models such as; Necessity-concern framework; Health Belief Model (Rosenstock, 1974); Theory of Planned Behavior (Ajzen, 1991); Theory of Reasoned Action (Ajzen & Fishbein, 1980); Ratter's Social Learning Theory, Social-Cognition Theory of Self regulation (Bandura, 1991); and Trans-theoretical Model (Prochaska & Velicer, 1997) have been demonstrated effective in evaluating health behavior. The brief explanation of the models:

#### **Health Belief model**

According to this model, the likelihood that someone will take action to prevent illness depends upon perceived susceptibility, perceived severity, perceived benefits, perceived

barriers, cues of action and self efficacy. However, these factors jointly or singly may influence the behavior.

### **Theory of Planned Behavior and Theory of Reasoned Action**

The constructs used in this model are: behavioral Intention; attitude; behavioral belief; evaluation of the behavioral belief; subjective norms; normative belief; motivation to comply; perceived behavioral control ; control belief ; and perceived power. The relative importance of these constructs may vary across health behaviors such as, smoking, consumption of liquor.

### **Trans-theoretical Model (Prochaska&Velicer, 1997)**

This model is based on the assumption that health behavioral changes are the result of a logical procedure i.e. precontemplation; contemplation; preparation; action; and maintenance. This shows that behavior change involves progress through these six stages. Without planned interventions, differentiating and documentation of the stage wise change may be difficult.

Necessity-concern framework has been used by the researchers to study the medication beliefs in chronic illness (Horne, 1997; Tibaldi et al. 2009), to learn patients' beliefs associated with non-adherence (Horne et al. 2004) and to predict non-adherent behavior among diabetic patients (Mann et al. 2009). Health Belief Model has been applied to predict the behavior of diabetic patients (Lewis, 1994; Mensberger, et al., 2013) and intentions to receive the vaccine (Coe, Gatewood, Moczygemba, Goode, & Beckner, 2012). The Theory of Planned Behavior has been successfully employed to determine factors affecting chronic patients' primary adherent behavior (Lee, Tseng, & Pan, 2011).

Researchers Leventhal & Cameron (1987) in their study of the use of behavioral theories in compliance research concluded that although the existing theories are effective, psychological approach can give new direction to compliance research. In 2003, WHO had emphasized the need for new comprehensive models to predict adherence to long term therapy. Taylor, et al. (2006) in their review have reported that there is a need to study the impact of social, economic and environmental factors on the health behavior. Mensberger, et al.(2013) have argued that the existing theories have similar themes for explaining patient adherent behavior. The recent developments in behavior prediction are Self Determination Theory (Ryan, Patrick, Deci, & Williams, 2008) and COM-B framework (Jackson, Eliasson, Barber, & Weinman, 2014).

In past four decades (1974-2014), various theoretical models have been used to predict non-adherent behavior. The constructs and variables studied have changed over the years. Recently psychological factors are emerging as strong predictors of adherence (Arias-Liovente, Garcia, & Diaz Martin, 2012).

### **Measurement methods used in non-adherence research**

Measurement of non-adherence is a challenging task. Both direct and indirect methods are used to measure non-adherence. Direct methods such as appointment records, medical device monitoring (Griffin & LaPlante, 2013) testing drug levels in the body or in urine and indirect methods such as questionnaires, pharmacy refill records and patient diaries (American Pharmacist Association, 2013), pill counts are in use. The Medication Event Monitoring System is commonly used method in clinical studies. Shi, Liu, Koleva, Fonseca, Kalsekar, & Pawaskar (2010) in a review to examine the association between direct and indirect method concluded that there is no consensus on the best method to measure adherence. Past research shows that direct methods to measure adherence require

technical skills, involvement of clinical professionals, and are mainly used in clinical trials. Horne (1997) stated that the direct methods do not predict time-course of non-adherent behavior. McDowell (2006) stated that the questionnaire method is effective in measuring the non-adherence.

The most commonly used scales to measure medication adherence/non-adherence across diseases are: Morisky Medication Adherence Scale (MMAS 4), a four item scale; (MMAS 8) an eight item scale (Morisky, 1986); and Medication Adherence Rating Scale (MARS), a ten item scale (Thompson, 2000). Recently, Morisky Medication Adherence Scale has been used by the researchers Stack, Bundy, Elliott, New, Gibson, & Noyce (2010) to measure non-adherence among diabetic patients ; Ramanath, Nagakishore, Mahesh Kumar, Balaji, & Bhanuprakash (2011), to study the impact of an intervention on the adherence and quality of life among chronic patients; Bhattacharya et al. (2012), to measure medication non-adherence; and Banerjee & Varma (2013), to identify the determinants of treatment non-adherence among psychiatric patients.

The self-developed scales have been also used by the researchers to measure adherence/non-adherence or a specific component of managing chronic diseases in their respective studies, such as; Dietary Regimen Adherence in Diabetes Mellitus Scale (Shobhana, Rama Rao, & Paul, 1998); Self-Efficacy for Managing Chronic Disease scale (Loring, Sobel, Ritter, Laurent, & Hobbs, 2001), Patient-Physician Relationship Index (Ostacoli, et al., 2007), Diabetes Foot Self-Care Behavior Scale (Chin & Huang, 2013), and 12 point scale to measure prevalence of medication non-adherence among psychiatry patients (Nirojini, Bollu, & Nadendla, 2014). Although non-adherence is widely examined, it is still claimed that there is no standard method of measuring adherence and non-adherence (Horne et al. 2005; Shi et al. 2010).

## **2.7 DETERMINANTS OF TREATMENT NON-ADHERENCE**

Till date there is no scale for measuring work compulsions, unaffordability, dissatisfaction with staff quality, lack of external support, frustration, inconvenience, social stigma and regimen difficulty as determinants of non-adherence. Past research has identified numerous associations between these determinants and treatment non-adherence but without consistent findings.

### **Work compulsions as a determinant of non-adherence**

Patients with chronic conditions in the working population may have a difficulty in balancing the vocational role and adopting behavior change to manage their chronic conditions. Studies have shown that work compulsions were associated with treatment non-adherence (Jaggarajamma, et al., 2007; Banerjee & Varma, 2013); medication non-adherence (Banerjee & Varma, 201; Talam, Gatongi, Rotich, & Kimaiyo, 2008; Griffin & LaPlante, 2013; Hinchagery et al. 2012) and lifestyle non-adherence (Arias-Llorente, Garcia, & Martin, 2012; Banerjee & Varma, 2013; Mumu et al. 2014).

The literature review indicates unintentional non-adherence among chronic patients in the working population.

### **Unaffordability as a determinant of non-adherence**

The poor with their low socio-economic conditions are more vulnerable to chronic diseases (WHO, 2005). In a research in selected 12 countries, it was found that average monthly spending for medication range from \$ 8 to \$114 and non-adherence ranged from 3% to 29% between the countries (Hirth et al. 2008). Literature review points out that throughout the world, poverty, cost of medicines and cost of care impact on medication non-adherence (Robert, 2009; Adisa, Alutundu, & Fakeye, 2009; Hinchagery et al. 2012; Shuler, 2014;



Naidoo et al. 2013; ABC, Report, 2012; Lemstra & Alsabbagh, 2014; Nirojini, Bollu, & Nadendla, 2014; Levesque, Li, & Pahal, 2012; and Mbuagbaw, et al., 2012) and also on lifestyle modification non-adherence (Bisiriyu, 2009). Contrary to this, it was observed in Denmark that, the rich people were non-adherent (Sergie, Simeonova, & Niels, 2013).

The literature shows that due to affordability, patients not only were non-adherent to medication, but also to Lifestyle modification, although it is relatively inexpensive.

### **Dissatisfaction with staff quality as a determinant of non-adherence**

Patients with chronic conditions, in a long-term therapeutic relationship, normally have minimum base-level expectations from the healthcare provider. Literature shows that dissatisfaction with various aspects of process quality of health care facility or quality of care impacts on non-adherence such as: patient-doctor communication (Ciechanowski et al. 2001; Sewith, et al., 2004); health care and health system related factors (WHO, 2003) ; satisfaction and trust in physician (George, Kong, Thoman, & Stewart, 2005; Sergie, Simeonova, & Niels, 2013); lack of information and short consultation (Banerjee & Varma, 2013; Nirojini, Bollu, & Nadendla, 2014). This shows that staff quality of the health care facility impacts on non-adherence.

### **Lack of external support as a determinant of non-adherence**

Individuals, when ill, expect emotional support from the family, relatives and friends. Elderly patients, due to multi-morbidities and financial limitations, are more likely to expect the social support. Throughout the world elderly population is expected to increase to 1 billion by the year 2050 (WHO, 2005). It is observed that the social and cultural values are changing. In a focus group study of the elderly with mental illness from Goa, it was found that, the traditional values of caring for the elderly people in the family are changing

(Patel & Prince, 2001). Research studies have reported that lack of social support affects medication adherence (Shuler, 2014; Hinchagery et al. 2012; Mbuagbaw, et al., 2012; Jin, Sklar, Min sen Oh, & Li, 2008; WHO, 2003; Ujjinappa et al. 2013; Banerjee & Varma, 2013) and lifestyle modification to diet and exercise (Bisiriyu, 2009). In a review of literature from 1948 to 2001, it was found that practical social support and family conflicts were associated with adherence (DiMatteo, 2004). In another review by Scheurer, Choudhary, Swanton, Matlin, & Shrank (2012), practical support for taking medication, doing household functions and transportation were consistently associated with greater medical adherence.

This indicates the positive association between lack of social support and non-adherence.

### **Frustration as a determinant of non-adherence**

Frustration is caused due to non-fulfillment of the set objectives. Past research shows that patients were non-adherent due to long term treatment (Robert, 2009); no benefit of treatment (Robert, 2009; Jin, Sklar, Min sen Oh, & Li, 2008; Hinchagery et al. 2012); long waiting hours (Banerjee & Varma, 2013); fed up of treatment (Adisa, Alutundu, & Fakeye, 2009), and restriction on diet (Shobhana, Rama Rao, & Paul, 1998). The review shows that both modifiable (long waiting hours, fed up of treatment) and non-modifiable factors (long term treatment, restriction on diet) lead to frustration and subsequently to non-adherence.

### **Inconvenience as a determinant of non-adherence**

Non-proximity of healthcare facility may be a hurdle to the elderly and seriously ill patients, to adhere to their treatment. Research findings show that inaccessibility, due to distance and lack of transport, were associated with non-adhering to medicine and exercise (WHO, 2003; Banerjee & Varma, 2013; Bisiriyu, 2009; Griffin & LaPlante, 2013). Adisa, Alutundu, & Fakeye (2009) have found that diabetic patients were non-adherent to

medication due to inconvenience by taking medicine outside the home. Shobhana, Rama Rao, & Paul (1998) discovered that diabetic patients experienced inconvenience to adhere to the diet. Bisiriyu, (2009) and Levesque, Li, & Pahal (2012) found out that due to winter season, patients were non-adherent to recommended lifestyle change.

This indicated that issues related to transportation, seasonal variations, and social stigma create inconvenience and in turn impact non-adherence.

### **Social stigma as a determinant of non-adherence**

Studies have found that HIV/AIDS patients were non-adherent to medication due to stigma (Talam et al. 2008; Griffin & LaPlante, 2013; and Mbuagbaw, et al., 2012). Shuler (2014) found that in case of patients with schizophrenia, stigma was associated with adherence to prescribed treatment. Shobhana, Rama Rao, & Paul (1998) found that diabetic patients were non-adherent to diet because of the difficulty to disclose the sickness in the social gathering. Mann et al. 2009 found that diabetic patients were non-adherent to medication, as they felt the sickness affects their social life.

The common belief is that the patients with communicable diseases keep their treatment a secret, but the review shows that patients with communicable disease as well as non-communicable disease were non-adherent due to stigma.

### **Regimen difficulty as a determinant of non-adherence**

Clarity of instructions on a prescription is a prerequisite for the successful follow up of the regimen. A prescription survey conducted in Goa found that the prescriptions were incomplete (Patel, Vaidhya, Naik, & Borker, 2005). Past research has reported that a complex treatment regimen (Robert, 2009; WHO, 2003), duration of the therapy (Bhattacharya, Easthall, Willoughby, Small, & Watson, 2012), confusion about medication

(Banerjee & Varma, 2013; George, Kong, Thoman, & Stewart, 2005); lack of clear instructions (Banerjee & Varma, 2013); poor understanding of the treatment regimen (Hinchagery et al. 2012), patient's unwillingness to medication (Furthauer, Maria, & Andreas, 2013) impacted on non-adherence. Christensen and Johnson, (2002) found that the rate of non-adherence vary with symptoms and the type of treatment regimen. Redzuan, Lee, & Shah (2014) in their study found that the number of medications did not significantly affect adherence and persistence, whereas Stack, Bundy, Elliott, New, Gibson, & Noyce (2010); Turner, Hochschild, Burnett, Zulfiqar, & Dyer (2012); Sabbatini, et al. (2014) and Nirojini, Bollu, & Nadendla (2014) found that varying number of medicines impact non-adherent behavior.

The literature review indicates that predictors of non-adherence vary across illness symptoms, type of regimen, type of illness, number of medicines and difficulties associated with understanding the regimen.

## **2.8 Literature Gap**

Review of literature has highlighted the various issues concerning non-adherence. Worldwide, despite many efforts made, non-adherence still prevails among patients with chronic conditions. A large body of literature on non-adherence research is mainly focused on medication non-adherence and most of the data is collected through control group trials. No theoretical model used in non-adherence research, studies medical and clinical aspects, the social, psychological and economic aspects of patients' non-adherent behavior. There are several adherence measurement scales but researchers still claim that none is considered as a gold standard. The existing scales measure medication adherence. No scale exclusively measures treatment non-adherence, medication non-adherence and lifestyle non-adherence. Most of the scales are capturing 'non-adherence' as a one-dimensional

construct. In non-adherence literature, lifestyle non-adherence is a less discussed dimension of non-adherence. There is very limited literature on simultaneous study of treatment, medication and lifestyle modification non-adherence. Although studies have mainly focused on quantifying the rates of prevalence of non-adherence among patients with certain medical conditions, specific determinants of non-adherence among chronic patients have been rarely evaluated empirically. Although studies have found the predictors of non-adherence, their interaction effects have rarely been researched.

Therefore, this study aims to take a different approach to study non-adherent behavior by exploring the experiences of patients, developing the non-adherent measurement scales, identifying the determinants of 'treatment non-adherence' and testing the interaction effects of moderating variables on the relationship between the independent variables and dependent variables.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

The dangers of chronic disease and the non-adherence pose challenges to the patient. The previous chapter revealed that despite the availability of extensive literature, there is a scope to develop non-adherence measurement scales and to explore additional determinants of treatment non-adherence, medication non-adherence and lifestyle non-adherence among patients with chronic conditions. This chapter outlines the details of the research methodology adopted in the study. It gives details about the underlying philosophy in the selection of research design and data analysis. The methods employed in the collection and analyses of data are described and the reasons for the adoption are also explained.

#### **3.1 RESEARCH DESIGN**

The research design is essential for the collection, measurement, and analysis of data (Cooper & Schindler, 2006. p 138). In a review of literature on methodologies employed, it was found that a qualitative research approach will be useful prior to quantitative study, as the present research topic is complex (Harris, 2012). Therefore, a qualitative study was conducted among patients with chronic conditions to have a deep understanding into the patients' experiences about their treatments and non-adherent behaviors. The research instruments were developed to measure the determinants and dimensions of treatment non-adherence. Pre-testing the research instruments was done through a pilot study among 107 patients with chronic conditions.

The quantitative study was undertaken among 479 patients with chronic conditions to explore the dimensions of determinants of 'treatment non-adherence', dimensions of

treatment non-adherence and to ascertain predictors of treatment non-adherence, medication non-adherence, and lifestyle modification non-adherence. Interaction Effects of moderating variables were tested on the relationship between determinants of ‘treatment non-adherence’ and treatment non-adherence, the relationship between determinants of ‘treatment non-adherence’ and medication non-adherence and the relationship between determinants of treatment non-adherence and lifestyle modification non-adherence.

### **3.2 UNIT OF ANALYSIS**

The unit of analysis for the present study is the ‘a patient with a chronic condition’. It was observed in one of the quantitative study conducted by the researcher at a Primary Health Centre, in Karnataka, India, that the patients with chronic conditions are more non-adherent to treatment than acute patients (Mekoth and Dalvi, 2015). Unlike in other services, the customer of a healthcare avails the services only when he/she is unwell, hence, patient behavior ought to be different from the consumer of other services.

### **3.3 SELECTION OF SAMPLES**

For the qualitative study, which aimed at exploring the determinants and dimensions of ‘treatment non-adherence’, 18 patients, representing 12 major communicable and non-communicable chronic conditions, seeking treatment across different health facilities in Goa and Karnataka and willing to participate in the interview, were selected. The snowball sampling method was employed.

For the pilot study, which aimed at pre-testing the scales, 107 chronic patients with chronic conditions seeking treatment across different health facilities in Goa, Karnataka

and Maharashtra and willing to participate in the interview, were selected. The convenience sampling method was employed.

For the quantitative study, which aimed at identifying the dimensions of determinants of ‘treatment non-adherence’ and the dimensions of treatment non-adherence and testing hypotheses, a sample of 479 outpatients with chronic conditions, representing 12 chronic diseases, seeking treatment at public and private health care facilities in Goa and Karnataka and willing to participate in the survey, was selected. The chronic disease groups, from which the patients were sampled, were chosen to reflect a variety of chronic conditions (Diabetes, Cancer, Cardiac problem, Arthritis, Dermatological problem, Chronic pain, HIV/AIDS, Epilepsy, Hypertension, Asthma, Mental illness) which require both medications as well as lifestyle modification. The convenience sampling method was employed.

### **3.4 DATA COLLECTION TOOLS**

For the qualitative study, a semi-structured questionnaire was used to elicit the chronic patients’ experiences and perceptions of their treatment and non-adherent behavior. For the pilot study and quantitative study, the scales (DOCDTNAS and CDTNAS) developed by the researcher to measure non-adherence were used to collect the data.

### **3.5 DATA COLLECTION PROCEDURE**

For the qualitative study, during August-September, 2013, by prior appointment, informed consent, willingness to participate in the interview, and with permission to record the narratives, each participant was interviewed at his/her residence. The researcher briefed the purpose of the study to each participant. Some participants did not wish to disclose their identity; hence, each patient was coded with a number. The



questions were asked by the researcher in Marathi, Konkani or English. The narratives were audio recorded.

For the pilot study, during December 2013-January 2014, the patients with chronic conditions were contacted personally to inquire about their willingness to participate in the pilot study. 107 participants volunteered to participate. The patients were contacted at waiting areas in private hospitals/clinics from Goa, Karnataka and Maharashtra. The researcher briefed the purpose of the study and the procedure of recording the responses to the scales to each of the participants in Marathi, Konkani, Hindi or English. Those who were able to read and respond in English filled the scales themselves. The rest were administered by the researcher. The filled-in scales were collected by the researcher the same day or in a week's time.

For the quantitative study, during March-June, 2014, outpatients with chronic conditions were contacted in the waiting areas of the hospitals/ clinics. 479 patients volunteered to participate in the quantitative study. The researcher briefed the purpose of the study and the procedure to fill the scale to each of the participants in Marathi, Konkani, Hindi, Kannada or English. Those knowing English filled the questionnaires themselves, the rest were administered by the researcher. The filled in questionnaires were collected by the researcher on the same day. Some questionnaires were collected by the researcher in a week's time at the respondents' convenient day, time and place.

### **3.6 DATA ANALYSIS TECHNIQUES**

#### **Qualitative study**

The literature review of the qualitative approaches to research indicated that, the researchers have successfully employed Interpretative Phenomenological Analysis in

their health psychology related studies (Harris, 2012; Griffiths, 2009; Gambling & Long, 2012; Biggerstaff & Thompson, 2008). Mesquita e Noronha & Mekoth (2015) have used Interpretative Phenomenological Analysis to explore the emotions of consumers of health care systems. Interpretative Phenomenological Analysis (IPA) developed by Smith Jonathan A. in 1990's was used for qualitative research.

Fleiss Kappa statistics were employed to evaluate multi item, multi rater agreement between the raters (Fleiss, 1971) and as stated by Polit & Beck (2006), content validity of the individual items and the scales were evaluated. Face validity and readability tests followed by inter-rater reliability and content validity. As recommended by Mathers, Fox, & Hunn (2007), each Scales' Fog Index and the Flesch Reading Ease Score were tested. Sony and Mekoth (2015) have used Flesch Reading Ease Score to test the readability of Fleadapt Scale, to measure employee adaptability. The results of readability test were achieved with the help of online calculator (Readability-Score.com).

### **Quantitative study**

Cronbach's Alpha coefficient, an indicator of internal consistency of the scale, was used for establishing scale reliability of both the scales. Exploratory Factor Analyses with Principal Component Analyses extraction and Varimax rotation method were performed to identify the dimensions of determinants of 'treatment non-adherence', and dimensions of treatment non-adherence. Multiple Regression Analyses were performed with calculated factor scores to find the predictors of treatment non-adherence, medication non-adherence and lifestyle non-adherence. SPSS version 16.0 was used for data analysis. For testing interaction effects, Multiple Regression Analyses were performed. The statistical outputs and the interaction graphs were achieved with the help of Interaction Version 1.7.2211 by Daniel Soper.

## **CHAPTER 4**

### **DEVELOPMENT OF HYPOTHESES AND SCALES**

The previous chapter gave the details of research methodology adopted for this research study. This chapter gives details of the qualitative study for development of hypotheses and development and validation of scales (DOCDTNAS and CDTNAS).

#### **4.1 QUALITATIVE STUDY**

During August and September, 2013, in-depth interviews were conducted by the researcher. 18 chronic patients with communicable and non-communicable conditions, seeking treatment across different health facilities in Goa and Karnataka and willing to participate in the interview were interviewed at their residences at their convenient timings. The snowball sampling method was employed. Semi-structured questionnaire developed by the researcher was used. With prior informed consent, in-depth interviews were conducted in Marathi, Konkani and English, to elicit their views on non-adherence to their treatments. Duration of each interview ranged from 30 to 60 minutes. The narratives were audio recorded on a mobile phone. The narratives were later converted into transcripts in English by the researcher.

The semi-structured questionnaire included the following questions:

1. Please tell me your personal details.
2. Please tell me details of your sickness.
3. Please tell me details of your treatment?
4. What was the doctor's advice to you?
5. Do you adhere/non- adhere to the doctor's advice?
6. If no, why are you not adhering to doctor's advice? Are there any special reasons?

## **Data Analysis**

Interpretative Phenomenological Analysis (IPA) was used for data analysis. Each transcript prepared from the patient narratives was read a few numbers of times, and the annotations within the scope of the study were drawn. This procedure was repeated for all transcripts. Whilst accepting the fact that the determinants of non-adherence may vary across the patients, the researcher has grouped the viewpoints together, to get a clearer understanding of the issues raised by the participants and to draw the annotations from patients' transcripts. **Appendix I** gives the details of the patients' narratives with annotations.

The frequency tabulation of the annotations drawn was done. The broad themes and subordinate themes were generated based on the highest frequency to lowest frequency. Subordinate themes were clubbed together to form broad themes to identify the proposed independent and dependent variables. Along with broad and subordinate themes, 70 items measuring the theme variables were generated, which were helpful in the development of hypotheses and the scales.

The broad themes generated were: Lifestyle modification non-adherence; Work compulsions; Unaffordability; Medication Non-adherence; Dissatisfaction with staff quality; Treatment non-adherence; Lack of external support; Frustration; Inconvenience; Social stigma; and Regimen difficulty.

The subordinate themes generated were: Lifestyle non-adherence to diet; Lifestyle non-adherence to exercise; No caretaker; No filling prescription in time; Free service; Family responsibility; Expensive health care; No necessity belief; Nonprofessional health services; Lifestyle non-adherence to rest; and Long waiting hours.

Based on the broad and subordinate themes and proposed conceptual framework on the study, eight independent variables; work compulsions; unaffordability; dissatisfaction with staff quality; lack of external support; frustration; inconvenience; social stigma; and regimen difficulty and three dependent variables; treatment non-adherence; medication non-adherence; and lifestyle modification non-adherence, were generated and later used for development of hypotheses and development of the scales.

#### **4.2 DEVELOPMENT OF HYPOTHESES**

Existing scales are disease specific, hence the need-based generic use scales to measure non-adherence among patients with chronic conditions were required. The independent and dependent variables generated from the qualitative research were considered to develop the hypotheses and the scales.

**The relationships between the determinants of ‘treatment non-adherence ‘and treatment non-adherence are given below:**

Some patients with chronic illnesses have to work although sick due to the fear of loss of pay and job, no other source of household income and family responsibility. Women, although sick, due to lack of help, have to do household functions. Individuals have to balance personal life responsibilities with work related demands. Loss of pay adds to the financial burden to the family. Patients may have difficulty in balancing the demands of work-life, financial problems and inflexible treatment schedules. The prescribed treatment regimen for most of the chronic conditions involves both medication and lifestyle change recommendations. In a study, it was found that 30.4% of the asthma patients forgot to take medicines due to occupation related problems (Hinchagery et al., 2012). Treatment adherence or non-adherence may be based on the value an individual places on the

personal responsibilities and the healthy living. The following are the extracts from the patients' narratives:

1. *“Doctor has advised for another eight days rest. But I had to go to work. Earlier I used to get night shifts and I used to avoid medicines and could not follow diet”*. (Patient No. 5, Male, Age 54, diabetes, piles and liver problem).
2. *“We told the doctor our financial constraint, loss of pay, leave and linguistic problems. Second time, I did not go for treatment in Bangalore. I resumed my duties. I cannot afford to rest”*. (Patient No. 6, Male, Age 30 years, Chronic back and stomach pain).
3. *“Not possible to go to the doctor as per his advice because of fear of loss of pay, work tension, transport and other expenditure”*. (Patient No. 7, Male, Age 35 years, Liver problem).

These statements depict that due to work related problems, patients are non-adherent to treatment.

Therefore, it is hypothesized that;

H1. There is a positive relationship between work compulsions and treatment non-adherence among patients with chronic conditions.

Chronic disease treatment cost is of a recurring nature. Poor households have very limited income at their disposal for the fulfillment of the necessities of life. Hence paying for medicines on an ongoing basis is a major concern for chronic patients. Research has reported that poverty and the cost of medicines impact non-adherence (Shuler KM, 2014; Naidoo et al, 2013). The following are the extracts from the patients' narratives:

1. *“The doctor again sent me for some tests to another hospital. There we had to spend lots of money. Next time, I will not go there”*. (Patient No. 5, Male, Age 54, Diabetes, piles and liver problem).

2. *“Last month I started getting stomach pain. Again, I was taken to the same doctor. She referred to a specialist. I had no money to take specialist treatment. I could not follow treatment”*. (Patient No. 6, Male, Age 30 years, Chronic back and stomach pain).

It is understood that, patients are unable to continue the treatment due to the financial difficulties.

Therefore, it is hypothesized that;

H2. There is a positive relationship between unaffordability and treatment non-adherence among patients with chronic conditions.

Patients are usually blamed for non-adherence, but the healthcare system factors also have an impact on patient non-adherence (WHO, 2003; WHO, 2005). The following are the extracts from the patient’s narrative:

1. *“The doctor was not available. The nurse gave some medicine. I asked the nurse the side effects of the medicine. Still, I had a doubt. If the doctor was there, it would have been good. I was very much worried. I took only two tablets. I did not take the remaining medicine and never went there”*. (Patient No. 8, female, 25 years, HIV/AIDS).

The patient was upset on the doctor’s absence, doubted the competence of the nurse and was concerned about the side effects of the medicine, hence, decided not to take medicines and not to revisit the healthcare facility. Therefore, it is hypothesized that;

H3. There is a positive relationship between dissatisfaction with staff quality and treatment non-adherence among patients with chronic conditions.

Patients with physical discomfort, psychological problems or both, with debilitated position, require support from the family members or others. Elderly patients, due to their medical problems and financial limitation are more likely to expect the social support. In a study of patients' with unipolar depression, lack of support to accompany to the hospital resulted in discontinuation of treatment (Banerjee and Varma, 2013). The following are the extracts from the patient's narrative:

1. *“One day, I was getting ready to go for job, started getting severe abdominal pain; unable to pass urine. How I manage to go to the hospital, I only know myself, got admitted without anybody's support. I wanted to take a second opinion from a doctor in Mumbai. Nobody accompanied me. I had taken appointment on phone. I could not take that treatment”*. (Patient No. 3, Female, Age 50 years, Cancer).

The patient could not seek a second opinion and the treatment due to lack of social support.

Therefore, it is hypothesized that;

H4. There is a positive relationship between lack of external support and treatment non-adherence among patients with chronic conditions.

A patient with chronic condition is frustrated once he/she realizes that the disease can be controlled but rarely cured. Frustration may also be caused due to long waiting hours for consultation, long term treatment, multiple medications, perceived risk in the treatment, no positive outcome, inhumane treatment from the healthcare professionals, and excessive financial burden. The following are the extracts from the patients' narratives:

1. *“More than 100 diabetic patients come on Fridays. Crowd. Waiting area gets flooded with people. It is frustrating. Seating capacity in the waiting area is just 10-15 people. I*



*spend at least 4-5 hours for consultation and getting medicines. I wish I could stop treatment here and take private treatment”.* (Patient No. 1, Male, Age 62 years, Diabetes).

2. *“Daughter pays doctor’s fees, so much expenditure, but no cure. What is the use? I feel bad, disappointed. I have discontinued the treatment”.* (Patient No. 14, Male, Age 70 years, Cancer).

The patients were frustrated due to long waiting time in a crowded area and no positive outcome, hence they either wished to discontinue or discontinued the treatment.

Therefore, it is hypothesized that;

H5. There is a positive relationship between frustration and treatment non-adherence among patients with chronic conditions.

The inconvenience may be caused due to inaccessibility and unavailability of the required healthcare facilities in the hospital under one roof. In rural places, the healthcare facilities are not accessible due to non-proximity of health care facilities to residential areas and unavailability of public transport. This is an unintentional treatment non-adherence. The following are the extracts from the patient’s narrative:

1. *“I work and stay in Belgaum. I was admitted to ESI hospital in Bangalore. Somehow, we managed to stay for four days. We told the doctor our financial constraint, loss of pay, leave and linguistic problems. Next time, though I felt little better, I did not go to Bangalore”.*

Although satisfied with the outcome, it was inconvenient for the patient to continue the treatment.

Therefore, it is hypothesized that;

H6. There is a positive relationship between inconvenience and treatment non-adherence among patients with chronic conditions.

The patients with chronic communicable diseases like HIV/AIDS and Tuberculosis as well as non-communicable diseases like cancer and psychiatry tend to keep their sickness and treatment a secret because of social trauma, disrespect, discrimination and exclusion. The following are the extracts from the patient's narrative:

1. *"Since neighbors were inquiring, mummy stopped my treatment"*. (Patient No. 17, Female, Age 43 years, Psychiatry).

The patient's family had a botheration for affecting their social life, hence the local doctor's treatment was stopped.

Therefore, it is hypothesized that;

H7. There is a positive relationship between social stigma and treatment non-adherence among patients with chronic conditions.

Complex long term therapies are inherent in managing chronic diseases. Research has shown that people with different age groups show different coping styles to treatment adherence/non-adherence. Illiterates do have difficulties in following prescriptions in English. The following are the extracts from the patient's narrative:

1. *"For some months, I took Ayurvedic medicine. A lot of difficulties in preparing, taking medicine and eat this, don't eat that. I could not, I stopped the treatment"*. (Patient No. 12, Male, Age 50 years, Diabetes).

The patient could not follow the complex treatment, hence discontinued the treatment.

Therefore, it is hypothesized that;

H8. There is a positive relationship between regimen difficulty and treatment non-adherence among patients with chronic conditions.

The hypothesized relationships between the independent variables and dependent variable are shown in Figure 1.

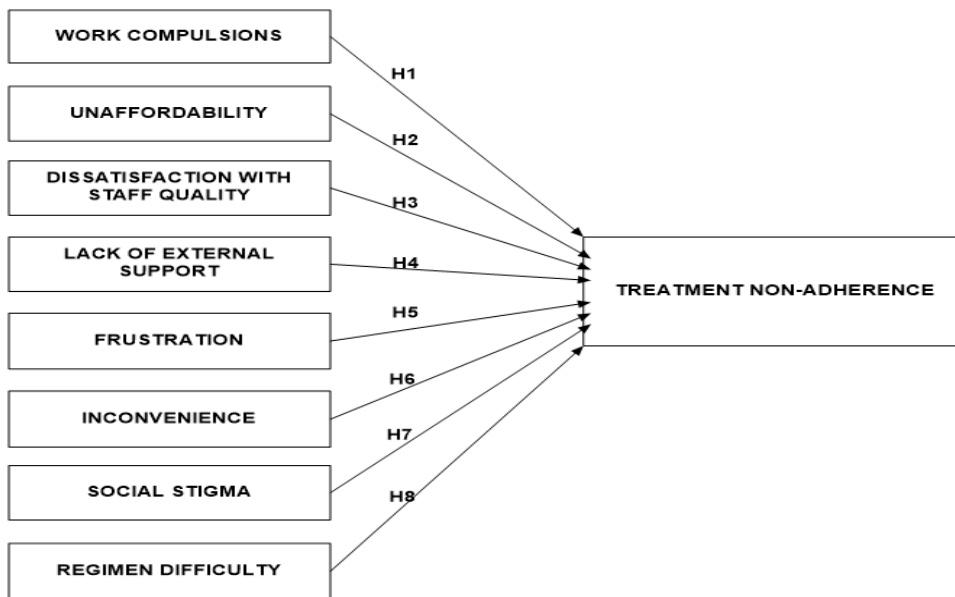


Figure 1. Hypothesized relationships

**The relationships between the determinants of ‘treatment non-adherence’ and medication non-adherence are given below:**

During working hours, those who are deeply engaged or involved in work ought to forget to take medicines. If one avoids lunch, tends to avoid a post lunch dose of medicine. Other reasons could be forgetting or avoiding carrying medicines to the place of work. Busy schedules also can be a hurdle for going for a consultation, doing diagnostic tests in time and following the doses and timings of medication. In a study assessing the reasons for non-adherent behavior of patients with unipolar depression from Kolkata, India, one of the significant factors affecting non-adherence to medication was the burden of household duties (Banerjee and Varma, 2013). The following are the extracts from the patients’ narratives:

1. “Earlier I used to get night shifts and I used to avoid medicines”. (Patient No. 5, Male, Age 54, diabetes, piles and liver problem).

2. *“I do not want to carry medicines to my place of work. During working hours, I do not take medicine. The Employer does not grant leave to go to the doctor”*. (Patient No. 9, Male, Age 29, Epilepsy).

3. *“Sometimes, because of a busy schedule, I miss doses of medicine”*. (Patient No. 10, Male, Age 58, Hypertension).

Young and middle aged patients showed unintentional non-adherent behavior towards medication due to night shift, unwilling to carry medicine and busy schedules.

Therefore, it is hypothesized that;

H9. There is a positive relationship between work compulsions and medication non-adherence among patients with chronic conditions.

Poverty is the main cause of malnutrition, under nutrition, inaccessibility to health care facilities, morbidity and mortality. Chronic disease treatment includes the direct costs: payment towards health care services, purchase of medicines, transport and indirect costs: loss due leave, loss of pay or loss of job. Fear of extra financial burden to the family may cause non-adherence. In a study of diabetic patients in Karnataka, 20% of the patients were non-adherent to medication due to poverty (Ujjinappa et al., 2013). The following are the extracts from the patients’ narratives:

1. *“Sometimes, medicines, I have to purchase. May be, I buy 20% of it, because of financial problem. I cannot spend my entire salary on medicines, we have other needs”*. (Patient No. 1, Male, Age 62 years, Diabetes).

2. *“I do not do diagnostic tests in time because of financial problem”*. *“Doctor’s charges are very high. I have kept the prescriptions. I bring the medicine from the pharmacy, avoid going to the doctor”*.

(Patient No. 4, Female, Age 69 years, tuberculosis, Arthritis and dermatological problem).

3. *“I cannot afford to buy entire course of medicine”*. (Patient No. 9, Male, Age 29, Epilepsy).

4. *“I take medicines, if available at home. I buy few tablets at one time depending upon how much money I have”*. (Patient No. 6, Male, Age 30 years, chronic back and stomach pain).

Young and elderly patients were non-adherent to medication because they could not afford to buy the entire course of medicine in time.

Therefore, it is hypothesized that;

H10 There is a positive relationship between unaffordability and medication non-adherence among patients with chronic conditions.

The present public and private health care systems are more focused towards acute diseases than towards chronic diseases. Minimum time is spent with chronic patients where as patients expect the health professional to communicate and negotiate the therapeutic regimen with them. Continuity of Care with one practitioner or one team results in better medication compliance (Humphreys and Wakerman 2008).The following are the extracts from the patient’s narrative:

1. *“For years, I have been doing home remedies as well as I take medication from a local doctor, but of no use. He does not even listen to me. Presently, I do not take his medicine”*. (Patient No. 17, Female, Age 43 years, Psychiatry).

The patient feels she is ignored by the doctor, and dissatisfied with doctor’s empathy and did not take medication.

Therefore, it is hypothesized that;

H11. There is a positive relationship between dissatisfaction with staff quality and medication non-adherence among patients with chronic conditions.

Those patients, unable to manage themselves with medication, diet, exercise, need physical, emotional and financial support. Lack of such support demoralizes the patient to be adherent. In a literature review, it was found that in case of patients with schizophrenia, lack of social support affected adherence to medication (Shuler, 2014). The following are the extracts from the patient's narrative:

1. *"I do not have a caretaker. Husband is busy with his job and other activities. Now I realized that my family and relatives are avoiding me. I do not remember, whether I have taken the medicine. I may be missing some doses. Who knows"?* (Patient No. 3, Female, Age 50 years, Cancer).

Patient lacked social support; hence she was non-adherent to medication. Therefore, it is hypothesized that;

H12. There is a positive relationship between lack of external support and medication non-adherence among patients with patients with chronic conditions.

It is quite obvious for those patients who follow lifetime preventive therapy, to take a break for medication, as they are fed up of too many medications and also permanent lifestyle changes. Sometimes perceived risk and concern leads to non-adherence. Forgetfulness is a barrier to non-adherence to medication (Banerjee and Varma, 2013).

The following are the extracts from the patient's narrative:

1. *"At my native place, a village, I started getting stomach pain. I went to the Primary health center. The doctor was good. He may be an Ayurvedic doctor. I was referred to a doctor in Belgaum. Doctor advised me to give up completely alcohol consumption. Gave*

*some tablets. I felt risky to take that medicine. I did not take that medicine”*. (Patient No. 7, Male, Age 35 years, Liver).

The patient was non-adherent to medication as he perceived the risk of taking medicine. Therefore, it is hypothesized that;

H13. There is a positive relationship between frustration and medication non-adherence among patients with chronic conditions.

The health care facilities should be located at the convenient places; otherwise they are inaccessible to the public especially the rural patients. Sometimes the situation is such that the public transport is unavailable and private transport is not affordable and patients have to suffer without any treatment. Inconvenience was a barrier to non-adherence to medication (Banerjee and Varma, 2013). The following are the extracts from the patient’s narrative:

1. *“For my skin problem, I do not take tablets, only use ointment. The hospital is far away. I have to spend a lot for transport”*. (Patient No. 4, Female, Age 69 years, Tuberculosis, Arthritis and Dermatological problem).

The patient is partly non-adherent to medication due to inconvenient hospital location. Therefore, it is hypothesized that;

H14. There is a positive relationship between inconvenience and medication non-adherence among patients with chronic conditions.

Patients with communicable diseases and psychiatric problems are always aware about the social stigma. Patients would like to stay away from unpleasant inquiries about sickness and treatment. At least at the place of work, they pretend to be fit and fine and avoid medication. The following are the extracts from the patient’s narrative:

1. *“I do not want to carry medicines to my place of work. During working hours, I do not take medicine. I do not want to disclose my sickness to my employer and colleagues”.*

(Patient No. 9, Male, Age 29 years, Epilepsy).

At the place of work, the patient neither wants to carry or take medication. Therefore, it is hypothesized that;

H15. There is a positive relationship between social stigma and medication non-adherence among patients with chronic conditions.

In an unfriendly doctor-patient relationship, patient may hesitate to seek clarification from the doctor to follow the regimen. Misunderstanding and confusion may lead to non-adherence. In Ireland, complex regimen resulted in medication non-adherence (Al-Lawati, 2014).

The following are the extracts from the patients’ narratives:

1. *“I get confused to follow medication and do exercises, so I miss the doses”.* (Patient No. 9, Male, Age 29 years, Epilepsy).

2. *“I am illiterate; I do not understand what the doctor told about medicines.*

*I do not know which medicine to take”.* (Patient No. 15, Male, Age 60 years, lung cancer).

Illiteracy and confusion to follow the regimen impacted on medication non-adherence.

Therefore, it is hypothesized that;

H16. There is a positive relationship between regimen difficulty and medication non-adherence among patients with chronic conditions.



**The relationships between the determinants of treatment non-adherence and lifestyle modification non-adherence are given below:**

Some Individuals with chronic diseases cannot take leave and have to work, and do household activities, although sick. At the place of work, due to unavoidable circumstances, it is rather difficult to take rest or follow diet. Mumu et al. (2014) found that 26.3% of the respondents were non-adherent to exercise due to lack of time.

The following are the extracts from the patient's narrative:

1. *“Doctor has advised for another eight days rest. But I had to go to work. Earlier I used to get night shifts and I used to avoid medicines and could not follow diet”*. (Patient No. 5, Male, Age 54 years, diabetes, Piles and Liver).

Therefore, it is hypothesized that;

H17. There is a positive relationship work compulsions and lifestyle modification non-adherence among patients with chronic conditions.

For lifestyle modifications mere patient's willingness to adopt the changes are not enough, there requires the financial support too. Financial constraint was a barrier for non-adherence to diet (Bisiriyu, 2009) and non-adherence to doctor's advice (Banerjee and Varma, 2013). The following are the extracts from the patients' narratives:

1. *“Vegetables are so costly; I don't follow the diet as per doctor's advice. I joined my duties. I cannot afford to rest”*. (Patient No. 6, Male, Age 30 years, Chronic back and stomach pain).

2. *“Doctor told to eat a particular type of food, vegetables and fruits. We rarely buy fruits, not affordable to poor, no question of eating”*. (Patient No.7, Male, Age 35 years, Liver problem).

The patients could not afford to rest and follow a diet.

Therefore, it is hypothesized that;

H18. There is a positive relationship between unaffordability and lifestyle modification non-adherence among patients with chronic conditions.

The responsibility of the doctor is not over, once the prescription is handed over to the patient. Patients' expect minimum responsiveness, care, respect, empathy, and assurance by the doctor. Patient centered care has an impact on clinical outcome. In case of chronic disease management, medication adherence and lifestyle modifications go hand in hand.

The following are the extracts from the patient's narrative:

1. *“Do not remember which exercise, how and when to do. Long time back, the doctor showed only once. Doctor never asked whether I am exercising. Therefore, exercising is not possible”*. (Patient No. 9, Male, Age 29 years, Epilepsy).

Doctor did not bother to inquire. The patient does not exercise, as he did not understand and remember the exercising steps.

Therefore, it is hypothesized that;

H19. There is a positive relationship between dissatisfaction with staff quality and lifestyle modification non-adherence among patients with chronic conditions.

Some patients, especially the aged, unable to manage their diet and exercising, require help. Patients were non-adherent to exercise due to lack of exercise partner (Bisiriyu, 2009). The following are the extracts from the patient's narrative:

1. *“Post operation and recovery, the doctor advised to go for a walk, if possible. But cannot, who has time to accompany me”*. (Patient No. 3, Female, Age 50 years, Cancer).

Lack of social support, had an impact on lifestyle modification non-adherence. Therefore, it is hypothesized that;

H20. There is a positive relationship between lack of external support and lifestyle modification non-adherence among patients with chronic conditions.

Sometimes patients' see no benefit of treatment, and feel no necessity of following treatment. They perceive more risk than benefit to follow treatment.

The following are the extracts from the patients' narratives:

1. *"The doctor has told to eat everything, but I do not feel eating"*. (Patient No. 14, Male, Age 70 years, Cancer)

*"The doctor said not to worry and told to follow his treatment for some years. I do not know how I will manage. It is risky, but I eat whatever I want"*. (Patient No.8, Female, Age 25 years, HIV/AIDS).

Long term therapy and perceived risk impacted on lifestyle modification non-adherence.

Therefore, it is hypothesized that;

H21. There is a positive relationship between frustration and lifestyle modification non-adherence among patients with chronic conditions.

Winter weather and exercising location away from home were the barriers to exercise (Bisiriyu, 2009). Contextual variations may cause inconvenience to individuals to adhere to doctor's instructions. The following are the extracts from the patient's narrative:

1. *"Nurse showed me some exercises and told to go for walk for at least 30 minutes a day. Not to sit down by folding legs. In villages, the majority of the housekeeping work is done by sitting down, I cannot avoid sitting down"*. (Patient No.16, Female, Age 65 years, Diabetes, Arthritis and Cataract).

Circumstances were such; the patient could not follow doctor's instructions. Therefore, it is hypothesized that;

H22. There is a positive relationship between inconvenience and lifestyle modification non-adherence among patients with chronic conditions.

Change in diet, exercising and sudden changes in lifestyles invite unpleasant inquiries, therefore chronic patients may avoid any lifestyle related changes. The following are the extracts from the patient's narrative:

1. *"I went for walk for two days. In the villages, you know how it is. People started asking me, why, what and so on. I was annoyed. Therefore, I stopped"*. (Patient No.16, Female, Age 65 years, Diabetes, Arthritis and Cataract).

Therefore, it is hypothesized that;

H23. There is a positive relationship between social stigma and lifestyle modification non-adherence among patients with chronic conditions.

Regimen difficulties are associated with confusion and inability to adopt lifestyle modifications related to diet, and exercises. If a healthcare provider expects the patient to exercise regularly, he has to train the patient accordingly or it may do more harm than good. The following are the extracts from the patient's narrative:

1. *"Doctor told to do yoga. Such difficult, my god. I do not remember those exercises. Even if I try something, body pains, I do not like, and will not do"*.

(Patient No. 17, Female, Age: 43 Years, Psychiatry)

Patient experienced the difficulty in remembering and exercising.

Therefore, it is hypothesized that;

H24. There is a positive relationship between regimen difficulty and lifestyle modification non-adherence among patients with chronic conditions.

The hypothesized relationships between the independent variables and dependent variables are shown in Figure 2.

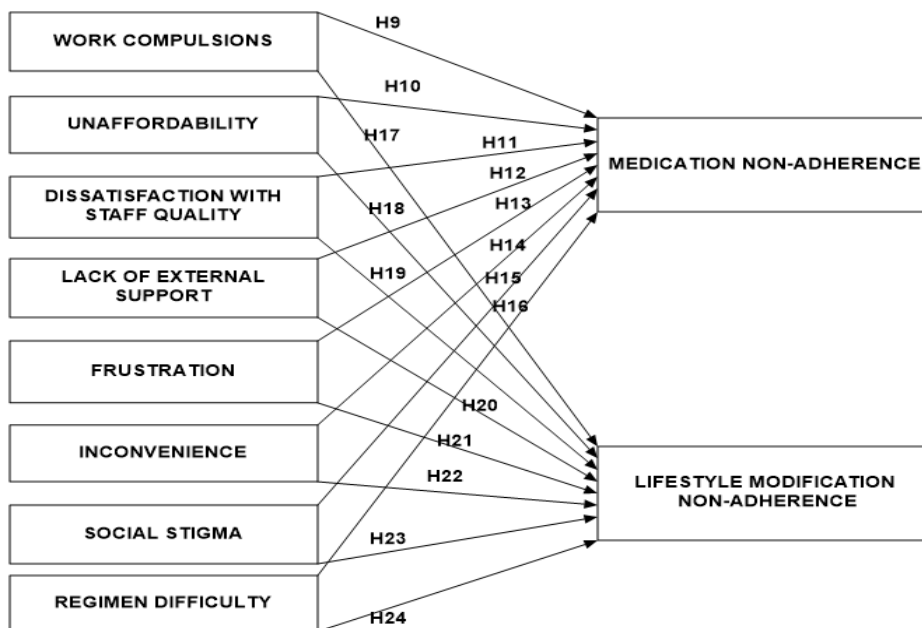


Figure 2. Hypothesized relationships

#### 4.3 DEVELOPMENT OF THE SCALES

It was realized through a literature review of the existing scales to measure non-adherence that no scale measures simultaneously treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions. Therefore, new scales were developed to attain the objectives of the study.

## **Item generation**

Along with broad and subordinate themes, the issues raised by the participants provided more information to draw some more items suitable for the development of the scales. Out of the total 70 statements generated, the items expressing the determinants of ‘treatment non-adherence’ and items indicating non-adherent behavior were separated. A pool of 48 items expressing the determinants of ‘treatment non-adherence’ and a pool of 22 items indicating non-adherent behavior were generated from the narratives and transcripts. The lists of independent items and dependent items in the form of statements are given in **Appendix II**.

### **The operational definitions of independent and dependent variables selected for the study**

- 1. Treatment non-adherence-** Treatment non-adherence is referred to as all degrees of patient non-conformity to prescribed medication and/or lifestyle modification related recommendation by the doctor.
- 2. Medication non-adherence-** Medication non-adherence is referred to as all degrees of patient discontinuation of the treatment, not filling the prescription, non-conformity to medication as prescribed by the doctor and /or not following up scheduled visits to the doctor, and not doing diagnostic tests as instructed by the doctor.
- 3. Lifestyle modification non-adherence-** Lifestyle modification non-adherence is referred to as all degrees of patient non-conformity to the exercises, diet and rest as advised by the doctor.
- 4. Work compulsions** – Compulsions to continue working, although sick.
- 5. Social stigma-** Social stigma of disease and fear of disclosure about the sickness and treatment.

6. **Dissatisfaction with Staff quality** – Patients’ dissatisfaction with hospital staff responsiveness, empathy and assurance.
7. **Frustration** - Perception of negative consequences of the medical treatment, inability to remember and the feeling of disappointment from non-attainment of clinical outcome.
8. **Regimen difficulty**- Inability to understand and follow up of the treatment regimen.
9. **Unaffordability**-Inability to make payments towards the purchase of medicines, doctor’s consultation fees and charges for diagnostic tests.
10. **Lack of External support**- The act of not providing financial and/ or other support from the family members, relatives and friends.
11. **Inconvenience**-Inaccessibility in seeking required healthcare facility and Unavailability of required healthcare related facilities at the hospital/ clinic.

### **Item selection**

The statements relevant from the proposed theoretical framework and potentially measuring the independent and dependent variables were selected. The statements depicting same meaning and not falling under any of the variables under study were dropped.

### **Independent Item selection**

Out of 48 independent statements, 27 statements, explaining the determinants of ‘treatment non-adherence’ were selected and categorized into 8 independent variables. The details are given in Table 4.1a.

**Table 4.1a Category-wise independent statements**

STATEMENTS		INDEPENDENT VARIABLES
1	I cannot leave the job, although sick	Work Compulsions
2	I have to do the work, although sick	
3	I have to work because people are dependent on me	
1	The doctor charges are not affordable	Unaffordability
2	The diagnosis tests charges are not affordable	
3	Medicines are costly	
1	Hospital staff is not cooperative	Dissatisfaction with staff quality
2	Doctor does not know my health status	
3	Doctor does not instill confidence to face the situation	
4	The doctor does not listen to me carefully	
5	Doctor did not explain the dangers of treatment non-adherence	
6	The Work culture of this hospital/clinic is not good	
1	I do not have a caretaker	Lack of external support
2	I do not get support from family and friends	



1	There is a long queue to meet the doctor at the hospital/clinic	Frustration
2	I am forgetful	
3	I am fed up of taking the treatment	
4	I perceive a lot of risk in the treatment	
5	I am not concerned about my health	
1	Hospital/clinic location is not convenient	Inconvenience
2	Hospital/clinic is not accessible by public transport	
3	Required health care facilities are not available at the hospital/clinic	
1	I am bothered of social stigma	Social stigma
2	I want to keep my treatment a secret	
3	I do not want others to know about my sickness	
1	Treatment Regimen is not easy to follow	Regimen difficulty
2	I am confused about the doses of medicine	

### **Dependent items selection**

Out of 22 dependent statements, 10 statements potentially measuring ‘treatment non-adherence’ were selected and categorized into two dependent variables, i.e. medication non-adherence and lifestyle non-adherence. The details are given in Table 4.1b.

**Table 4.1b Category-wise dependent statements:**

<b>Sr. No.</b>	<b>Statements</b>	<b>Dependent variables</b>
1	I have discontinued the treatment	Medication non-adherence
2	I am not following scheduled visits to the doctor	
3	I did not do diagnostic tests as advised by the doctor	
4	I avoid taking medicine	
5	I skip the doses of medicine	
6	I do not fill the prescription in time	
7	I take a lower dose of medicine than prescribed by the doctor	
8	I am not following diet as recommended by the doctor	Lifestyle modification
9	I am not exercising as instructed by the doctor	non-adherence
10	I am not taking rest as advised by the doctor	

#### **4.4 RELIABILITY, VALIDITY AND READABILITY OF THE SCALES**

The reliability and validity of the potential items have been carried out in two phases: phase I comprised of evaluation of the inter-rater agreement between the experts and phase II comprised of testing content validity, face validity and readability of the scales.

## **Phase I**

### **Inter-rater agreement**

The purpose of Phase I was to test whether potential items represent the specific variable. Since the Kappa statistic is an important supplement to the Content Validity Index because it yields an index of the degree of agreement beyond chance agreement, the multi-item, multi-rater reliability of the scale was assessed by using Fleiss Kappa (Fleiss, 1971).

### **Inter rater agreement for the items for Determinants of Chronic Disease Treatment**

#### **Non-adherence Scale (DOCDTNAS)**

A list of 15 items representing the constructs: work compulsions (3 items); dissatisfaction with staff quality (6 items); unaffordability (3 items); and Inconvenience (3 items), was rated by an inter-rater panel comprised of nine experts: a general practitioner, a psychiatrist, a physiotherapist, two research authorities in health care management, a research authority in financial management, a research authority in economics, an expert caretaker and a healthcare researcher cum diabetic patient. Another list of 12 items representing the constructs: social stigma (3 items); frustration (5 items); regimen difficulty (2 items) and lack of external support (2 items), was rated by an inter-rater panel comprised of nine experts: a general practitioner, a psychiatrist, a neurologist, two research authorities in healthcare management, a research authority in sociology, a research authority in economics, an expert caretaker and a linguistic expert cum asthma patient. The experts were informed about the purpose of the study and given a summary of each variable. The expert raters were asked to rate each item, in a category closest to the

category of determinants of ‘treatment non-adherence’. The inter-rater agreement documents are given in **Appendix III**.

### **Inter rater agreement for items for Chronic Disease Treatment**

#### **Non-adherence Scale (CDTNAS)**

7 items explaining the medication non-adherent behavior were rated by an inter-rater panel comprised of five experts: a general practitioner, a psychiatrist, a caretaker, a research authority in healthcare management and a diabetic patient and 3 items explaining the lifestyle non-adherent behavior were rated by an inter-rater panel comprised of five experts: a general practitioner, a psychiatrist, a physiotherapist, a research authority in healthcare management and a healthcare researcher cum patient. The experts were informed about the purpose of the study and given a summary of each of the construct. The expert raters were asked to rate each item, in a category closest to the category of dimensions of ‘treatment non-adherence’.

Details of Expert rating agreements as per Fleiss kappa are given in **Appendix III**.

### **Phase II**

#### **Content validity**

After evaluation of the inter-rater agreement for items of the scales, the purpose of the phase II was to identify the specific items, which are relevant to the theme, clear to understand and simple to follow through expert assessment. It was also to test face validity and readability of each scale.

The content validity of a measuring instrument is the extent to which it provides adequate coverage of the investigative questions guiding the study. As stated by Polit and Beck (2006), according to Lynn’s content validity procedure through expert assessment, content

validity of each individual item as well as for the entire scale has been evaluated in terms of relevance, clarity and simplicity,. The expert panel comprised of six experts: a general practitioner, a psychiatrist, a physiotherapist, a research authority in health care management, a caretaker and a diabetic patient, was asked to rate each item on a scale of 1-4 as mentioned below:

Relevance: 1. Not relevant; 2. Items needs some revision; 3. Relevant but needs minor revision; 4. Very relevant.

Clarity: 1. Not clear; 2. Items needs some revision; 3. Clear but needs minor revision; 4. Very clear.

Simplicity: 1. Not simple; 2. Items needs some revision; 3. Simple but needs minor revision; 4. Very simple.

The content validity document and expert ratings are given in **Appendix IV**.

### **Face validity**

To asses face validity of scales (DOCDTNAS and NACDTS); the proposed drafts of the scales were reviewed by three experts, a medical surgeon, a general physician cum researcher in the area of diabetes and a physiotherapist.

### **Readability test of the scales**

An attempt was made to draft the statements as simple as possible to read, understand and fill the scales completely. The Scales' Fog Index and the Flesch Reading Ease Score were tested.

## **4.5 FINAL DRAFT OF THE SCALES**

Once each scale was tested for inter-rater reliability, content validity, face validity and reading ease, the final drafts of the scales were prepared.

The DOCDTNAS, consisted of 27 items to identify the determinants of ‘treatment non-adherence’ and the CDTNAS, consisted of 10 items to test patient non-adherent behavior. The response to each item was scored on a five point Likert scale where: 1. SD=Strongly Disagree, 2. D= Disagree, 3. U= Undecided 4. A= Agree, 5. SA= Strongly Agree.

The questions pertaining to the respondents’ characteristics, i.e. gender, marital status, number of members in the family, educational qualification, occupation, type of chronic condition, duration of illness, system of healthcare facility availed by the patient, type of health care facility availed by the patient, present health position of the patient, age, monthly household income of the family and medical expenditure per month were also included in the final combined draft of the scale.

The final combined draft of the scales is given in **Appendix V**.

## CHAPTER 5

### PILOT STUDY, QUANTITATIVE STUDY AND INTERACTION EFFECTS

The previous chapter dealt with the qualitative study, development of hypotheses and development of scales. This chapter gives details of the pilot study and the quantitative study undertaken for construct validity and identification of the determinants of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence. It also gives details about the testing of interaction effects of moderating variables on the dependent variables.

#### 5.1 PILOT STUDY

A pilot study was conducted to detect weaknesses of the scales and to seek a clue for the selection of an appropriate unit of analysis for the proposed cross-sectional study (Cooper and Schindler, 2006, p 76).

##### **Inclusion criteria**

1. The patients with chronic condition and
2. Those patients who were willing to participate in the study were included.

##### **Data collection**

During December, 2013 and January 2014, 107 chronic patients were recruited to participate in the pilot study. Prior permissions to conduct survey from hospital superintendent and general practitioners were sought. The patients were contacted in waiting areas in private hospitals/clinics from Goa, Karnataka and Maharashtra. The scales developed by the researcher were used. 32 patients filled the questionnaires and the rest were administered by the researcher and the investigators appointed and trained by the

researcher. Filled-in scales were collected the same day or within a week's time. Convenient sampling method was used.

### **Data analysis**

Data analysis was not conducted since the sample size was not suitable for statistical analysis.

## **5.2 QUANTITATIVE STUDY**

It was a cross-sectional study. Prior permissions to conduct the survey among patients were sought from the hospital authorities. With prior informed consent, the respondents were recruited from public and private health care facilities from Goa and Karnataka. The study sample included 479 patients with chronic conditions, seeking health care across health care facilities in Goa and Karnataka, India. During March 2014 to June 2014, self-reported, structured scales developed by the researcher were administered to the respondents. Convenience sampling method was used for sample selection.

### **Inclusion criteria:**

1. Outpatient with chronic condition and
2. Those who were willing to participate in the study.

### **Data collection**

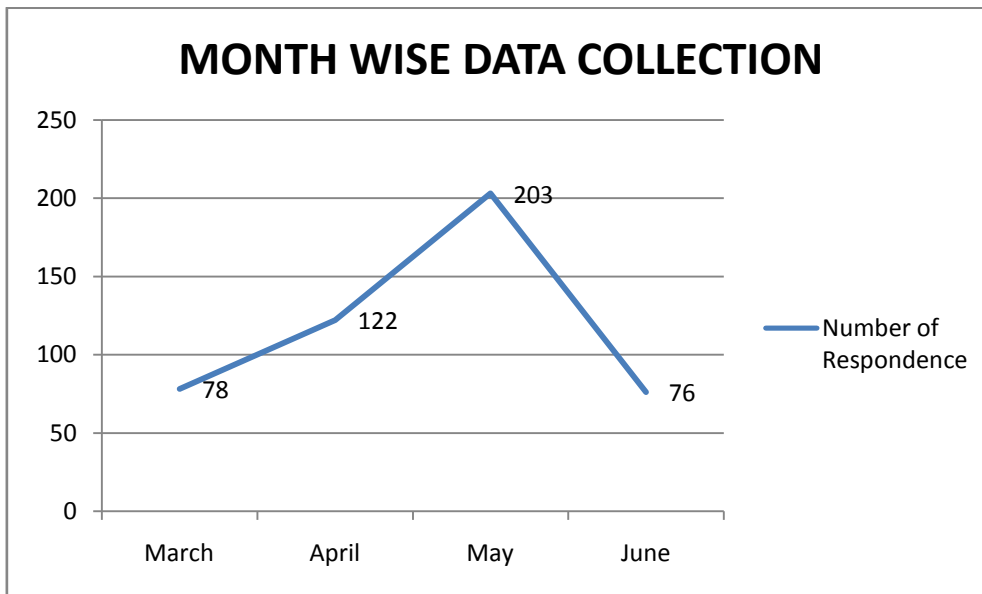
The respondents were contacted in the waiting areas in various hospitals/clinics. Each respondent was briefed with the purpose of the study and was requested to fill the scale completely. The time required for filling a scale was 20 to 30 minutes. Filled-in scales were collected by the researcher on the same day. Some scales were collected by the researcher in a week's time at the respondents' convenient day, time and place. The



month wise data collection and line graphic representation of data are given in Table 5.1.and Graph 5.1a respectively.

**Table 5.1 Month wise data collection**

Month and Year	No. of Respondents
March, 2014	78
April, 2014	122
May,2014	203
June, 2014	76
Total	479



**Graph 5.1a Line graph showing month wise data collection**

### **Data Analysis**

Internal consistencies of the scales were tested. Descriptive analysis, factor analyses and multiple regressions were performed. SPSS Version 16.0 was used for data analysis.

## 5.2a Testing Interaction effects on the relationships between determinants of ‘treatment non-adherence’ and treatment non-adherence, medication non-adherence and lifestyle modification non-adherence

As suggested by Baron and Kenny (1986), the moderator variables were introduced as the researcher expected inconsistent relation between the independent and the dependent variable across the subgroups. The researcher predicted from theory as well as noticed during data screening of the pilot study conducted by the researcher that the relationships between determinants of non-adherence and treatment non-adherence, medication non-adherence and lifestyle modification non-adherence may vary with patients’ demographics, social, psychological, geographical and economic factors. The interaction terms may reduce the unexplained variance in the dependent variables, i.e. treatment non-adherence, medication non-adherence and lifestyle non-adherence. The interaction effects are important for planning intervention strategies to reduce treatment non-adherence. To explore these possibilities, the interaction terms were introduced in multiple regression analyses. The basic model for testing two-way interaction effect is shown in figure 3.

### A Basic model for testing two-way interaction effect

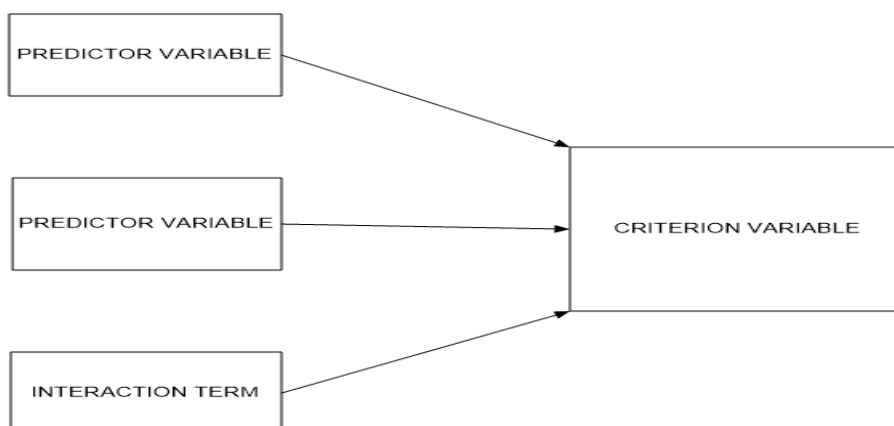


Figure 3. Interaction effect

### Assumptions

Preliminary checks were conducted to ensure that there is no violation of the assumptions of multiple regressions.

### **1. Sample size:**

The sample size for the statistical power of 0.80 at  $\alpha$  0.05 level was calculated with expected  $R^2$  for the main effect 0.20 and  $R^2$  with interaction effect 0.25, is 119 (Aiken and West, 1991, Table 8.2). The present study sample size of 479 is fairly high to detect interaction effects.

### **2. Multicollinearity:**

Multicollinearity was checked for each interaction effect model separately, as the criterion variables, independent variables and moderators were different for each model. The variables are not correlated.

### **3. Outliers:**

Only two outliers i.e. case number 14 and 144, were detected and original mean values are transformed accordingly. Normality, linearity and homoscedasticity were checked.

### **Interaction terms**

The interaction terms were formed as: Gender by work compulsions; Gender by regimen difficulty; State by social stigma; State by regimen difficulty; State by unaffordability; Type of health care facility by work compulsions; Age by social stigma; Age by regimen difficulty; Monthly income of the patient's family by dissatisfaction with staff quality; and Monthly expenditure for treatment by social stigma.

### **Dependent (criterion) variables**

The interaction effects were tested on treatment non-adherence, medication non-adherence and lifestyle modification non-adherence.

## **Data Analysis**

To test the potential two-way interaction effects, multiple regression analyses were performed; the statistical outputs and the interaction graphs were achieved with the help of Interaction version 1.7.2211 by Daniel Soper.

## CHAPTER 6

### ANALYSIS AND RESULTS

The previous chapter gave the details about the pilot study and the quantitative study. This chapter deals with the data analyses and results. The chapter is divided into three parts. Part I deals with qualitative study analysis and results, Part II deals with pilot study results and Part III deals with the quantitative study analysis and results; and interaction effects and results.

#### PART I

##### 6.1 ANALYSIS AND RESULTS OF QUALITATIVE STUDY

The qualitative study was undertaken to get a deeper understanding into the experiences of patients about their treatment and non-adherence to chronic disease treatment. Interpretative Phenomenological Analysis was employed for data analysis. The narratives with annotations are given in **Appendix I**.

The Tables 6.1a and 6.1b give details about the broad and subordinate themes drawn from the patients' annotations.

**Table 6.1a Broad themes with frequencies**

Sr. No	Broad Themes	Frequency
1	Lifestyle modification non-adherence	14
2	Work related problem	12
3	Unaffordability	11
4	Medication non-adherence	11

5	Dissatisfaction with staff quality	8
6	Treatment non-adherence	6
7	Lack of external support	6
8	Frustration	5
9	Inconvenience	5
10	Social stigma	5
11	Regimen difficulty	4

**Table6.1b Subordinate themes with frequencies**

Sr. No	Subordinate Themes	Frequency
1	Lifestyle non-adherence to diet	8
2	Lifestyle non-adherence to exercise	6
3	No care taker	6
4	No filling prescription in time	5
5	Free service	4
6	Family responsibility	4
7	Expensive health care	4
8	No necessity belief	4
9	Nonprofessional health services	3
10	Lifestyle non-adherence to rest	2
11	Long waiting hours	2

### **Sample characteristics**

A Total of 18 respondents participated in the personal interviews, 66.67% were male. Respondent age ranged from 25 years to 78 years, average age was 52.61 years. The

respondents were taking treatment for: Diabetes (3 participants), Cardiac problems (2 participants), Cancer (3 participants), Arthritis (2 participants), Chronic Back and stomach pain, HIV/AIDS, Epilepsy Hypertension, Psychiatry, Nephrological problem, Liver problem and Asthma (1 participant each), representing 12 chronic conditions. The Duration of sickness ranged from 1 year to 15 years. This indicates that the sample had heterogeneity in terms of patients' characteristics.

### **Results of Interpretative Phenomenological Analysis**

The subordinate theme, 'free service'; 'non-professional health services' and 'no necessity belief' were away from the scope of the present research, hence not considered in the present research. Other subordinate themes were clubbed together to form main themes, for exploring the independent and dependent variables for the development of the hypotheses. Eight independent variables and three dependent variables and 70 items to measure these variables were explored from the annotations.

The lists of independent variables and dependent variables along with broad and subordinate themes are given in Table 6.1c and Table 6.1d respectively.

**Table 6.1c Independent variables (with broad and sub-ordinate themes)**

<b>Sr. No.</b>	<b>Independent variables</b>
1	<b>Work compulsions</b> Family responsibility
2	<b>Unaffordability</b> Expensive health care
3	<b>Dissatisfaction with staff quality</b>
4	<b>Lack of external support</b>

	No care taker
5	<b>Frustration</b> Long waiting hours
6	<b>Inconvenience</b>
7	<b>Social stigma</b>
8	<b>Regimen difficulty</b>

**Table 6.1d Dependent variables (with broad and sub-ordinate themes)**

Sr. No.	Dependent variables
1	<b>Medication non-adherence</b> No filling prescription in time
2	<b>Lifestyle non-adherence</b> Lifestyle non-adherence to diet Lifestyle non-adherence to exercise Lifestyle non-adherence to rest
3	<b>Treatment non-adherence</b>

#### **Inter-rater agreement for the scale (DOCDTNAS)**

Fleiss Kappa was employed to test inter-rater agreement between the expert raters. A document consisting of 27 independent items to be categorized into a construct, closest in meaning was given to 9 expert raters. Fleiss Kappa was calculated after consolidation of expert raters' scores.



Fleiss Kappa for the independent items for the scale of 0.833 indicates excellent inter-rater agreement between the raters. The details are given in **Appendix III**.

#### **Inter-rater agreement for the scale (CDTNAS)**

A document consisting of 10 dependent items to be categorized into a construct, closest in meaning was given to 5 expert raters. Fleiss Kappa was calculated after consolidation of expert raters' scores.

Fleiss Kappa for the dependent items of the scale of 0.57 indicates moderate inter-rater agreement. The details are given in **Appendix III**.

#### **Content validity of the scales**

As stated by Polit and Beck, (2006) Individual Item Content Validity Index (I-CVI) is calculated as the number of raters giving a rating of 3 or 4, divided by the total number of raters and Scale Content Validity Index (S-CVI) is calculated as total of I-CVI scores divided by the number of items rated by the raters. Polit and Beck (2006) stated that a scale to be judged by six experts, as having excellent content validity should meet Lynn's (1986) I-CVI and S-CVI of .78 and .9 or higher respectively.

#### **Content validity of the scale (DOCDTNAS)**

The scale's Individual Content Validity Index (I-CVI), in terms of relevance ranged from 0.667 to 1.00, clarity ranged from 0.833 to 1.00 and simplicity ranged from 0.833 to 1.00; revealing the high individual content validity and the Scale Content Validity Index validity (S-CVI), in terms of relevance 0.907, clarity 0.969 and simplicity 0.963 reveal the high content validity. The details are given in **Appendix IV**.

### **Content validity of the scale (CDTNAS)**

The scale's Individual Content Validity Index (I-CVI), in terms of relevance ranged from 0.833 to 1.00, clarity 1.00 each and simplicity 1.00 each reveal the high content validity and the Scale Content Validity Index validity (S-CVI), in terms of relevance 0.9, clarity 1 and simplicity 1 reveal the high content validity. The details are given in **Appendix IV**.

### **Results of face validity**

The scales were evaluated by the experts in the medical field. As per experts' reports face validity of both the scales was satisfactory. All independent statements were negative, therefore, as suggested by experts, four negative independent statements: 'Doctor does not know my health status'; 'Work culture of this hospital/clinic is not good'; 'Required health care facilities are not available at the hospital/clinic'; and 'I am not concerned about my health' were converted into positive statements as; 'Doctor knows my health status'; 'The work culture of this hospital/ clinic is good'; 'The hospital/clinic has all up-to-date health care facilities' and 'I am deeply concerned about my health'.

### **Results of readability test**

The scales' items were entered into the online calculator. The results of readability of the scales (DOCDTNAS and CDTNAS) were achieved with the help of online Flesch-Kincaid Reading Ease Score calculator (Readability-Score.com). Flesch-Kincaid Reading Ease Score- Scores usually range from 0 to 100. A higher score indicates easier readability. The scales' (DOCDTNAS and CDTNAS) readability scores of 73.3 and 75.1 respectively, were very satisfactory.

The final drafts of the scales were prepared which are given in **Appendix V**.

## PART II

### 6.2 RESULTS OF PILOT STUDY

A total of 107 chronic patients participated in the pilot study. It was found that, the time required filling the scales ranged from 20 to 30 minutes. It was decided to select ‘the outpatient with a chronic condition’ as a unit of analysis for the quantitative study. The scales’ variables totaled to 37 (27+10) and the total responses totaled to 107. Further data analysis was not conducted as the variable-observations ratio was less than 1:5 (37:107).

## PART III

### 6.3 ANALYSIS AND RESULTS OF QUANTITATIVE STUDY

Descriptive analysis of data, given in Table 6.3a, indicates frequency counts and percentages. Frequency tabulations of the characteristics of the respondents were done in order to find out the nature of the sample and to ascertain heterogeneity among respondents.

**Table 6.3a Patients’ Characteristics (n=479 patients with chronic conditions)**

<b>Characteristics</b>		<b>Frequency</b>	<b>Percent</b>
<b>Gender</b>	Male	275	57.4
	Female	204	42.6
<b>Marital Status</b>	Married	367	76.6
	Unmarried	56	11.7
	Widowed	56	11.7

<b>Number of members in family</b>	One	19	4
	Two	62	12.9
	Three	94	19.6
	Four	139	29
	Five and above	165	34.4
<b>Education</b>	Illiterate	87	18.2
	Primary level	130	27.1
	Secondary level	111	23.2
	Graduation	108	22.5
	Post Graduation	43	9
<b>Occupation</b>	Agriculture	39	8.1
	Service	162	33.8
	Business	79	16.5
	Unemployed	46	9.6
	Housewife	89	18.6
	Retired	34	7.1
	Others	30	6.3

<b>Type of chronic condition</b>	Cancer	24	5
	Asthma	68	14.2
	Orthopedic	79	16.5
	Diabetes	155	32.4
	Cadiological	26	5.4
	Nephrological	35	7.3
	HIV/AIDS	20	4.2
	Other Chronic conditions	72	15
<b>Duration of illness</b>	Less than 1 Year	44	9.2
	1 Year – 2 Years	65	13.6
	2 Years – 3 Years	92	19.2
	3 Years – 4Years	135	28.2
	4 Years and above	143	29.9
<b>Health system used by respondent</b>	Allopathic	459	95.8
	Ayurvedic	20	4.2
<b>Type of health care facility used by the respondent</b>	Public	216	45.1
	Private	263	54.9
<b>State (Place of residence)</b>	Goa	294	61.4
	Karnataka	185	38.6

The other details of the respondents are given in Table 6.3b.

Table6.3b .Other details of the patients

Other details	Mean	Standard deviation
Monthly medical expenditure (Rs.)	1081.5	1460.396
Monthly income of the family (Rs.)	26698.54	41870.71
Age ( in years)	52.52	13.68

### Results of Patients' Characteristics

A total of 479 outpatients with chronic conditions completed the questionnaires. The average age of the respondents was 52.52 Years and standard deviation 13.68. The sample comprised of 42.6 % female. 18.2% of the respondents were illiterate. 4% were staying alone. 33.8% were employed. 4.2 % were taking treatment for HIV/AIDS and 32.4 % for Diabetes. 95.8% patients were seeking an allopathic system of treatment. 45.1 % patients were using public healthcare facilities. 9.2% of the patients were taking treatment for less than one year and 29.9 % of the patients for more than 4 years. 61.4% of the respondents are from Goa and 38.6% are from Karnataka. Average monthly income is Rs. 26698.54 and standard deviation 41870.71, and average monthly medical expenditure for treatment is Rs. 1081.50 and standard deviation 1460.396. This indicates that the sample had heterogeneity in terms of patients' characteristics.

### Internal consistencies of the scales (DOCDTNAS and CDTNAS)

*“Internal reliability is a measure of how a scale can be relied on to produce similar measurements every time we use the scale”* (Naragundkar, 2008. P 64). Cronbach's Alpha coefficient, an indicator of internal consistency of the scale, was used for establishing

scale reliability. A value of Cronbach Alpha above 0.70 is considered as a reasonable test of reliability.

The Item-Total Statistics of the scales (DOCDTNAS and CDTNAS) are given in Table A6.1 and Table A6.2 respectively.

#### **Results of Internal consistencies of (DOCDTNAS)**

With 479 valid cases and 27 items, the overall alpha value of DOCDTNAS was 0.750, indicating a high level of internal consistency. Deleting three items, the alpha value would have been slightly increased, but those items were felt necessary to measure ‘treatment non-adherence’. Therefore, no item was deleted.

#### **Results of Internal consistency of the scale (CDTNAS)**

With 479 valid cases and 10 items, the overall alpha value of CDTNAS was of 0.863, indicating a high level of internal consistency. Deleting an item ‘I am not taking rest as advised by the doctor’, the alpha value would have been increased to 0.870, but that item was felt necessary to measure lifestyle modification non-adherence. Therefore, no item was deleted.

### **6.4 RESULTS OF FACTOR ANALYSES**

The reverse coding was done for four positive statements. The negative coded response was converted to an equivalent positive coded response e.g. on a five point Likert scale (5= Strongly agree and 1= Strongly Disagree) 5 is converted into 1 and vice versa. For factor analysis, the recommended sample size should be at least 300 participants, and the observations to variable ratio should be at least 5:1 or 10:1 (Gie and Pearce, 2013). In this study, for independent variables, the observations to variable ratios of 17.74: 1 and for

dependent variables the ratio of 47.9:1 (479: 37 and 479:10), indicate that the sample size was adequate for factor analyses.

**Results of factor analysis for independent variables (DOCDTNAS)**

The details about sampling adequacy, total variance explained, and factor loading score are of independent variables are given in Table 6.4a, 6.4b and 6.4c respectively.

**Table 6.4a**KMO Sampling Adequacy and Bartlett's Test of Sphericity

Kaiser-Meyer-Olkin Measure of Sampling Adequacy	.735
Bartlett's Test of Sphericity Approx. Chi-Square	3838
Df	351
Sig.	.000

**Table 6.4b Total variance explained**

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	2.596	9.615	9.615
2	2.517	9.324	18.939
3	2.207	8.175	27.114
4	1.966	7.282	34.36
5	1.959	7.257	41.653
6	1.925	7.129	48.782
7	1.846	6.837	55.619
8	1.489	5.514	61.133



	Component							
	1	2	3	4	5	6	7	8
I have to work because there are people dependent on me	.823							
I have to work, although sick	.815							
I cannot leave the job, although sick	.672							
I want to keep my treatment a secret		.883						
I am bothered about social stigma		.882						
I do not want others to know about my sickness		.844						
The hospital/clinic staff are not cooperative			.694					
The doctor does not listen to me carefully			.688					
RC-The work culture of this hospital/clinic is good			.613					

RC-The doctor knows my health status			.566					
The doctor did not explain the dangers of non-adherence			.533					
I perceive a lot of risk in the treatment				.731				
I am fed up of taking treatment				.726				
There is a long queue in the clinic/hospital to meet the doctor				.542				
The treatment regimen was not easy to follow					.906			
I am confused about the doses of medicines					.869			
The doctor's charges are not affordable						.724		
The diagnostic tests charges are not affordable						.723		
Medicines are costly						.677		
I do not get support from my family and							.721	

friends								
I do not have a caretaker							.711	
Rc- I am deeply concerned about my health							.547	
The doctor does not instill confidence								
I am forgetful								
Rc-The hospital/clinic has all up -to-date health care facilities								.708
The hospital/clinic's location is not convenient								.579
The hospital/clinic is not accessible by public transport								.544

Extraction method: Principal Component Analysis. Rotation method: Varimax with Kaiser Normalization. Rotation converged in 7 iterations.

### **Results of Factor analysis for independent variables (DOCDTNAS)**

Principal Component Factor Analysis obtained a Kaiser-Meyer-Olkin Measure of 0.735 sampling adequacy indicated suitability of the data for factor analysis. With Bartlett's test of Sphericity of 383.83 which is significant at 1% level, shows a high correlation between items. Communalities of all the variables were more than 0.4. Factor analysis resulted in grouping 25 independent items into 8 Factors with a total variance explained of 61.133%. Two statements: 'Doctor did not instill confidence', and 'I am forgetful' did not load on any factor. The factor loading scores for each item was more than 0.5.

**Factor 1**, Explained the variance of 9.615%, labeled as 'Work compulsions', measured the extent to which, chronic patients' helplessness to do work, although sick, predict 'treatment non-adherence'. Three items loaded on this factor.

**Factor 2-** Explained the variance of 9.324%, labeled as 'Social stigma', measured the extent to which patients' perceptions of social stigma and efforts to keep the sickness and treatment a secret predict 'treatment non-adherence'. Three items loaded on this factor.

**Factor 3-** Explained the variance of 8.175%, labeled as 'Dissatisfaction with staff quality', measured the extent to which patients' perceive the dissatisfaction with health care professionals and other staff' responsiveness, empathy, assurance, and overall work culture predict 'treatment non-adherence'. Five items loaded on this factor.

**Factor 4-** Explained the variance of 7.282%, labeled as 'Frustration', measured the extent to which, patients' frustration due to long waiting hours, fed up of long term treatment, high perceived risk in the treatment predict 'treatment non-adherence'. Three items loaded on this factor.

**Factor 5-** Explained the variance of 7.257%, labeled as ‘Regimen difficulty’, measured the extent to which patients’ confusion and difficulty in following the treatment regimen predict ‘treatment non-adherence’. Two items loaded on this factor.

**Factor 6-** Explained the variance of 7.129%, labeled as ‘Unaffordability’, measured the extent to which patients’ unaffordability to purchase medicines and pay towards the doctor’s fees and diagnostic test charges, predict ‘treatment non-adherence’. Three items loaded on this factor.

**Factor 7-** Explained the variance of 6.837%, labeled as ‘Lack of external support’, measured the extent to which unavailability of a caretaker and other external social support to patients, predict ‘treatment non-adherence’. Three items loaded on this factor.

**Factor 8-** Explained the variance of 5.514%, labeled as ‘Inconvenience’, measured the extent to which inaccessibility to health care facility due to unavailability of required facilities at the hospital, inconvenient location of the hospital, lack of public transport, predict ‘treatment non-adherence’. Three items loaded on this factor.

**Results of factor analysis for dependent variables (CDTNAS)**

The details about sampling adequacy, total variance explained, and factor loading score are of dependent variables are given in Table 6.4d, 6.4e and 6.4f respectively.

**Table 6.4d**KMO Measure of Sampling Adequacy and Bartlett's Test of Sphericity

Kaiser-Meyer-Olkin Measure of Sampling Adequacy	.793
Bartlett's Test of Sphericity Approx. Chi-Square	1700
Df	28
Sig.	.000

Table 6.4e Total variance explained

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	3.069	38.363	38.363
2	1.852	23.150	61.513

Table 6.4f Rotated component Matrix <sup>a</sup>

	Component	
	1	2
I skip the doses of medicine	.870	
I do not fill the prescription in time	.867	
I avoid taking medicine	.848	
I am not doing follow-up visits as advised by the doctor	.645	
I have discontinued the treatment	.544	
I am not exercising as instructed by the doctor		.786
I am not taking rest as advised by the doctor		.782
I am not following the diet recommended by the doctor		.679

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization

Rotation converged in 3 iterations.

## **Results of Factor analysis for dependent variables (CDTNAS)**

Principal Component Factor Analysis obtained a Kaiser-Meyer-Olkin Measure of 0.793 sampling adequacy indicated suitability of the data for factor analysis. With Bartlett's test of Sphericity of 170.03 which is significant at 1% level shows a high correlation between items. Communalities of all the variables were more than 0.4 except one variable, 'I have discontinued the treatment'. Total of 2 Factors were extracted with a total variance explained of 61.513%. Two statements: 'I take a lower dose of medicine than prescribed by the doctor' and 'I did not do diagnostic tests as per doctor's advice' loaded on two factors, hence deleted from the factor analysis. The factor loading scores for each item was more than 0.5.

**Factor 1**, Explained the variance of 38.36%, labeled as, 'Medication non-adherence', measured the extent to which patients are non-adherent due to discontinuation of treatment, not following the scheduled visits to the doctor, skipping and avoiding the medication, not filling the prescription in time. Five items loaded on this factor.

**Factor 2**- Explained the variance of 23.15%, labeled as, 'Lifestyle modification non-adherence', measured the extent to which patients are non-adherent due to not doing exercises, not dieting and taking the rest as per doctor's advice. Three items loaded on this factor.

'**Treatment Non-adherence**', a dependent variable, is calculated as the average of ten dependent statements scores, measured the extent to which patients are non-adherent to medication and lifestyle related advice from the doctor.

### **Construct validity of the scales**

Exploratory Factor analyses were performed to identify the dimensions of the constructs. Exploratory factor analyses were also aimed at establishing theoretical relationship and

examining the empirical relationship between the variables. Factor analyses were performed to support the construct validity.

#### **Construct validity of the scale (DOCDTNAS)**

For independent variables, as expected, eight dimensions of determinants were extracted, confirming the construct validity. The order in which the factors emerged is different than expected. The statement, 'I am concerned about my health' loaded on Factor 7- 'Lack of external support', instead of Factor 4-'Frustration'. Factor analysis results supported the construct validity.

#### **Construct validity of the scale (CDTNAS)**

For dependent variables, as expected, two dependent variables were extracted: 'Medication non-adherence', and 'Lifestyle modification non-adherence', confirming the construct validity of the scale.

### **6.5 RESULTS OF REGRESSION**

Regression analyses had been used to examine the impact of the independent variables: work compulsions, unaffordability, dissatisfaction with staff quality, lack of external support, frustration, inconvenience, social stigma and regimen difficulty, on the dependent variables: treatment non-adherence, medication non-adherence and lifestyle modification non-adherence. The coefficient of correlation ( $R^2$ ) is used to assess the strength of the relationship between the determinants of treatment non-adherence and the dependent variables.

#### **Dependent variable: Treatment Non-adherence**

The Tables 6.5a, 6.5b, 6.5c and 6.5d show the details of regression on the dependent variable: Treatment Non-adherence



**Table 6.5a** Variables entered/Removed

Model	Variables Entered	Variables Removed	Method
1	Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction With Staff Quality, Social Stigma, Work Compulsions <sup>a</sup>		Enter

a. All requested variables entered.

b. Dependent Variable: **TREATMENTNON-ADHERENCE**

Table 6.5b Model summary

Model	R	R Square	Adjusted R Square	Std. Error Of The Estimate
1	.492 <sup>a</sup>	.242	.229	.790

a. Predictors: (Constant), Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction With Staff Quality, Social Stigma, Work Compulsions

Table 6.5c ANOVA

ANOVA <sup>b</sup>						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	93.753	8	11.719	18.755	.000 <sup>a</sup>
	Residual	293.686	470	.625		
	Total	387.439	478			

a. Predictors: (Constant), Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction with Staff Quality, Social Stigma, Work Compulsions.

b. Dependent Variable: TREATMENT NON-ADHERENCE

Table 6.5d Coefficients

Coefficients <sup>a</sup>						
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	2.907	.036		80.477	.000
	Work Compulsions	.061	.036	.068*	1.685	.093
	Social Stigma	-.123	.036	-.136**	-3.397	.001
	Dissatisfaction With Staff Quality	.103	.036	.114**	2.843	.005

	Frustration	.078	.036	.087**	2.165	.031
	Regimen Difficulty	.200	.036	.223***	5.541	.000
	Unaffordability	.065	.036	.072*	1.787	.075
	Lack of External Support	.336	.036	.373***	9.289	.000
	Inconvenience	.059	.036	.066	1.644	.101

Notes \*\*\* Significant at 1% level, \*\* Significant at 5% level, \* Significant at 10% level.

a. Dependent Variable: TREATMENT NON-ADHERENCE

Treatment non-adherence is regressed on calculated 8 factor scores. Overall model is fit and statistically significant at F ratio of 18.755 and p level < .001. The R<sup>2</sup> value of 0.242 indicate that 24.2% of the variance in treatment non-adherence is explained jointly by all the independent variables in the model. Two factors: lack of external support and regimen difficulty were found to contribute significantly to the variance explained in treatment non-adherence.

**Dependent variable: Medication non-adherence**

The Tables 6.5e, 6.5f, 6.5g and 6.5h show the details of regression on the dependent variable: Medication Non-adherence

Table 6.5e Variables entered/Removed

Model	Variables Entered	Variables Removed	Method
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1	Inconvenience, Lack of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction with Staff Quality, Social Stigma, Work Compulsions <sup>a</sup>		Enter
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a. All requested variables entered.

b. Dependent Variable: **MEDICATION NON-ADHERENCE**

**Table 6.5f Model Summary**

Model	R Square	Adjusted R Square	Std. Error of the Estimate
1	.460 <sup>a</sup>	.212	.89521557

**Table 6.5g ANOVA**

Model		Sum of Squares	df	Mean Square	f	Sig.
1	Regression	101.337	8	12.667	15.806	.000 <sup>a</sup>
	Residual	376.663	470	.801		
	Total	478.000	478			

a. Predictors: (Constant), Inconvenience, Lack Of External Support,

Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction with Staff Quality, Social Stigma, Work Compulsions.

b. Dependent Variable: **MEDICATION NON-ADHERENCE**

Table 6.5h Coefficients

Coefficients <sup>a</sup>						
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	3.654E-17	.041		.000	1.000
	Work Compulsions	-.043	.041	-.043	-1.046	.296
	Social Stigma	-.161	.041	-.161***	-3.941	.000
	Dissatisfaction With Staff Quality	.146	.041	.146***	3.555	.000
	Frustration	.045	.041	.045	1.106	.269
	Regimen Difficulty	.186	.041	.186***	4.550	.000
	Unaffordability	.064	.041	.064	1.556	.120
	Lack of External Support	.342	.041	.342***	8.352	.000
	Inconvenience	.072	.041	.072*	1.754	.080

Notes \*\*\* Significant at 1% level, \* Significant at 10% level.

a. Dependent Variable: MEDICATION NON-ADHERENCE

Medication non-adherence is regressed on calculated 8 factor scores. Overall model is fit and statistically significant at F ratio of 15.806 and p level < .001. The R<sup>2</sup> value of 0.212 indicate that 21.2% of the variance in medication non-adherence is explained jointly by all the independent variables in the model. Three factors: dissatisfaction with staff quality, regimen difficulty and lack of external support were found to contribute significantly to the variance explained in medication non-adherence.

**Dependent variable: Lifestyle modification non-adherence**

The Tables 6.5i, 6.5j, 6.5k and 6.5l show the details of regression on the dependent variable: Lifestyle Modification Non-adherence

Table 6.5i Variables entered/Removed

Model	Variables Entered	Variables Removed	Method
1	Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction With Staff Quality, Social Stigma, Work Compulsions <sup>a</sup>		Enter

a. All requested variables entered.

b. Dependent Variable: **LIFESTYLE MODIFICATION NON-ADHERENCE**

Table 6.5j Model summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.289 <sup>a</sup>	.083	.068	.96550280

- a. Predictors: (Constant), Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction With Staff Quality, Social Stigma, Work Compulsions

Table 6.5k ANOVA

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	39.868	8	4.984	5.346	.000 <sup>a</sup>
	Residual	438.132	470	.932		
	Total	478.000	478			

- a. Predictors: (Constant), Inconvenience, Lack Of External Support, Unaffordability, Regimen Difficulty, Frustration, Dissatisfaction With Staff Quality, Social Stigma, Work Compulsions.
- b. Dependent Variable: LIFESTYLE MODIFICATION NON-ADHERENCE

Table 6.51 Coefficients

Model		Unstandardized	Standardized		t	Sig.
		Coefficients	Coefficients			
		B	Std. Error	Beta		
1	(Constant)	8.933E-19	.044		.000	1.000
	Work Compulsions	.182	.044	.182***	4.118	.000
	Social Stigma	.015	.044	.015	.349	.727
	Dissatisfaction With Staff Quality	-.048	.044	-.048	- 1.093	.275
	Frustration	.111	.044	.111**	2.516	.012
	Regimen Difficulty	.086	.044	.086*	1.950	.052
	Unaffordability	-.041	.044	-.041	-.917	.359
	Lack Of External Support	.162	.044	.162***	3.676	.000
	Inconvenience	.003	.044	.003	.071	.943

Notes \*\*\* Significant at 1% level, \*\* Significant at 5% level, \* Significant at 10% level.



a. Dependent Variable: LIFESTYLE MODIFICATION NON-ADHERENCE

Lifestyle modification non-adherence is regressed on calculated 8 factor scores. Overall model is fit and statistically significant at F ratio of 5.346 and p level < .001. The R<sup>2</sup>value of 0.083 indicate that 8.3% of the variance in lifestyle modification non-adherence is explained jointly by all the independent variables in the model. Two factors: work compulsions and lack of external support were found to contribute significantly to the variance explained in lifestyle modification non-adherence.

Table 6.5m shows the variances explained in dependent variables.

**Table 6.5m**The variances in dependent variables explained are:

Dependent variables	Variance explained
Treatment Non-adherence	24.2%
Medication non-adherence	21.2%
Lifestyle modification non-adherence	8.3%

## 6.6 TESTING OF HYPOTHESES

### Dependent variable: Treatment Non-adherence

The hypotheses H1 to H8 were tested. The summary of hypotheses accepted/rejected is given in Table 6.6a.

Table 6.6aHypotheses acceptance/rejection (Treatment Non-adherence)

No.	Hypothesis	$\beta$	t-test value Sig.	Accepted / Rejected
H1	There is a positive relationship between work compulsions and treatment non-adherence among patients with chronic conditions	.068	0.093	Accepted
H2	There is a positive relationship between unaffordability and treatment non-adherence among patients with chronic conditions	.072	0.075	Accepted
H3	There is a positive relationship between dissatisfaction with staff quality and treatment non-adherence among patients with chronic conditions	.114	0.005	Accepted
H4	There is a positive relationship between lack of external support and treatment non-adherence among patients with chronic conditions.	.373	.000	Accepted
H5	There is a positive relationship between frustration and treatment non-adherence among patients with chronic conditions.	.087	0.031	Accepted
H6	There is a positive relationship between inconvenience and treatment non-adherence among patients with chronic conditions.	.066	0.101	Rejected

H7	There is a positive relationship between social stigma and treatment non-adherence among patients with chronic conditions.	-.136	0.001	Accepted
H8	There is a positive relationship between regimen difficulty and treatment non-adherence among patients with chronic conditions.	.223	0.000	Accepted

The t- test for significance of each independent variable indicates that at the significance level of 1% (confidence level of 99%), lack of external support and regimen difficulty are positively correlated; social stigma is negatively correlated at the significance level of 5% (confidence level of 95%), dissatisfaction with staff quality and frustration are positively correlated; and at the significance level of 10% (confidence level of 90%), unaffordability and work compulsions are positively correlated to treatment non-adherence.

**Dependent variable: Medication non-adherence**

The hypotheses H9 to H16 were tested. The summary of hypotheses accepted/rejected is given in Table 6.6b

Table 6.6b Hypotheses acceptance/rejection (Medication Non-adherence)

No.	Hypothesis	$\beta$	t-test value Sig.	Accepted / Rejected
H9	There is a positive relationship between work compulsions and	-.043	0.101	Rejected

	medication non-adherence among patients with chronic conditions			
H10	There is a positive relationship between unaffordability and medication non-adherence among patients with chronic conditions	.064	0.121	Rejected
H11	There is a positive relationship between dissatisfaction with staff quality and medication non-adherence among patients with chronic conditions	.146	0.000	Accepted
H12	There is a positive relationship between lack of external support and medication non-adherence among patients with chronic conditions.	.342	0.000	Accepted
H13	There is a positive relationship between frustration and medication non-adherence among patients with chronic conditions.	.045	0.269	Rejected
H14	There is a positive relationship between inconvenience and medication non-adherence among patients with chronic conditions.	.072	0.080	Accepted
H15	There is a positive relationship between social stigma and medication	.161	0.000	Accepted

	non-adherence among patients with chronic conditions.			
H16	There is a positive relationship between regimen difficulty and medication non-adherence among patients with chronic conditions.	.186	0.000	Accepted

The t- test for significance of each independent variable indicates that at the significance level of 1% (confidence level of 99%), social stigma is negatively correlated, whereas lack of external support, regimen difficulty and dissatisfaction with staff quality are positively correlated and at the significance level of 10% (confidence level of 90%), inconvenience is positively correlated medication non-adherence.

#### **Dependent variable: Lifestyle Modification Non-adherence**

The hypotheses H17 to H24 were tested. The summary of hypotheses accepted/rejected is given in Table 6.6c.

Table 6.6c Hypotheses acceptance/rejection (Lifestyle Modification Non-adherence)

No.	Hypothesis	$\beta$	t-test value Sig.	Accepted / Rejected
H17	There is a positive relationship between work compulsions and lifestyle modification non-adherence among patients with chronic conditions	.182	0.000	Accepted

H18	There is a positive relationship between unaffordability and lifestyle modification non-adherence among patients with chronic conditions	-.041	0.359	Rejected
H19	There is a positive relationship between dissatisfaction with staff quality and lifestyle modification non-adherence among patients with chronic conditions	.048	0.275	Rejected
H20	There is a positive relationship between lack of external support and lifestyle modification non-adherence among patients with chronic conditions.	.162	0.000	Accepted
H21	There is a positive relationship between frustration and lifestyle modification non-adherence among patients with chronic conditions.	.111	0.012	Accepted
H22	There is a positive relationship between inconvenience and lifestyle modification non-adherence among patients with chronic conditions.	.003	0.943	Rejected
H23	There is a positive relationship between social stigma and lifestyle modification non-adherence among patients with chronic conditions.	.015	0.727	Rejected
H24	There is a positive relationship between	.086	0.052	Accepted

	<p>regimen difficulty and lifestyle modification non-adherence among patients with chronic conditions.</p>			
--	--	--	--	--

The t- test for significance of each independent variable indicates that at the significance level of 1% (confidence level of 99%), work compulsions and lack of external support are positively correlated; at the significance level of 5% (confidence level of 95%), frustration is positively correlated; and at the significance level of 10% (confidence level of 90%), regimen difficulty is positively correlated to lifestyle non-adherence.

### 6.7 ANALYSIS AND RESULTS OF TESTING INTERACTION EFFECTS

Following interaction effects were tested on treatment non-adherence, medication non-adherence and lifestyle modification non-adherence:

#### Gender by work compulsions interaction on Treatment non- adherence

The research model and the interaction graph for testing gender by work compulsions interaction on treatment non-adherence are given in Table 6.7a and Interaction graph 6.7-1 respectively.

**Table 6.7a Research model**

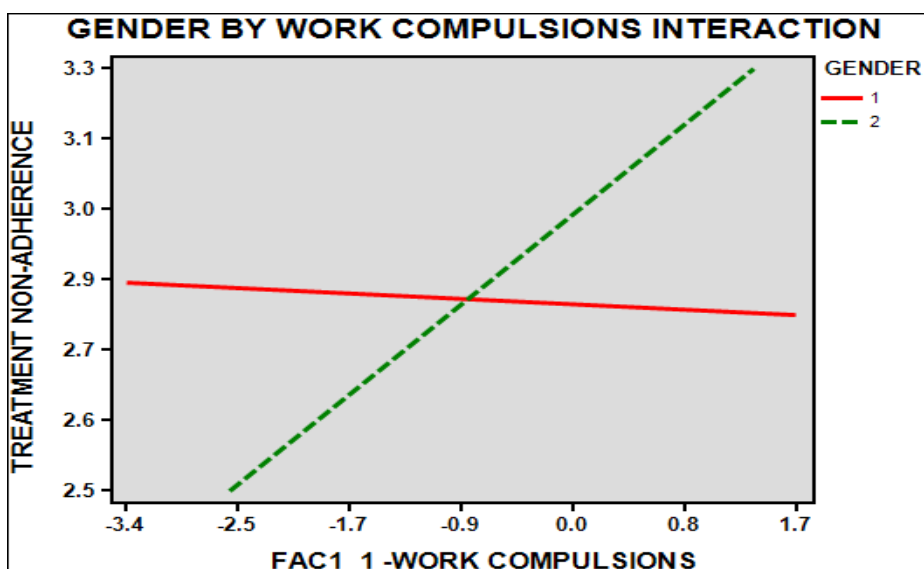
<p>Research Model</p>	<p>Y= B1X1          +B2D1          +B3X1D1          +B0          Where- Y= Treatment Non-adherence          X1= Work Compulsions</p>
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	D1= Gender 1 Bo= Regression constant
Model Summary	R Square : 0.026 R Square contribution of the interaction term: 0.011
Model Analysis of Variance	F(df 3,475) = 4.259 P value < 0.05
Model Coefficients	Interaction term b= 0.210  t= 2.391  P value < 0.05
Effect Size	0.026

The  $R^2$  0.026, indicates 2.6 % variance in treatment non-adherence, which is explained by work compulsions, gender, and gender by work compulsions. The  $R^2$  contribution of the interaction term 0.011 indicates 1.1% of the variance exclusively explained by the interaction term. The interaction term is statistically significant at  $F(df3, 475) = 4.259$  and  $P$  value < .05. For the interaction term, the unstandardized regression slope is  $b = 0.210$ ,  $t = 2.391$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant; this implies that the slope that predicts the relationship between work compulsions and treatment non-adherence differs significantly between the male and female groups. The effect size of 0.026, indicates, small magnitude of the combined impact of the predictors on the dependent variable.



**Interaction graph 6.7-1 Gender by work compulsions interaction on Treatment non-adherence**



Gender 1= Male, 2= Female

The interaction graph shows, the slope is positive for female, indicating higher the work compulsions, the greater is the treatment non-adherence. The slope is negative for male, indicating a negative relation between work compulsions and treatment non-adherence.

**Gender by regimen difficulty interaction on medication non- adherence**

The research model and the interaction graph for testing gender by regimen difficulty interaction on medication non- adherence are given in Table 6.7b and interaction graph 6.7- 2 respectively.

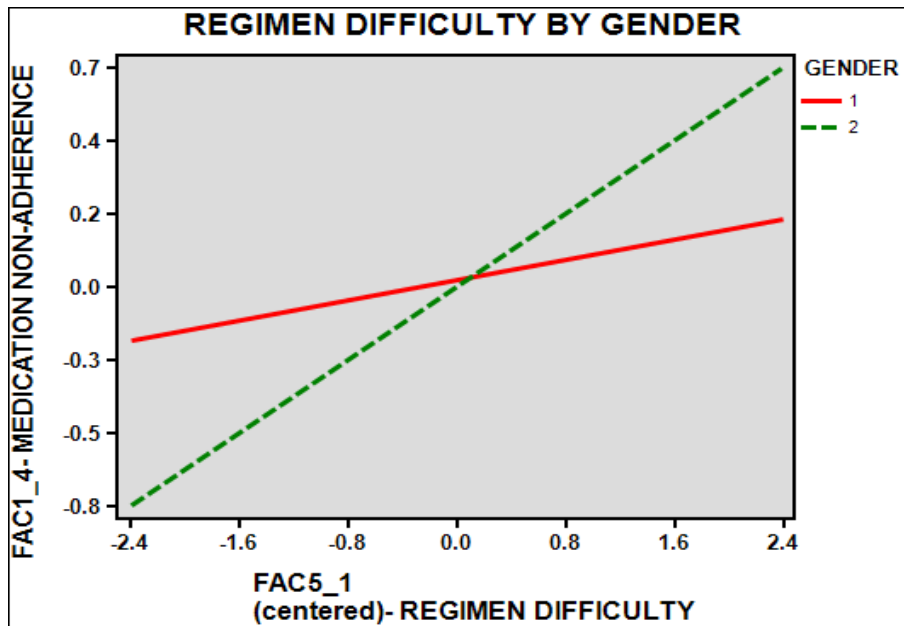
**Table 6.7b Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence</p> <p style="text-align: center;">X1= Work Compulsions</p> <p style="text-align: center;">D1= Gender 1</p> <p style="text-align: center;">Bo= Regression constant</p>
Model Summary	<p>R Square : 0.046</p> <p>R Square contribution of the interaction term: 0.011</p>
Model Analysis of Variance	<p>F(df 3,475) = 7.7074</p> <p>P value &lt; 0.05</p>
Model Coefficients	<p>Interaction term b= 0.219</p> <p style="text-align: center;">t= 2.412</p> <p style="text-align: center;">P value &lt; 0.05</p>
Effect Size	0.048

The  $R^2$  0.046, indicates 4.6 % variance in medication non-adherence, which is explained by regimen difficulty, gender, and the gender by regimen difficulty. The  $R^2$  contribution of the interaction term 0.011 indicates 1.1% of the variance which is explained exclusively by the interaction term. The research model is statistically significant at  $F(df 3,475) = 7.707$  and  $P$  value < .05. For the interaction term, the unstandardized regression slope is  $b = 0.219$ ,  $t = 2.412$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between regimen difficulty and

medication non-adherence differs significantly between the male and female groups. The effect size of 0.048, indicates, small magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph6.7-2 Gender by regimen difficulty interaction on medication non-adherence**



Gender 1= Male, 2= Female

The interaction graph shows, that the slopes are positive for both the levels of moderating variables indicating a positive relation between regimen difficulty and medication non-adherence. However the impact of regimen difficulty on medication non-adherence is greater for females than males.

**Gender by work compulsions interaction on lifestyle non- adherence**

The research model and interaction graph for testing gender by work compulsions interaction on lifestyle non- adherence are given in Table 6.7c and interaction graph6.7-3 respectively.

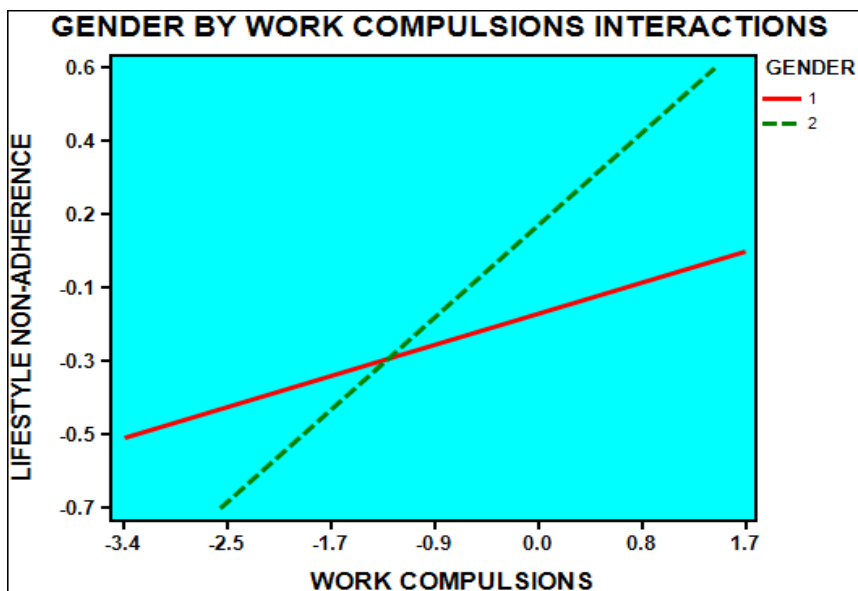
**Table 6.7c Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Lifestyle Modification Non-adherence  X1= Work Compulsions  D1= Gender 1  Bo= Regression constant</p>
Model Summary	R Square : 0.06012 R Square contribution of the interaction term: 0.0093
Model Analysis of Variance	$F(df\ 3,475) = 10.128$ P value < 0.05
Model Coefficients	Interaction term $b = 0.208$ $t = 2.17$ P value < 0.05
Effect Size	0.06

The  $R^2$  of 0.06 indicates 6 % variance in lifestyle non-adherence, which is explained by work compulsions, gender, and gender by work compulsions. The  $R^2$  contribution of the interaction term of 0.009 indicates 0.9% of the variance which is exclusively explained by the interaction term. The research model is statistically significant at  $F(df\ 3,475) = 10.128$  and P value < 0.05. For the interaction term, the unstandardized regression slope is  $b =$

0.208,  $t = 2.170$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant; this implies that the slope that predicts the relationship between work compulsions and lifestyle non-adherence differs significantly between the male and female groups. The effect size of 0.06, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

### Interaction Graph 6.7-3 Gender by work compulsions interaction on lifestyle non-adherence



Gender 1= Male, 2= Female

The interaction graph shows that, the slopes are positive for both the levels of moderating variables indicating a positive relation between work compulsions and lifestyle non-adherence. However the effect of work compulsions on lifestyle non-adherence is greater for females than males.

### State by regimen difficulty interaction on treatment non- adherence

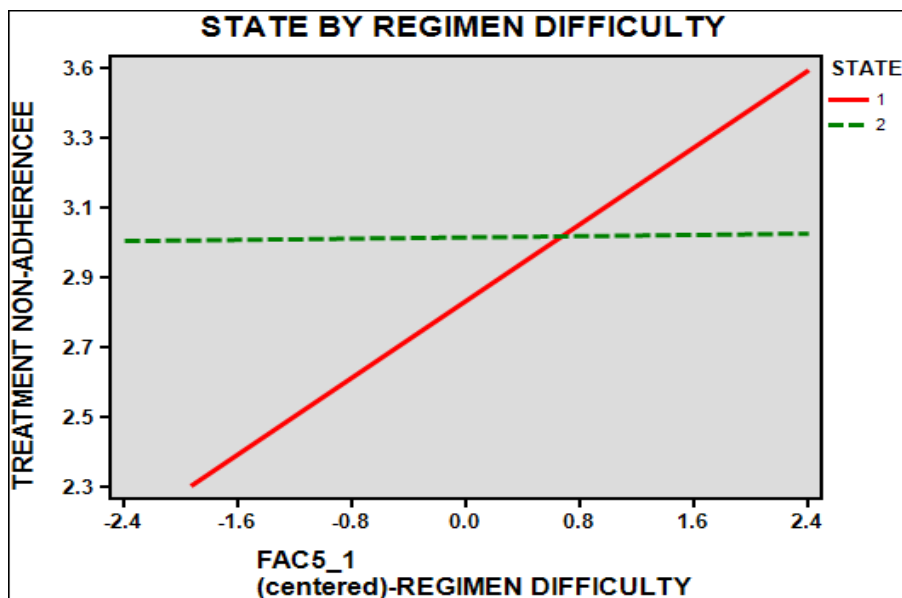
The research model and interaction graph for testing state by regimen difficulty interaction on treatment non- adherence is given in Table 6.7d and interaction graph 6.7- 4 respectively.

**Table 6.7d Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Treatment Non-adherence  X1= Regimen Difficulty  D1= State 1  Bo= Regression constant</p>
Model Summary	R Square : 0.08 R Square contribution of the interaction term: 0.023
Model Analysis of Variance	$F(df3,475) = 13.787$ P value < 0.0000
Model Coefficients	Interaction term $b = 0.287$ $t = -3.446$ P value < 0.01
Effect Size	0.08

The  $R^2$  0.08 indicates 8 % variance in treatment non-adherence, which is explained by regimen difficulty, state and state by regimen difficulty. The  $R^2$  contribution of the interaction term 0.023 indicates 2.3% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F(df 3,475) = 13.787$  and  $P$  value  $< 0.05$ . For the interaction term, the unstandardized regression slope is  $b = -0.287$ ,  $t = -3.446$ ,  $p < .001$ . The coefficient for the interaction term is statistically significant; this implies that the slope that predicts the relationship between regimen difficulty and treatment non-adherence differs significantly between the patients from Goa and from Karnataka. The effect size of 0.08, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-4 State by regimen difficulty interaction on treatment non-adherence**



State 1 = Goa, 2 = Karnataka.

The interaction graph indicates that the slope for the state of Goa is positive, indicating positive correlation between regimen difficulty and treatment non-adherence where as the

slope for the state of Karnataka is indicating that regimen difficulty has no impact on treatment non-adherence.

### State by social stigma interaction on medication non- adherence

The research model and interaction graph for testing state by social stigma interaction on medication non- adherence are given in Table 6.7e and interaction graph 6.7-5 respectively

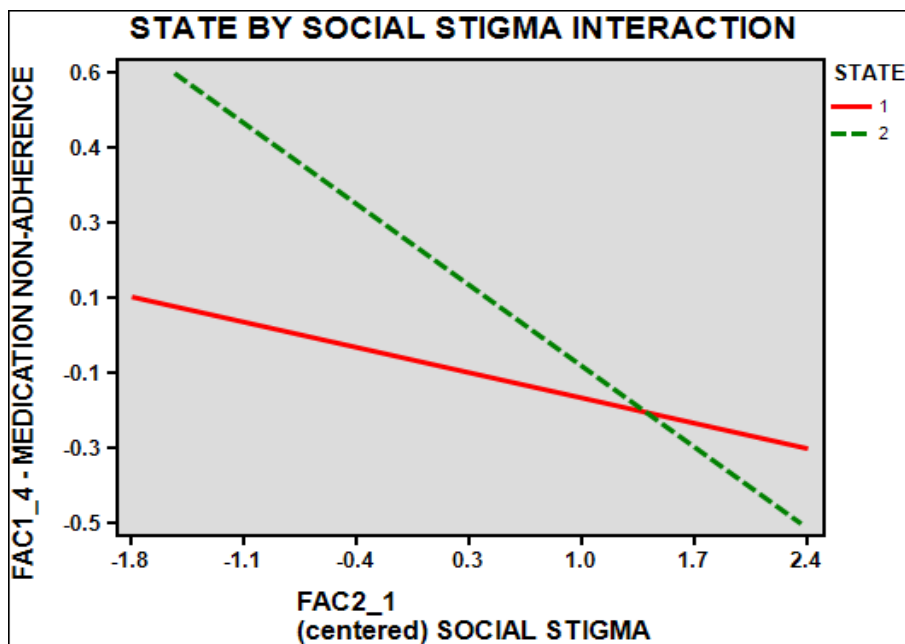
**Table 6.7e Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence  X1= Social Stigma  D1= State 1  B0= Regression constant</p>
Model Summary	R Square : 0.053 R Square contribution of the interaction term: 0.009
Model Analysis of Variance	F(df 3,475) = 8.909 P value < 0.0000
Model Coefficients	Interaction term b= 0.219 t= 2.169 P value < 0.05
Effect Size	0.06



The  $R^2$  0.053 indicates 5.3 % variance in treatment non-adherence, which is explained by social stigma, state, and the state by social stigma. The  $R^2$  contribution of the interaction term 0.009 indicates 0.9% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F$  (df 3,475) =8.909 and  $P$  value  $< 0.05$ . For the interaction term, the unstandardized regression slope is  $b = -0.219$ ,  $t = -2.169$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between social stigma and medication non-adherence differs significantly between the patients from Goa and from Karnataka. The effect size of 0.06, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-5 State by social stigma interaction on medication non-adherence**



State 1 = Goa, 2 = Karnataka.

The interaction graph shows that the slopes are negative for both the states indicating, lower the social stigma, the higher the medication non-adherence. However the effect of

social stigma on medication non-adherence is greater among the patients with chronic conditions from the state of Karnataka than Goa.

**State by regimen difficulty interaction on medication non- adherence**

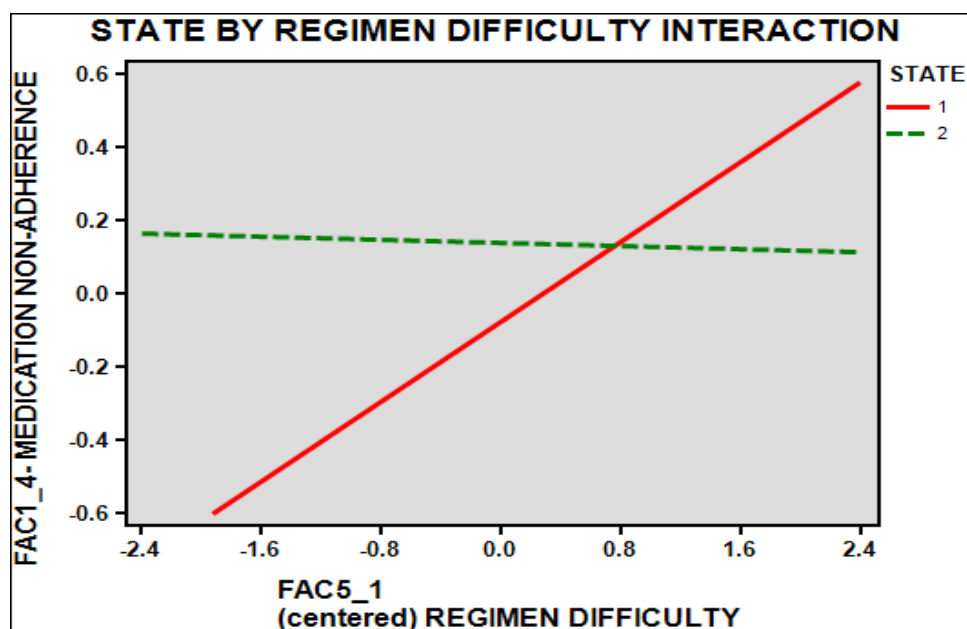
The research model and interaction graph for testing state by regimen difficulty interaction on medication non- adherence are given in Table 6.7f and interaction graph 6.7-6 respectively.

**Table 6.7f Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ Where- Y= Medication Non-adherence $X_1 =$ Regimen Difficulty $D_1 =$ State 1 $B_0 =$ Regression constant
Model Summary	R Square : 0.06 R Square contribution of the interaction term: 0.018
Model Analysis of Variance	$F(df\ 3,475) = 10.324$ $P\ value < 0.0000$
Model Coefficients	Interaction term $b = 0.219$ $t = -2.169$ $P\ value < 0.05$
Effect Size	0.06

The  $R^2$  0.06 indicates 6 % variance in medication non-adherence, which is explained by regimen difficulty, state and state by regimen difficulty. The  $R^2$  contribution of the interaction term 0.018 indicates 1.8% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F(df 3,475) = 10.324$  and  $P$  value  $< 0.05$ . For the interaction term, the unstandardized regression slope is  $b = -0.219$ ,  $t = -2.169$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between regimen difficulty and medication non-adherence differs significantly between the patients from Goa and from Karnataka. The effect size of 0.06, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-6 State by regimen difficulty interaction on medication non-adherence**



State 1 = Goa, 2 = Karnataka.

The interaction graph indicates that the slope for the state of Goa is positive indicates the higher the regimen difficulty, the greater is the medication non-adherence for the patients

with chronic conditions from the state of Goa whereas the slope for the State of Karnataka is negatively correlated, indicating lower the regimen difficulty, the greater is the medication non-adherence for the patients with chronic conditions.

**State by unaffordability interaction on medication non- adherence**

The research model and interaction graph for testing state by unaffordability interaction on medication non- adherence are given in Table 6.7g and interaction graph 6.7-7 respectively.

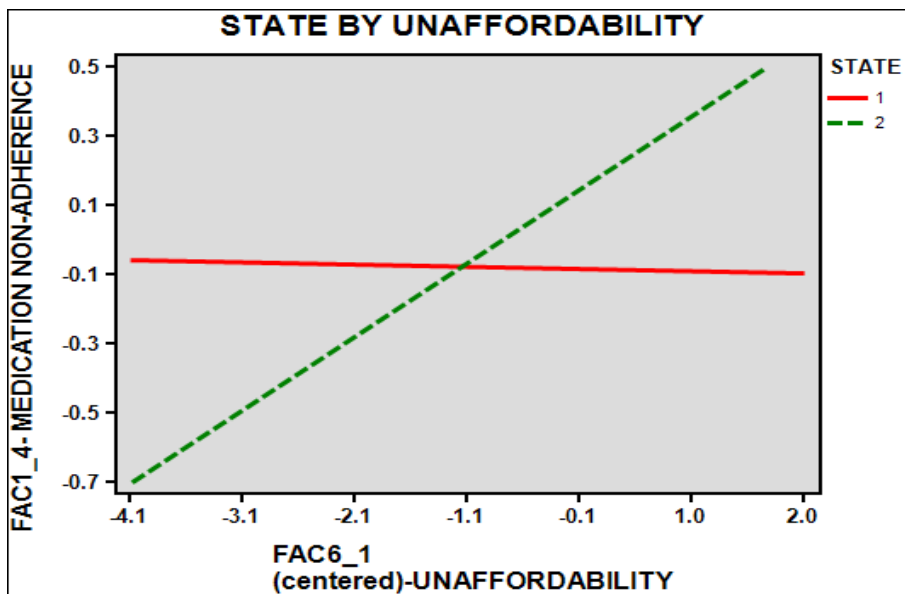
**Table 6.7g Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence  X1= Unaffordability  D1= State 1  Bo= Regression constant</p>
Model Summary	R Square : 0.028 R Square contribution of the interaction term: 0.001
Model Analysis of Variance	F(df 3,475) = 4.613 P value < 0.005
Model Coefficients	Interaction term b= 0.216 t= 2.245 P value < 0.05

Effect Size	0.029
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The  $R^2$  0.028 indicates 2.8 % variance in medication non-adherence, which is explained by unaffordability, state and state by unaffordability. The  $R^2$  contribution of the interaction term 0.001 indicates 0.1% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F(df 3,475) = 4.613$  and  $P$  value  $< 0.05$ . For the interaction term, the unstandardized regression slope is  $b = 0.216$ ,  $t = 2.245$ ,  $p < .005$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between unaffordability and medication non-adherence differs significantly between the patients from Goa and from Karnataka. The effect size of 0.029, indicates, small magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-7 State by unaffordability interaction on medication non-adherence**



State 1 = Goa, 2 = Karnataka.

The interaction graph indicates that the slope for the state of Karnataka is positive, indicating, higher the unaffordability, higher the medication non-adherence where as the slope for the state of Goa, indicates that unaffordability do not impact on medication non-adherence.

**Type of health care facility by work compulsions interaction on lifestyle non-adherence**

The research model and interaction graph for testing type of health care facility by work compulsions interaction on lifestyle non- adherence are given in Table 6.7h and interaction graph 6.7-8 respectively.

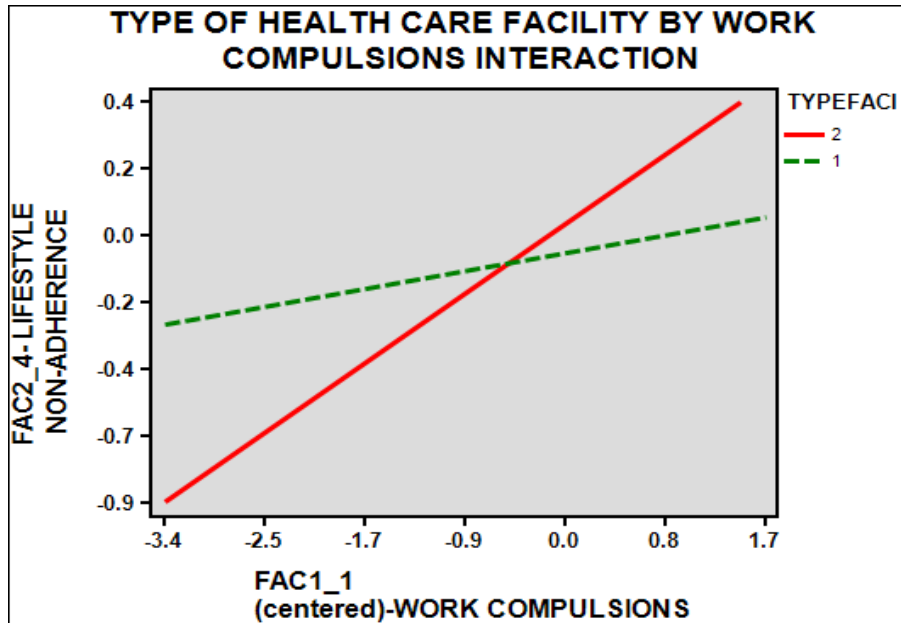
**Table 6.7h Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Lifestyle Modification Non-adherence  X1= Work Compulsions  D1= Type of Health care facility 1  Bo= Regression constant</p>
Model Summary	R Square : 0.045 R Square contribution of the interaction term: 0.001
Model Analysis of Variance	F(df 3,475) = 7.605 P value < 0.05
Model Coefficients	Interaction term b= 0.203 t= 2.254

	P value < 0.05
Effect Size	0.048

The  $R^2$  0.045 indicates 4.5 % variance in lifestyle non-adherence, which is explained by type of health care facility, work compulsions, and type of health care facility by work compulsions. The  $R^2$  contribution of the interaction term 0.001 indicates 0.1% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F (df 3,475) = 7.605$  and  $P \text{ value} < 0.05$ . For the interaction term, the unstandardized regression slope is  $b = 0.203$ ,  $t = 2.254$ ,  $p < .005$ . The coefficient for the interaction term is statistically significant; this implies that the slope that predicts the relationship between work compulsions and lifestyle non-adherence differs significantly between the type of health care facility used by the patients. The effect size of 0.048, indicates, small magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-8 Type of health care facility by work compulsions interaction on lifestyle non- adherence**



Type of health care facility 1 =Public health care facility 2 = Private health care facility.

The interaction graph indicates that the slopes of both the levels of moderating variable are positive, indicating the positive relation between work compulsions and lifestyle non-adherence. However the impact of work compulsions on lifestyle non-adherence is greater among the patients using private health care facility than a public health care facility.

**Age by social stigma interaction on treatment non- adherence**

The research mode and interaction graph 1 for testing age by social stigma interaction on treatment non- adherence are given in Table 6.7i and interaction graph 6.7-9 respectively.



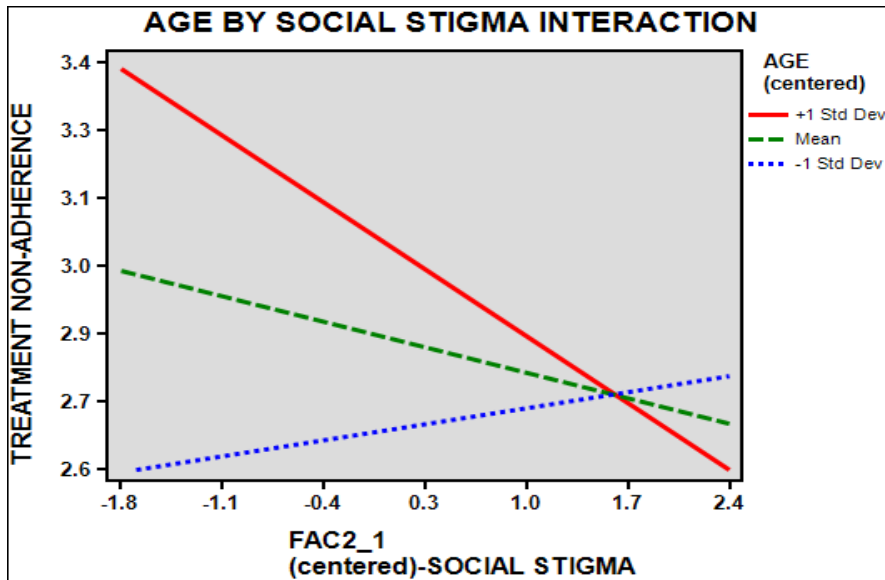
**Table 6.7i Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Treatment Non-adherence</p> <p>X1= Social Stigma</p> <p>D1= Age</p> <p>B<sub>0</sub>= Regression constant</p>
Model Summary	<p>R Square : 0.066</p> <p>R Square contribution of the interaction term: 0.017</p>
Model Analysis of Variance	<p>F(df 3,475) = 11.288</p> <p>P value &lt; 0.05</p>
Model Coefficients	<p>Interaction term b= -0.008</p> <p>t= -2.967</p> <p>P value &lt; 0.05</p>
Effect Size	0.071

The  $R^2$  0.066 indicates 6.6 % variance in treatment non-adherence, which is explained by age, social stigma, and age by social stigma. The  $R^2$  contribution of the interaction term 0.017 indicates 1.7% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F(df 3,475) = 11.288$  and  $P$  value < 0.05. For the interaction term, the unstandardized regression slope is  $b = -0.008$ ,  $t = -2.967$ ,  $p < .005$ . The coefficient for the interaction term is statistically significant, this implies that the slope

that predicts the relationship between social stigma and treatment non-adherence differs significantly between the patients' age groups. The effect size of 0.071, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-9 Age by social stigma interaction on treatment non- adherence**



The interaction graph indicates that the slope at +1 standard deviation level of age, the relationship between social stigma and treatment non-adherence is negative, for older patients, lower the social stigma, higher the treatment non-adherence. The slope at -1 standard deviation level of age, the relationship between social stigma and treatment non-adherence is positive. This shows that at lower age, the higher the social stigma, the higher is the treatment non-adherence.

**Age by social stigma interaction on medication non- adherence**

The research model and interaction graph for testing age by social stigma interaction on medication non- adherence is given in Table 6.7j and interaction graph 10 respectively.

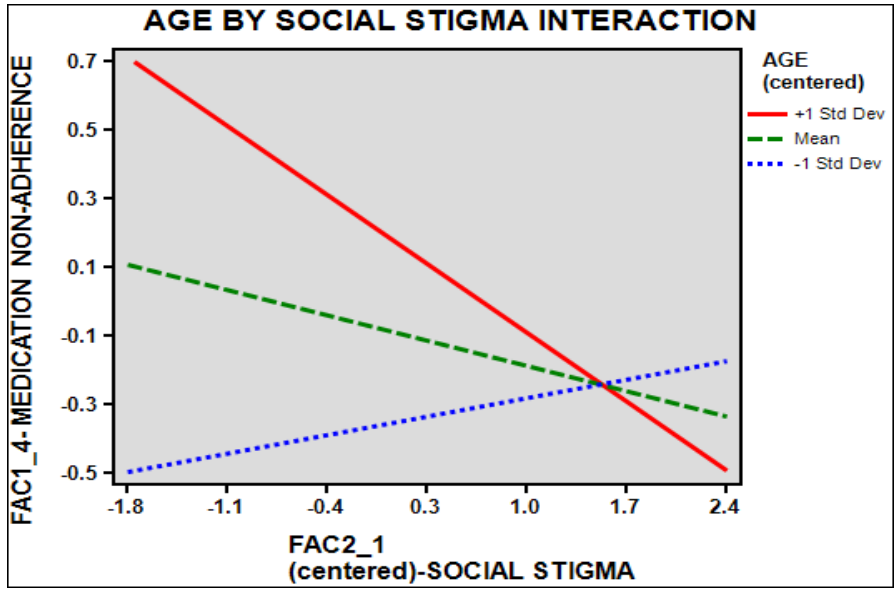
**Table 6.7j Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence</p> <p>X1= Social Stigma</p> <p>D1= Age</p> <p>B<sub>0</sub>= Regression constant</p>
Model Summary	<p>R Square : 0.098</p> <p>R Square contribution of the interaction term: 0.028</p>
Model Analysis of Variance	<p>F(df 3,475) = 17.207</p> <p>P value &lt; 0.05</p>
Model Coefficients	<p>Interaction term b=- 0.012</p> <p>t= -3.842</p> <p>P value &lt; 0.001</p>
Effect Size	0.108

The  $R^2$  0.098 indicates 9.8 % variance in treatment non-adherence, which is explained by age, social stigma, and age by social stigma. The  $R^2$  contribution of the interaction term 0.028 indicates 2.8% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F ( df 3,475) = 17.207$  and  $P$  value < 0.05. For the interaction term, the unstandardized regression slope is  $b = -0.012$ ,  $t = -3.842$ ,  $p < .001$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between social stigma and medication non-adherence differs

significantly between the patients' age groups. The effect size of 0.108, indicates, large magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-10 Age by social stigma interaction on medication non-adherence**



The interaction graph indicates that the slope at +1 standard deviation level of age, the relationship between social stigma and medication non-adherence is negative. This shows that for older patients, lower the social stigma, the higher is the medication non-adherence. The slope at -1 standard deviation level of age is positive. This shows that at lower age, higher the social stigma, the higher is the medication non-adherence.

**Age by regimen difficulty interaction on medication non- adherence**

The research model and interaction graph for testing age by regimen difficulty interaction on medication non- adherence are given in Table 6.7k and interaction graph 6.7-11 respectively.

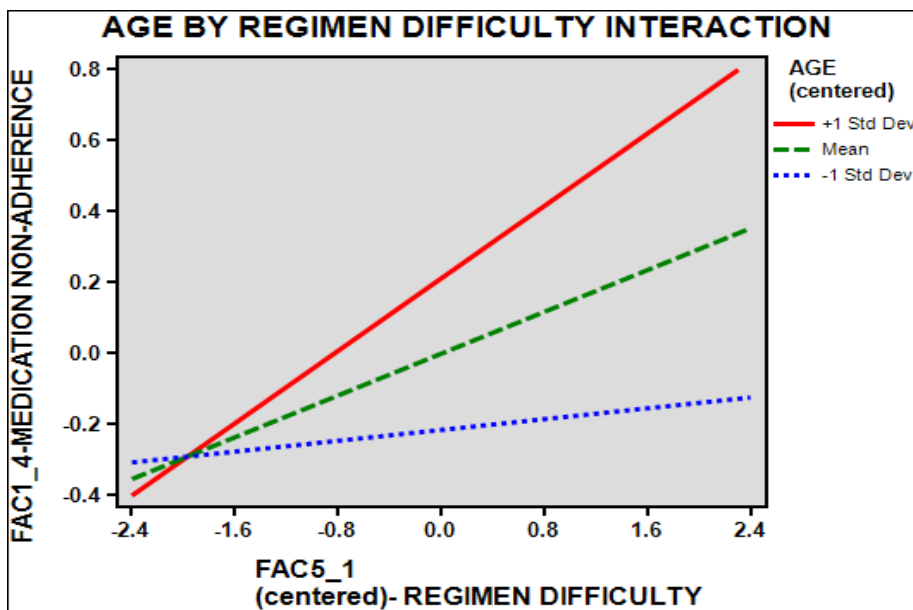
**Table 6.7k Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence</p> <p>X1= Regimen Difficulty</p> <p>D1= Age</p> <p>B<sub>0</sub>= Regression constant</p>
Model Summary	<p>R Square : 0.102</p> <p>R Square contribution of the interaction term: 0.013</p>
Model Analysis of Variance	<p>F(df 3,475) = 11.288</p> <p>P value &lt; 0.05</p>
Model Coefficients	<p>Interaction term b= 0.008</p> <p>t= 2.654</p> <p>P value &lt; 0.01</p>
Effect Size	0.114

The  $R^2$  0.102 indicates 10.2 % variance in treatment non-adherence, which is explained by age, regimen difficulty, and age by regimen difficulty. The  $R^2$  contribution of the interaction term 0.013 indicates 1.3% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F ( df 3,475) = 11.288$  and  $P$  value < 0.05. For the interaction term, the unstandardized regression slope is  $b = 0.008$ ,  $t = 2.654$ ,  $p < .01$ . The coefficient for the interaction term is statistically significant,

this implies that the slope that predicts the relationship between regimen difficulty and medication non-adherence differs significantly between the patients' age groups. The effect size of 0.114, indicates, large magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-11 Age by regimen difficulty interaction on medication non-adherence**



The interaction graph indicates that the slopes at -1 and +1 standard deviation levels of age are positive, the relationship between regimen difficulty and medication non-adherence are positive. This shows for the patients both young and old, higher the regimen difficulty, the higher is the medication non-adherence. However, the impact of regimen difficulty on medication non-adherence was higher among old patients than young patients.

**Monthly income of the patient's family by dissatisfaction with staff quality interaction on medication non- adherence**

The research model and interaction graph for testing monthly income of the patient's family by dissatisfaction with staff quality interaction on medication non- adherence are given in Table 6.71 and interaction graph 6.7-12 respectively.

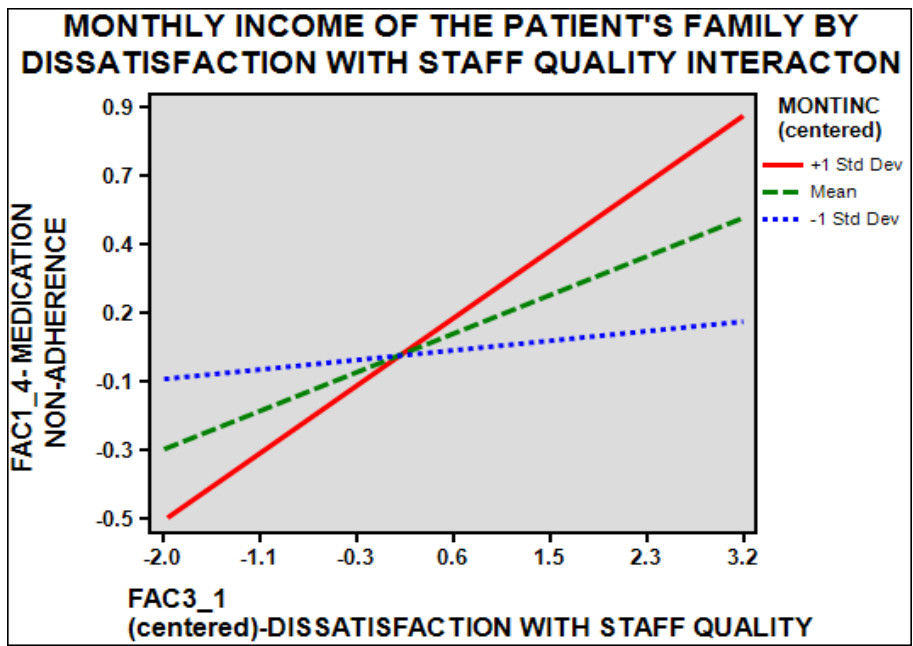
**Table 6.71 Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Medication Non-adherence  X1= Dissatisfaction with staff quality  D1= Monthly income of the patient's family  B0= Regression constant</p>
Model Summary	R Square : 0.037 R Square contribution of the interaction term: 0.011
Model Analysis of Variance	$F(df\ 3,475) = 6.180$ P value < 0.05
Model Coefficients	Interaction term $b = -0.008$ $t = -2.967$ P value < 0.05
Effect Size	0.039

The  $R^2$  0.037 indicates 3.7 % variance in treatment non-adherence, which is explained by patient's monthly household income, dissatisfaction with staff quality, and patient's monthly household income by dissatisfaction with staff quality. The  $R^2$  contribution of the interaction term 0.011 indicates 1.1% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F (df\ 3,475) = 6.180$  and  $P\ value < 0.05$ . For the interaction term, the unstandardized regression slope is  $b = -0.008$ ,  $t = -2.967$ ,  $p < .005$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between dissatisfaction with staff

quality and medication non-adherence differs significantly between the patients' monthly household income groups. The effect size of 0.039, indicates, small magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-12 Monthly income of the patient's family by dissatisfaction with staff quality interaction on medication non- adherence**



The interaction graph indicates that the slopes at -1 and +1 standard deviation levels of monthly income of the patient's family, the relationship between dissatisfaction with staff quality and medication non-adherence are positive. This shows that patients with lower and higher monthly income, higher the dissatisfaction with staff quality, the higher is the medication non-adherence. However the impact of dissatisfaction with staff quality on medication non-adherence was higher in patients with higher monthly income than the patients with lower monthly income.



**Monthly expenditure for treatment by social stigma interaction on treatment non-adherence**

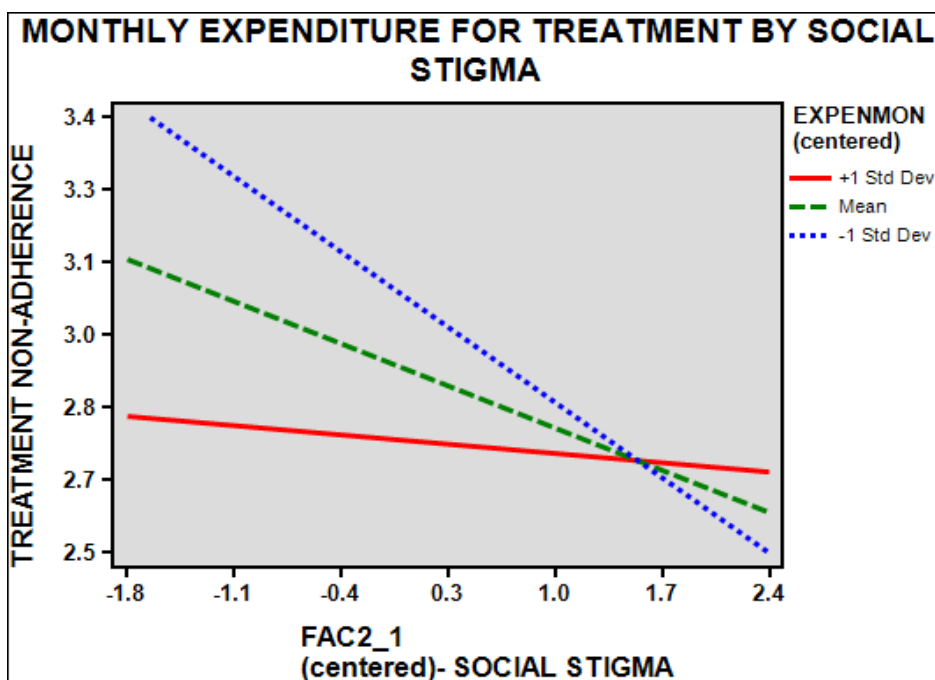
The research model and interaction graph for testing monthly expenditure for treatment by social stigma interaction on treatment non- adherence is given in Table 6.7m and interaction graph 6.7-13 respectively.

**Table 6.7m Research model**

Research Model	$Y = B_1X_1 + B_2D_1 + B_3X_1D_1 + B_0$ <p>Where- Y= Treatment Non-adherence  X1= Social Stigma  D1= Monthly expenditure for treatment  Bo= Regression constant</p>
Model Summary	R Square : 0.063 R Square contribution of the interaction term: 0.011
Model Analysis of Variance	F(df 3,475) = 10.722 P value < 0.000
Model Coefficients	Interaction term b=- 0.001 t= 2.436 P value < 0.05
Effect Size	0.06

The  $R^2$  0.063 indicates 6.3 % variance in treatment non-adherence is explained by monthly expenditure for treatment, social stigma, and monthly expenditure for treatment by social stigma. The  $R^2$  contribution of the interaction term 0.011 indicates 1.1% of the variance exclusively explained by the interaction term. The research model is statistically significant at  $F$  (df 3,475) =10.722 and  $P$  value < 0.05. For the interaction term, the unstandardized regression slope is  $b = -0.001$ ,  $t = 2.436$ ,  $p < .05$ . The coefficient for the interaction term is statistically significant, this implies that the slope that predicts the relationship between social stigma and treatment non-adherence differs significantly between the patients' monthly expenditure for the treatment groups. The effect size of 0.06, indicates, moderate magnitude of the combined impact of the predictors on the dependent variable.

**Interaction graph 6.7-13 Monthly expenditure for treatment by social stigma interaction on treatment non- adherence**



The interaction graph indicates that the slopes at -1 and +1 standard deviation levels of monthly expenditure for treatment, the relationship between social stigma and treatment non-adherence are negative. This shows that for patients with higher monthly expenditure for treatment, the relationship between social stigma and treatment non-adherence is stronger than the patients with lower monthly expenditure for treatment.

The summary of the results of interaction effects is given in Table 6.7n.

**Table 6.7 n Results of interaction effects:**

<b>Dependent variable</b>	<b>Interaction term</b>	<b>Variance explained</b>
Treatment non-adherence	Gender by work compulsions	1.1%
	State by regimen difficulty	2.3%
	Age by social stigma	1.7%
	Monthly expenditure for treatment by social stigma	1.1%
Medication non-adherence	Gender by regimen difficulty	1.1%
	State by social stigma	0.9%
	State by regimen difficulty	1.8%
	State by unaffordability	0.1%
	Age by social stigma	2.8%
	Age by regimen difficulty	1.3%
	Monthly income of the patient's family by dissatisfaction with staff quality	1.1%
Lifestyle modification	Gender by work compulsions	0.9%
	Type of health care facility by work	0.1%

non- adherence	compulsions	
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## **CHAPTER 7**

### **DISCUSSIONS AND CONCLUSIONS**

In the previous chapter detailed analyses and results of the qualitative and quantitative studies and interaction effects are given. This chapter gives details about the key findings and discussions, conclusions of the qualitative study, quantitative study, hypothesis testing and interaction effects, theoretical contribution and managerial implications, limitations of the study and areas for future research.

#### **7.1 FINDINGS AND DISCUSSIONS OF QUALITATIVE STUDY**

Pharma (2011) stated that qualitative insights in adherence are lacking. As stated by NICE (2009) the first step to address the non-adherence issue is to explore the patients' perspectives on non-adherence than to motivate them to take medication. The in-depth interviews and Interpretative Phenomenological Analysis have been helpful in exploring the important themes and items measuring these themes, which were useful in the development of hypothesis and the development of the scales. The qualitative study results have revealed the probable nature and structure of treatment non-adherence. Self-reported, structured, reliable, valid, easy to read, multidimensional scales viz. Determinants of Chronic Disease Treatment Non-adherence Scale (DOCDTNAS) and Chronic Disease Treatment Non-adherence Scale (CDTNAS) have been developed and pre-tested on 107 chronic patients.

#### **7.2 FINDINGS AND DISCUSSIONS OF PILOT STUDY**

Pilot study findings have helped in designing quantitative study related work and selecting the appropriate unit of analysis for quantitative study.

### **7.3 FINDINGS AND DISCUSSIONS OF QUANTITATIVE STUDY**

The survey of 479 outpatients with chronic conditions from Goa and Karnataka has revealed the nature and structure of treatment non-adherence. The factor structure has indicated the perception of patients' towards their non-adherent behavior. Factor analyses have confirmed the construct validity for both the scales. The multiple regression analyses results have demonstrated that different combinations of determinants predict treatment non-adherence, medication non-adherence and lifestyle modification non-adherence.

Regression model has explained 24.2% of the variance in treatment non-adherence. The available evidences indicate that during the last decade (2004-2014), researchers, (Horne et al. 2004; Kondryn et al. 2011; Evans et al. 2012; Banerjee and Varma 2013; Naidoo et al. 2013; Al-Ramahi Rowa 2014; Lemstra and Alsabbagh 2014; and Syed et al. 2014), have mostly quantified the rates of non-adherence and not the variances in treatment non-adherence across diseases. Study findings of 21.2% variance in medication non-adherence varies from and is comparatively higher than variance of 19.5% reported in a cross sectional study in Australia among COPD patients (George et al. 2005). This may be due to the difference in non- adherent behavior of patients with communicable and non-communicable diseases who comprise the sample in the present study. A study among adults from northern Canadian community, found 28% of the variance in medication adherence (Levesque, Li and Pahal, 2012). In the present study, the variance reported in lifestyle modification non-adherence is just 8.3%, but cannot be ignored. Lifestyle non-adherence is a less discussed dimension of non-adherence. The studies by Bisiriyu (2009) and Mumu et al. (2014) exclusively measured lifestyle non-adherence among diabetic patients but did not report the variance in lifestyle modification non-adherence. 19% of the variance in lifestyle modification adherence has been reported in a study with Canadian adult patients (Levesque, Li and Pahal, 2012).

## **7.4 HYPOTHESES TESTING**

### **Treatment non-adherence**

The study findings support hypotheses: H1, H2, H3, H4, H5, H7, and H8. The most significant determinants of treatment non-adherence are identified as: regimen difficulty, lack of external support, dissatisfaction with staff quality, frustration, work compulsions and unaffordability. Confusion to follow complex treatment is associated with treatment non-adherence. This finding is at par with the WHO (2003) report on adherence to long term therapy and a study with Asthma patients in India (Hinchagery et al., 2012). Whereas, in a review DiMatteo (2004) found that regimen had a moderating effect on non-adherence. Lack of external support, dissatisfaction with staff quality, frustration, and unaffordability are the predictors of treatment non-adherence, these results are at par with other research studies by Shuler (2014); Ciechanowski et al. (2001); and Al-Ramahi (2014). Although social stigma emerged as a significant determinant, it is negatively correlated to treatment non-adherence; however, Shuler (2014) found a positive association between social stigma and the treatment non-adherence. The hypothesis H6 is not supported. Inconvenience does not predict treatment non-adherence, may be due to age, rural settings and lack of transport facilities. In contrast to this, Shuler (2014) demonstrated a positive relationship between access to health care and non-adherence.

### **Medication non-adherence**

The study findings support hypotheses H11, H12, H14, H15, and H16. The most significant determinants of medication non-adherence are identified as: social stigma, dissatisfaction with staff quality, regimen difficulty, lack of external support, and inconvenience. Social stigma is negatively correlated to medication non-adherence. Dissatisfaction with staff quality, regimen difficulty, lack of external support, and

inconvenience are the predictors of medication non-adherence. These findings are at par with other studies by Sewith et al. (2004); Doggrell (2010); Ujjinappa et al. (2013); and Mbuagbaw et al. (2012). The H9, H10, H13 hypotheses are not supported. Expensive private health care services, long term treatments, and busy work schedules might have influenced medication non-adherence. Work compulsions, frustration and unaffordability do not predict medication non-adherence, whereas, Mbuagbaw et al. (2012) found a positive association between being busy, forgetfulness and medication non-adherence. Banerjee and Varma (2013) and Adisa et al. (2009), found frustration due to long waiting hours and daily injection of drugs impact non-adherence. Piette, Heisler and Wagner (2004); Hirth et al. (2008) and Doggrell (2010) found out-of pocket cost as a predictor of medication non-adherence.

### **Lifestyle Modification Non-adherence**

The study findings support hypotheses H17, H20, H21 and H24. The most significant determinants of lifestyle modification non-adherence are identified as; work compulsions, lack of external support, frustration and regimen difficulty. These findings are similar to other studies by Mumu et al. (2014), Bisiriyu, (2009) and Shobhana, Rao and Paul (1998). The hypotheses H18, H19, H22, and H23 are not supported. It shows that social, personal, economic and geographical factors do not affect the routine activities such as following diet, exercising, and taking rest, of the respondents. Social stigma, dissatisfaction with staff quality, unaffordability and inconvenience do not predict lifestyle modification non-adherence. Whereas Shobhana, Rao and Paul, (1998) found that social stigma was affecting non-adherence to diet. Bisiriyu, (2009) found that financial constraint, winter season impact lifestyle non-adherence. Banerjee and Varma (2013) found, lack of time and space was associated with lifestyle non-adherence.



When the treatment regimen is complex, the chance of non-adherence is more. This study finding indicates that regimen difficulty is a significant predictor of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence. In a free atmosphere and cordial relationship between patient and doctor, the treatment regimen can be negotiated (WHO, 2003). Therefore, as suggested by Syed and Lynn (2009) the regimen can be streamlined for the purpose of ease and for the reduction the out-of pocket cost to the patient.

The study findings about the associations of lack of external support with treatment non-adherence, medication non-adherence and lifestyle non-adherence are similar to the other studies. Scheurer et al.(2012) in a review of association between different types of social support and medication adherence found that practical social support was associated with medication adherence and have suggested the provision of cost effective practical social support to patients for better chronic disease management. DiMatteo (2004) in a Meta analysis of 122 studies found that practical support affects adherence to medical treatment.

Although social stigma emerged as a determinant having negative correlation to treatment non-adherence and medication non-adherence, its relevance in the changing scenario of chronic diseases cannot be ignored. Other studies have shown that social determinants and stigma were associated with poor adherence (Juvekar, et al 1995; Talam et al., 2008).

The findings of this study also show that unaffordability does not impact on medication non-adherence and lifestyle non-adherence. This may be due to the availability of free medicines and free consultations at public healthcare facilities and patients might have felt lifestyle changes relatively inexpensive. Contrary to this, researchers have identified that patients were not filling the prescription and not following treatment even if it was cost

free ( (Lee, Tseng, & Pan, 2011; Sarna et al., 2008). Majority of the studies have reported poverty and healthcare related cost as predictors of medication non-adherence.

The study findings indicate that one of the most significant determinants of treatment non-adherence and medication non-adherence is dissatisfaction with staff quality. Faith in the doctor impacts on the patients' healthcare seeking behavior (Kumari, Idris, Bhushan, Khanna, Agarwal, & Singh, 2009). Routine enquiry of non-adherence in chronic patients should be performed in clinical practice. As suggested by researchers, Leventhal, Li and Pahal (2012); and Sergei et al. (2013), doctors can play an important role in promoting adherence among patients and thereby improving health outcomes (Cerimagic 2013).

## **7.5 FINDINGS AND DISCUSSION OF INTERACTION EFFECTS**

Gender has interaction effects on the relationships between work compulsions and lifestyle non-adherence; work compulsions and treatment non-adherence; and regimen difficulty and medication non-adherence. The study results show that females with higher work compulsions and higher regimen difficulty have greater treatment non-adherence, lifestyle non-adherence and medication non-adherence respectively than males. Although researchers Sergie et al. (2013) and Talam et al. (2008), have found gender impacting on non-adherence, its interaction effects has not been examined. The only study which examined interaction effect was by Dikokole et al. (2011), and they found that gender had interacted significantly with adherence to Highly Active Antiretroviral Therapy (HAART). Hence, as suggested by Banerjee and Varma, 2013, there is a need for gender sensitive research studies.

State (the place of patient residence) has interaction effects on the relationships between social stigma and medication non-adherence; regimen difficulty and medication non-adherence; regimen difficulty and treatment non-adherence and unaffordability and

medication non-adherence. Patients from Goa with higher regimen difficulties have greater treatment non-adherence and medication non-adherence than patients from Karnataka. This may be due to linguistic and patient-physician communication problems. Patients from Karnataka with lower social stigma had greater medication non-adherence and those with higher unaffordability had greater medication non-adherence than patients from Goa. The patients from Karnataka experienced higher out-of-pocket cost for medication than patients from Goa. Kris Denhaerynck (2006) and Syed et al. (2014) found geographical region as a predictor of non-adherence but they did not examine its moderation effects.

The type of health care facility (public/private) has an interaction effect on the relationship between work compulsions and lifestyle modification non-adherence. Patients seeking private health care facility with higher work compulsions had greater lifestyle modification non-adherence than patients seeking public health care facility. Patients with chronic conditions in working population have difficulties in balancing work schedules and lifestyle modification recommendations.

Age has interaction effects on the relationships between social stigma and medication non-adherence; social stigma and treatment non-adherence; and regimen difficulty and medication non-adherence. Young patients with higher social stigma had greater treatment non-adherence and medication non-adherence than old patients. This result is at par with Horne (1997) which stated that young chronic patients were less adherent than the old patients. It was observed that younger patients wished to keep the sickness and treatment a secret. Another finding is that, patients of all ages with greater regimen difficulty had higher medication non-adherence. However, the impact of regimen difficulty on medication non-adherence was higher among old patients than young patients. Whereas, Sergei et al. (2013) and Leventhal, Li and Pahal (2012) found that older patients were more likely to adhere to medication and lifestyle change than younger patients. Although

researchers Al-Lawati (2014); Sharma et al. (2012); Mandal et al. (2012); and Mumu et al. (2014), have found age impacting on non-adherence, however, its interaction effects have not been examined. In a study of patients with HIV/AIDS, age was found to interact significantly with adherence to Highly Active Antiretroviral Therapy HAART (Dikokole et al., 2011).

The monthly income of the family has an interaction effect on the relationship between dissatisfaction with staff quality and medication non-adherence. Both higher and lower income chronic patients with higher dissatisfaction with staff quality had greater medication non-adherence. However the impact of dissatisfaction with staff quality on medication non-adherence was higher in patients with higher monthly income than the patients with lower monthly income. This indicates that patients irrespective of their level of household income had some expectations from their health care providers.

The monthly expenditure for the treatment has an interaction effect on the relationship between social stigma and treatment non-adherence. Chronic patients both with higher and lower expenditure for treatment with lower social stigma had greater treatment non-adherence. For patients with higher monthly expenditure for treatment, the relationship between social stigma and treatment non-adherence is stronger than the patients with lower monthly expenditure for treatment. This may be due to a variety in sample structure, economic and social determinants that had an impact on treatment non-adherence.

The results indicate that the moderating variables: gender, state (place of residence), type of health care facility, age, monthly income of the family and monthly expenditure for treatment have interaction effects on the relationships between determinants of ‘treatment non-adherence’ and treatment non-adherence, medication non-adherence and lifestyle

modification non-adherence. While patient characteristics have been studied as predictors of non-adherence, their interaction effects have been rarely tested on non-adherence.

## **7.6 THEORETICAL CONTRIBUTIONS**

The contribution to literature in this study is that a number of determinants of treatment non-adherence which are less researched are identified and a number of moderating variables which are adding variances to treatment non-adherence, medication non-adherence and lifestyle modification non-adherence are also identified. The new scales have been developed to measure the ‘treatment non-adherence’ among patients with chronic conditions. The idea underlying the development of these scales was, treatment non-adherence is influenced by multiple factors; and neglecting lifestyle non-adherence, medication non-adherence cannot be a sole concern for the researchers, health care professionals and policy makers. The scales, with their ease in employing, can be applied in the research and clinical fields. The conceptual framework derived from the study is a result of many factors viz. social factors, psychological factors, health system related factors, and economic factors, which may change the focus of non-adherence research. Hence, a multi-disciplinary approach is suggested to solve the non-adherence problem.

## **7.7 MANAGERIAL IMPLICATIONS**

Patient non-adherence leads to poor health outcomes, increases health care cost (American Pharmacists Association, 2013); results in waste and underutilization of available health resources (WHO, 2003). Unless the important and specific determinants of ‘treatment non-adherence’ are not explored and addressed, routine intervention programmes may not be useful.

The scales developed by the researcher will be of specific as well as generic use to medical practitioners and managers of health facilities to measure treatment non-adherence.

Given the prevalence and impact of non-adherence, the study results suggest that considering geographical differences, gender based, age based interventions like; electronic reminders to patients; personal psychosocial counseling to address social stigma related barriers; provision of affordable and patient-centered health care service may help to reduce treatment non-adherence, medication non-adherence, and lifestyle modification non-adherence among patients with chronic conditions.

Worldwide numerous interventions trialed so far, have been shown to improve adherence. The findings of the study will inform the healthcare providers, managers of healthcare facilities, employers, non-government organizations and policy makers to design and implement specific interventional strategies focusing on the determinants of ‘treatment non-adherence’ and specific needs of the patients. The combined efforts to increase adherence and self-management practices can benefit the patients and reduce the burden on healthcare systems.

## **7.8 LIMITATIONS OF THE STUDY**

The study is not without limitations. Being cross sectional in design, the results may not be as appropriate as the results derived from a longitudinal study given that non-adherence occurs over time. Furthermore, data was collected by using self-reported scales; hence, there may be selection bias and response bias which may have a bearing on the accuracy of measurements. The convenience sampling method adopted in the present study may also limit the scope of generalization. This study was not an all inclusive study of all components of medication and lifestyle non-adherence. Only two-way interaction effects of moderating variables are tested.

## **7.9 DIRECTIONS FOR FUTURE RESEARCH**

Non-adherence to chronic disease treatment has not been well investigated and documented in the study population. A longitudinal study, replicating the research with larger sample size will add to the existing knowledge in non-adherence research. Studies exclusively assessing lifestyle modification non-adherence are required to be undertaken. Further studies are required to study three-way interaction effects with additional moderating variables on the associations between the independent and dependent variables.

## **7.10. CONCLUSIONS**

The study is aimed to explore the determinants of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence among patients with chronic conditions.

Qualitative approach and Interpretative Phenomenological Analysis are the effective methods to explore the deeper insights into patient experiences. The qualitative research findings are notable with respect to development of new scales. The uniqueness of the scales is that they measure majority components of treatment non-adherence unlike the existing non-adherence measurement scales.

The quantitative study findings are notable in identifying the determinants of treatment non-adherence, medication non-adherence and lifestyle modification non-adherence and testing the moderating variables' interaction effects.

Both, the qualitative and quantitative study, demonstrated two important aspects of chronic diseases in Goa and Karnataka. First, treatment non-adherence is prevalent among chronic patients and second, multiple determinants are predicting non-adherence. Treatment non-

adherence, medication non-adherence and lifestyle modification non-adherence have been reported among patients with chronic conditions. The variance in treatment non-adherence is high, followed by medication non-adherence and further followed by lifestyle modification non-adherence. This is the first study to report variances in non-adherence and has examined the interaction effects of demographic, geographical, and economic independent variables on non-adherence in study population. Few studies have documented treatment non-adherence among patients with chronic conditions in India especially in the study population.

The treatment non-adherence is higher when regimen difficulty, lack of external support, dissatisfaction with staff quality, frustration, work compulsions and unaffordability are higher and social stigma is lower among patients with chronic conditions. Inconvenience does not impact on treatment non-adherence.

Medication non-adherence is higher when dissatisfaction with staff quality, regimen difficulty, lack of external support, and inconvenience are higher among patients with chronic conditions. Social stigma is negatively correlated to medication non-adherence. Work compulsions, frustration and unaffordability do not predict medication non-adherence.

Lifestyle modification non-adherence is higher when work compulsions, lack of external support, frustration and regimen difficulty are higher among patients with chronic conditions. Social stigma, dissatisfaction with staff quality, unaffordability and inconvenience do not predict lifestyle modification non-adherence.

The study results indicate that, that non-adherent behavior towards treatment, medication and lifestyle modification is a result of many factors viz. social factors, psychological factors, health system related factors and economic factors. The demographic factors like



gender, age; geographical factors and economic factors have explained additional variances in treatment non-adherence, medication non-adherence and lifestyle non-adherence beyond what was explained by the other independent factors.

Adequate management of chronic diseases is complex, requiring long term medication as well as self-management. As reported by Aitken and Volkova, 2013, non-adherence related complications are more expensive than medicines and as per NICE, 2009; non-adherence is a “*hidden problem*”, which is to a large extent solvable. Recent research demonstrates the need for high quality research to identify the psychosocial predictors of non-adherence (Zwikkar et al., 2014; Arias-LLorente et al., 2012). Past research has demonstrated the positive association between interventions and increased adherence (WHO, 2003; Dulman, Sluijs, Dijk, Ridder, Heerdink, & Bensing, 2007; Conn et al., 2009; Ramnath et al., 2011; Aitken and Volkova, 2013). Recent research has suggested the implementation of interventions such as: practical social support (Scheurer et al., 2012); health education and counseling (Iloh et al., 2014; Ramnath et al., 2011); health care team related interventions (Syed and Lynn 2009; WHO, 2003; Leventhal, Li and Pahal, 2012; Sergei et al., 2013) to improve patients involvement in their treatment and thereby improve adherence. Patient non-adherence is not viewed as an important element of public health policy. The public health care policies need to be comprehensive to identify and implement effective interventions to reduce medication non-adherence as well as lifestyle non-adherence. Overall the health care systems should be reoriented to address the challenge posed by the rising chronic diseases as well as prevalence of treatment non-adherence and should aim at fulfilling the patients’ needs, wants and expectations by focusing on care, comfort and convenience at an affordable cost.

A multi-disciplinary approach incorporating patient-centered care is required to improve adherence among patients with chronic conditions who are at risk of non-adherence.

Considering the multiple determinants and moderating variables predicting non-adherence, there is a need to identify individuals vulnerable to chronic diseases and who are at risk of non-adherence and implement effective interventions to enhance adherence customized to the needs of patients with chronic conditions.

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## APPENDICES

### APPENDIX I

#### PATIENTS' NARRATIVES

Patient No.1; Gender: Male; Age: 62 Years; Health related Problem: Diabetes and High Blood Pressure; Duration of Sickness: 15 Years.

Annotations drawn along with transcripts with only patient's narratives

<b>Annotations drawn</b>	<b>Transcripts with only patient's narratives</b>
Public healthcare facility Unaffordability Frustration Long waiting hours Treatment non-adherence No expectations Staff is good Free medicines	<p>My wife is 57 years old. She is also not well. I have two sons.</p> <p>Last fifteen years, I take diabetes and High blood pressure treatments at the Hospicio Hospital. I cannot afford private doctor. More than 100 diabetic patients come on Fridays. Crowd. Waiting area gets flooded with people. It is frustrating. Seating capacity in waiting area is just 10-15 people. I spend at least 4-5 hours for consultation and getting medicines. I wish to stop treatment here.</p> <p>Government hospital, how we can expect cleanliness, cannot. I am not lying, but some staff is good. Staff where tests are done is very good.</p> <p>Everything is free and medicines also. Insulin is very expensive but that is also given free. Doctors are good. They speak in our language, listen, and tell</p>

Dissatisfaction with doctor's empathy	whatever I ask. Doctor has taught me to inject insulin but doctors do not ask anything. Nurses shout and scream.
Medication non-adherence	Sometimes, medicines, I have to purchase. I buy may be 20% of it, because of financial problem. I cannot spend my entire salary on medicines, we have other needs.
Unaffordability	
Medication non-adherence	I take medication both for diabetes and blood pressure and inject insulin myself in time, except if I am travelling and lot of work tension.
Inconvenience	I come home for lunch. I follow the diet to the extent of 90%. Sometimes, I am tempted to eat sweets, rice, and food with salt. Wife yells.
Lifestyle non-adherence to diet	
Adherence to exercise	I exercise as per doctor's advice. I go cycling to the job and to the hospital. I am not well. It is a problem. No bus available. Doctor has advised to be tension free, which is not possible because of personal problems. I have lot of family tensions.
Lack of external support	
Work related problems	Two sons working, but both are alcoholic, not supporting the family. I cannot leave the job, because my family is dependent on me. What to do? At this age, still I have feed my grown up sons.
Family responsibility	My fate.

Patient No. 2; Gender: Female; Age: 78 Years; Health related problem: Cardiac;

Duration of Sickness: 1 Year.

Annotations	Transcripts with only patient's narrative
Physical discomfort	I and my husband both are pensioners. One son stays with us.
Long waiting time	One day, because of some pain and uneasiness, I went to our family doctor. He checked and advised to go to Apollo for second opinion as he suspected heart problem.
Frustration	Next day, I and husband went to Apollo. My god,
Family support	you have to wait and wait for hours to meet the
Staff quality- No good	doctor and he talked for less than five minutes.
Work culture	No personal touch. Staff treated me as a
Dissatisfaction with staff	commodity and not human being plus I am old
quality	also. Some concern for old.
Happy with outcome	When we came to know about operation, my family was worried. I am bold. I knew I will manage. It's a surprise you know, for operation, we have to arrange for blood. Blood donors were arranged with great difficulty. On the day of operation, myself and my family members were mentally prepared for the operation. Money, blood and other arrangements were done. One

Dissatisfaction with staff	nurse informed that the operation was postponed to next day. One has to understand, what the patient the family go through. I was upset. Family members convinced me and the donors.
quality	Nurses were good, But I felt, they were just
Work culture is not good	doing their job. I wanted to know about my treatment. On enquiry, hardly any explanation was give. Once I accompanied my daughter- in-
Expensive health care	law, who died of cancer, to a hospital in Madras. You know, our bad luck, and she expired few
Discontinued treatment	months back. Cancer. That hospital was good, gave all information.
	Ok, I was telling about my operation, successful and I am happy.
	We never thought that the expenditure would be so much. Spent a lot. Fortunately I had taken mediclaim policy, thanks to my relative, who had
Medical insurance	forced me to buy policy. Full amount was not reimbursed. Common man cannot afford this
	medical service. I discontinued that treatment, because of staff attitude and money. Post operation, even for simple check up, they were charging Rs. 500-700. Disgusting.
	So many formalities and too many documents. For mediclaim. The hospital staff should

Medication non-adhere	complete these formalities, why burden the patient's family. One side you are in such a state, and this is another torture. My husband, poor fellow, 82 years old had to do all running around.
Health cautious	Service was good but I will not tell others to go to that hospital, common man cannot afford that service.
Lifestyle adherence to exercise	I strictly followed doctor's advice, as we had spent heavily. Took medication as prescribed only for the heart ailment and not for fever, strength
Lifestyle non-adherence to rest	etc. I bought the medicine but did not take.
Lack of external support	Post operation I am fit and fine. I did not continue the treatment.
Hospital tangible	I am bothered about my health.
Dissatisfaction with food quality, staff quality	After operation, doctor told to take rest for at least 15 days. I could not take rest. I had to do all house-keeping work, earlier my daughter-in-law used to manage. I used to help her. At this age, I have to cook.
Frustration	Let it be. Hospital is clean, decor is good, and they are charging for that. So it should be clean.
Negative behavioral intensions	No crowd, maintenance may be possible. All facilities are available.
	Food was very bad. No taste. Even after complaining, food was the same. Good food is

	<p>required to get strength. Food was not eatable. No proper ventilation in ladies ward. It's dark. If alone, it is scary. Post operation, when shifted to ladies ward, doctor did not enquire in detail. He would come, see records, talked to nurses and go.</p> <p>On the day of discharge, I am old, doctor did not even ask who will care for me, how I will manage etc. But he started asking about my husband when he is getting admitted, because he came to know my husband also has heart problem. It was very disgusting. We have decided, even for my husband, not to go to that hospital again.</p>
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Patient No.3; Gender: Female; Age: 50 Years; Health related problem: Cancer; Duration of Sickness: 2 Years.

Annotations	Transcripts with only patient's narrative
Lack of external support	<p>I am married but no children. Husband is working. I was getting pain, months together, I was avoiding going to doctor. Tried home remedies. One day, I was getting ready to go for job, started getting severe abdominal pain; unable to pass urine. How I manage to go to hospital, I only know myself. Got admitted in the hospital</p>



<p>No proper information</p>	<p>without anybody's support. Later some relatives came. I was told that I am operated for removal of fibroids and uterus. I had to stay in the hospital for eight days. I realized that my family and relatives are not bothered about me. At the time of discharged, I asked the cause of my sickness. It was not disclosed to me.</p>
<p>Social stigma</p>	<p>Few months later, I started getting severe headache, vomiting and ear pain. I consulted many doctors. At Goa Medical College and Hospital, I was been told that there is tumor in brain and operation is a must. Next day I was successfully operated. Later, it was diagnosed as</p>
<p>Keeping sickness a secret</p>	<p>cancer.</p> <p>I did not want to tell the cause of sickness to anyone other than my husband and sister.</p>
<p>Avoiding social contacts</p>	<p>Chemotherapy was started. I became bald. I am bothered about social stigma. I am avoiding my colleagues, friends and relatives. Post operation and recovery, doctor advised to go for a walk.</p>
<p>Lack of external support</p>	<p>But cannot, who has time to accompany me.</p>
<p>No care taker</p>	<p>I do not have a caretaker. Husband is busy with</p>

Affordability	his job and other activities. Now I realized that my family and relatives are avoiding me. I do not remember, whether I have taken medicine. I may be missing some doses. Who knows? I do not want to be a burden on others.
Regimen difficulty	I am working and earning sufficiently. I am on
Lifestyle non-adherence to exercise	sick leave. I do not have financial problem. I need a caretaker, a nurse, a maid. At present, I have a
Lack of external support	problem of a home. So to say, I have a big family. Nobody volunteered to give me shelter. I am at
Present health status-bad	my mother's place. She is very old. Now I can not follow the regimen. I am confused
Importance of health service	about the doses of medicines. I am told to do some exercises. I am unable to do myself. I need support. I have helped many people in life. But today, I feel, I am alone and helpless. My health condition is very bad. I understood the importance of good doctors in my life. I wanted to take second opinion from a doctor in Mumbai. Nobody accompanied me. I had taken appointment on phone. I could not take that treatment.

Patient No. 4; Gender: Female; Age: 69 Years; Health related problem: Tuberculosis, Arthritis, Dermatological problems; Duration of Sickness: Arthritis and dermatological problem- 7 Years, TB - One Year.

Annotations	Transcripts with only patient's narrative
<p>Multiple health problems</p> <p>Financially independent</p> <p>Home remedies</p> <p>Social stigma</p> <p>Long duration of treatment</p> <p>Keeping treatment a secret</p> <p>Treatment adherence</p> <p>Positive outcome</p> <p>Dissatisfaction with staff quality</p>	<p>We are four in the family. My son, his wife and his son. I am doing all my routine work. So far not dependent.</p> <p>I have many health related problems, legs pain, skin problem, cataract but I am strong. I get my husband's pension. I am independent. Especially, I won't want to be dependent on my daughter- in- law as far as possible. Future who knows?</p> <p>Last year, I was sick with cough and fever. I tried home remedies. I consulted a doctor. It was diagnosed as tuberculosis. I was scared, some years back, my sister-in-law had expired of Tuberculosis. Doctor said I will be cured completely, provided I take three months treatment. I told only my daughter and son. We decided not to disclose this to my daughter in law because she may ill treat me. I was bothered of people. I avoided social contacts, giving excuse of sickness. I know this disease,</p>

<p>Medication adherence</p> <p>Inconvenience</p> <p>Dissatisfaction with staff quality</p> <p>Lack of external support</p>	<p>what you say I don't know, but from me others can get. I strictly followed doctor's advice.</p> <p>Now I am cured. Actual doctor should tell what will happen if you do not take medicines in time. They are not bothered. For arthritis and dermatological problems, I consult an Ayurvedic doctor. I like to eat good food. I don't miss a single dose rather sometimes I take overdose than prescribed. I want to live longer. As long as possible, I want to be healthy. I don't want to trouble my son.</p>
<p>Unaffordability</p> <p>Discontinued treatment</p>	<p>I always keep the stock of medicine because my house is little away from the city. It is very inconvenient to visit the doctor. I don't go to Government Hospital, as I know, at Government hospital, doctors are not caring and the surroundings are very dirty.</p> <p>I do not do diagnostic tests in time because of financial problem, transport problem and I do not want to request people for help. My son hates to take me to the doctor and wait. Some treatments I have discontinued. For my skin problem, I do not take tablets, only use ointment. Hospital is far away. Doctor's</p>

	charges are very high. I have kept the prescriptions. I bring the medicine from the pharmacy, avoid going to the doctor.
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Patient No.5; Gender: Male; Age: 54 Years; Health related problem: Diabetes, piles, liver problem; Duration of Sickness: diabetes- 5 Years, piles – 5 Years, Liver problem- 2 years.

Annotations	Transcripts with only patient's narratives
<p>Many health problems</p> <p>Non-professional health care service</p> <p>Discontinuation of treatment</p> <p>Free service</p> <p>Satisfied with service quality</p> <p>Expensive service</p> <p>Discontinuation of treatment</p> <p>Lifestyle non-adherence to rest</p> <p>Work related problems</p>	<p>I have a wife and two children. Daughter has married. For diabetes and piles, I was taking medicines given by quacks from Miraj and Kerala. Only temporary relief.</p> <p>Last month I felt weakness; feet were slightly swollen and started omitting. Forcibly, son took me to a general practitioner. Listening to my medication history, she was shocked and asked me to discontinue the quacks treatments immediately and referred to a doctor at Marmgoa Port trust hospital, as I am a MPT employee. I am taking treatment for Jaundice and diabetes. MPT medical service is free, only few medicines were bought from outside for first two days. Doctor again sent me for some</p>

Medication non-adherence	<p>tests to another hospital. There we had to spent lot of money. Next time, I will not go there.</p> <p>MPT service is very good. Doctor has advised for another eight days rest. But I had to go to work. Earlier I used to get night shifts and I used to avoid medicines and could not follow diet. Now since mining is stopped, there is no work, just be physically present at work place.</p> <p>I still feel the weakness, don't feel like eating food. Wife is forcing me to follow diet. I like</p>
Beliefs in black magic	<p>spicy food. I am fed up of treatment, taking medications and following diet. In the absence of my wife, I skip the doses of medicines.</p> <p>My family believes, somebody has done some black magic on me. I believe in Ghadpan and I often go to various places.</p>

Patient No. 6; Gender: Male; Age: 30 Years; Health related problem: Chronic back and stomach pain; Duration of Sickness: 1 year.

Annotations	Transcripts with only patient's narrative
Private consultation Unaffordability Satisfied with doctor's quality	<p>My family, my wife and two daughters. From Last year, I was suffering from Fever and back pain. We went to a private doctor known to us. Minor operation was done. Some fluid from</p>

Work related problems	the back was removed. Knowing our financial problems, doctor did not charge anything. Doctor is very nice.
Family responsibility	I am very irregular for my job, salary is deducted. I have two daughters. I am worried. My wife has started working at the same
Medication non-adherence Not filling prescription in time	hospital. I am grateful to the doctor for employing my wife. I take medicines, if available at home. I buy
Lifestyle non-adherence to diet	few tablets at one time depending upon how much money I have. Vegetables are so costly; I don't follow the diet as doctor suggested.
Unaffordability	Last month I started getting stomach pain. Again I was taken to the same doctor. She
Free service	referred to a specialist. I had no money to take specialist treatment. I could not follow treatment. As suggested by my friend (co-worker), I consulted a doctor at Employees State Insurance hospital, Belgaum, because of the free service. He referred me to a specialist at Employees State Insurance hospital, Bangalore.
Linguistic problem Discontinuation of treatment	I was admitted to Employees State Insurance hospital in Bangalore. Anyhow, we managed to stay for four days. We told the doctor our

Lifestyle non-adherence to rest	financial, leave, loss of pay and linguistic problems. He had a telephonic conversation with a doctor in Belgaum and he suggested continuing the treatment at Employees State Insurance hospital in Belgaum. I did not go for treatment in Bangalore. I joined my duties. I cannot afford rest. In case of unbearable pain, I consult the doctor. My wife is taking lot of trouble for my family. She manages house-keeping work, children's education, stitching clothes and job. My wife takes all the decisions, which I do not mind. I am worried about my family. Doctor has advised me to stop eating gutka. Sometimes, because of temptations, I eat gutka.
Work related problems	
Social support	
Temptation	
Tobacco use	

Patient No. 7; Gender: Male; Age: 35 Years; Health related problem: Liver Problem; Duration of Sickness: 1 year.

Annotations	Transcripts with only patient's narrative
Public health care facility	I may be 34-35 years old. Have two young children. Wife is a house-keeper. Who will look after them? Family is dependent on me.
Alcohol consumption	At my native place, a village, I started getting stomach pain. I went to the Primary health



Medication non-adherence	center. Doctor was good. He may be an Ayurvedic doctor. I was referred to a doctor at Belgaum. Doctor advised me to give up completely alcohol consumption. Gave some tablets. I felt risky to take that medicine .I did not take that medicine.
Doctor explained- non-adherence	
Medication non-adherence	Next day, we came to Goa; I consulted a doctor at Bambolim Hospital. Doctor explained about my sickness and told to follow all his instructions and the dangers also, if I do not follow.
Did not follow Scheduled visits	
Unaffordability	
Inconvenience	Not possible to go to the doctor as per his advice because of fear of loss of pay, work tension, transport and other expenditure.
Dissatisfaction with continuity of care	Hospital timings are not convenient. I go for checkup if needed. Each time I go to GMC, the doctor on duty is not the earlier doctor. Why do not they put same doctor? I purchase the costly medicines just enough for four days.
No filling prescription in time	
Family responsibility	
Alcohol consumption	
Peer group pressure	
Work related problem	I have given up alcohol consumption. At the place of work, co-workers pressurize for alcohol use. I want to leave Goa and want to work In Belgaum. I used to consume 10 sachets of gutka, now reduced to two or three
Tobacco consumption	
Lifestyle non-adherence to diet	

Spiritual support	sachets a day. In spite of being sick, I go to work. I am a daily wage earner. On work, cannot follow diet and forget to take medicine  I cannot give up eating non-vegetarian food. I cannot digest non-vegetarian food but still I am tempted to eat. Doctor told to eat particular type of food, vegetables and fruits. We rarely buy fruits, not affordable to poor, no question of eating. With god's grace and doctor's help, I am ok. I avoid taking medicines because they are very costly. The test charges are also very high.
Medication non-adherence	
Avoid taking medicine	
Medicines are costly	

Patient No. 8; Gender: Female; Age: 25 Years; Health related problem: HIV/AIDS;  
Duration of sickness: More than 1 year.

Annotations	Transcripts with only patient's narrative
Health cautious	I am 25 years old, married last year. No child. It is a joint family.
Public health care facility	I had fever and omitting. I was very much concerned about my health. We were on holidays at our native place. I went to the
Inconvenience	Primary health center. It was a night time. We
Not accessible by public transport	had to walk quite a distance. The location of the Primary health Center is not convenient. It is not

Work culture not good	<p>accessible by public transport. Doctor was not available. Nurse gave some medicine. I asked the nurse the side effects of the medicine. She said no side effects. Still I had a doubt. If doctor was there, it would have been good. I was very much worried. I took only two tablets. I did not take remaining medicine and never went there.</p> <p>No cure. I started coughing. Next day went to another doctor in Belgaum. Blood tests were done. It was diagnosed as HIV/AIDS. Doctor referred me to a specialist. Doctor explained the cause of sickness and the proposed treatment.</p> <p>Doctor gave me confidence to face the situation.</p> <p>Hospital staff is very cooperative. Work culture is very good.</p>
Doubt of professional competence	
Medication non-adherence	
No positive outcome	
Satisfied with doctor's quality, staff quality, work culture	
Sickness as a secret	
Social stigma	
Work related problems	
Medication non-adherence	
Skip the doses of medicine	
Do not keep the scheduled visits	
No Diagnostic tests in time	
Feeling of no necessity of	<p>I skip the doses of medicine. Medicines are costly. I do not visit the doctor. I am worried about family's and neighbor's enquiries.</p>

treatment	I do not do tests in time.
Avoid social contacts	I feel it is not required at this stage of my illness.
Risk perception	
Frustration	We want to leave this place, Stay away from the family, relatives and friends.
Lifestyle non-adherence to diet	Doctor told not to worry and told to follow his treatment for some years. I do not know how I will manage. It is risky, but I eat whatever I want.

Patient No. 9; Gender: Male; Age: 29 Years; Health related problem: Epilepsy; Duration of Sickness: 4 years.

Annotations	Transcripts with only patient's narrative
Lack of external support	I stay along with my parents and one brother. Mother sells fish. Father is alcoholic. My parents are not bothered about me.
Long term sickness	
Medicines are costly	I am having this problem from childhood. Few years back, I met with an accident. From that time, very often, I faint. I am consulting a doctor at GMC Hospital, Bambolim. Medicines are very costly. For cold, fever etc. I even take the medicine of others.
Regimen difficulty	
Medication non-adherence	
Lifestyle non-adherence to exercise	

<p>Dissatisfaction with doctor's quality, staff quality</p>	<p>I get confused to follow medication and do exercises, so I miss the doses. At hospital, not much of waiting time. Doctor does not listen to me carefully. He only nods his head. Nurses and other staff are least bothered. Only few medicines are given free, rest I buy.</p>
<p>Work related problems</p>	
<p>Medication non-adherence</p>	
<p>No care taker</p>	
<p>Social stigma</p>	<p>Earlier I was a tempo driver. I had to leave that job. At present, I am working as a peon.</p>
<p>Sickness as a secret</p>	
<p>No filling prescription in time</p>	<p>I have to work, although sick. There is nobody to look after me. I do not want to carry medicines to my place of work. During working hours, I do not take medicine.</p>
<p>Unaffordability</p>	
<p>Regimen difficulty</p>	
<p>Lifestyle non-adherence to exercise</p>	<p>Employer does not grant leave to go to the doctor. I do not want to disclose my sickness to my employer and colleagues.</p>
<p></p>	<p>I cannot afford to buy entire course of medicine.</p>
<p></p>	<p>I am confused to follow the treatment regimen. I am busy and do not remember which exercise, how and when to do. Long time back, doctor showed only once.</p>
<p></p>	<p>Therefore exercising is not possible.</p>

Patient No. 10; Gender: Male; Age: 58 Years; Health related problem: Hypertension;  
Duration of Sickness: 4 years.

Annotations	Transcripts with only patient's narrative
Ayurvedic consultation	I am working. Wife is working. I have two children.
Medication non-adherence	I have high blood pressure and some related problem. I consult an ayurvedic doctor. I take the
Work related problems	medicine as per doctor's advice. My blood pressure is in control. Sometimes, because of busy schedule,
Forget to take medicine	I miss doses of medicine.
Lifestyle non-adherence to diet and exercise	I am advised for a normal diet with minimum salt, tension free life and change the life style. Changing
	lifestyle is not a one day job. I have some mental
	tension. Doctor says it will develop more health related problems. I am not very particular about
	exercising and diet as per doctor's advice. If I am in mood, I go for morning walk and do some
	exercises. But it is ok.
Non availability of medicine	The medicine is not available at all pharmacies. I keep the medicine quota for three months. Doctor
Doctor's fee Reasonable	purchases the medicine on our behalf and informs the patients to collect it. Fees are very reasonable.
Satisfied with doctor's quality	Doctor is very generous and available during emergencies.

Advice to Discontinue the Treatment	<p>Many of my friends and relatives told me to discontinue ayurvedic treatment because results are slow. People want instant and fast relief. One has to do comparative study of allopathic, ayurvedic and homeopathic treatments, in terms of cost, nature, time and cure. Then one will come to know ayurveda is best. I am very satisfied for medical outcome.</p> <p>I always recommend my doctor to friends and relatives, colleagues.</p>
Positive outcome	
Positive behavioral intentions	

Patient No. 11; Gender: Male; Age: 55 Years; Health related problem: Cardiac, Piles;  
Duration of Sickness: 4 years.

Annotations	Transcripts with only patient's narrative
Multiple health problems	<p>I am 55 years old and I have a big family to look after.</p> <p>I have multiple health problems. I am elder son, old parents, and bad financial position. I am only earning member. Past many years, I have consulted many doctors, and spent a lot on my treatments.</p> <p>For my cardiac problem, I consulted many doctors in Goa and Bombay and finally Open Heart surgery was done at KLE's Hospital,</p>
High cost of treatment	
Unaffordability	
Financial difficulty	

Mediclaim Insurance	Belgaum.
policy	I spent Rs.1, 75,000; it was minimum amongst
Reimbursement of medical	the doctors consulted. Lot of difficulties to
expenditure	raise the finance. Got money back from
	insurance company. Not all money.
Positive outcome	Post operation, very few medicines were
	prescribed. Check up once a year.
	Now I am fine. Doctor has advised not to lift
Financial burden	any heavy things beyond 5 kgs., not to do any
	hard work. That I follow.
	For poor and middle class people, heart
	problem means financial burden and poverty.
	To my bad luck, Last year, piles problem again
	started. I had this problem in 2001, which was
	cured at that time. I consulted a doctor, he said,
	open heart surgery patient cannot be operated
	for piles. Luckily, my friend took me to a
Dissatisfaction with staff	doctor in Bicholim. Hospital staff should
quality	convince and instill confidence to face the
	situation. Operation was successful. I spent
	approximately Rs.35, 000. Now I am on strict
	diet. At this hospital, I was not happy with
	nurse service.
	I would like to advise people that one must
	enquire about Government facilities. Now



<p>Work related problems</p> <p>Family responsibility</p>	<p>days, at government hospitals, majority of health care services are available. For major health problem, one must consult at least two or three doctors.</p> <p>I have suffered a lot. But I did not get scared of operations. My entire family is dependent on me. Therefore, in spite of being sick, I had to join my job, could not take sufficient rest. I have to remain healthy to look after my family.</p>
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Patient No. 12; Gender: Male; Age: 50 Years; Health related problem: Diabetes;  
Duration of Sickness: 3 years.

Annotations	Transcripts with only patient's narrative
<p>Leave the Job</p> <p>Frustration</p> <p>Fed up of treatment</p> <p>Regimen difficulty</p> <p>Stopping treatment</p> <p>Social support</p> <p>Unaffordability</p>	<p>I stay with my son. It is a family of five members. I was working in a factory. I was injured on the machine. The wounds were not healing. Blood tests were done. I am suffering from diabetes. Some months I took ayurvedic medicine. Lot of difficulties in preparing, taking medicine and eat this, don't eat that. Could not do, I stopped the treatment</p> <p>Because of amputation of a leg, I have left the job. I am bed ridden. My wife is looking after me. I have got bed sores. My son is working in</p>

No option than to go to public health facility	the factory. He is single earning member.
Free treatment	Sometimes, I need hospitalization at Employees State Insurance Hospital, Belgaum.
Dissatisfaction with staff quality	Since, the treatment is free, at the hospital, nobody is bothered. Hospital staff is not good.
Medication non-adherence	Work culture at the hospital is not good. If we were financially sound, we would have taken treatment with the private doctor.
Lifestyle non-adherence to diet	
Treatment non-adherence	I have become a burden on my son. I take lower doses of medicines. I cannot follow the treatment completely. Diet cannot be followed. Whatever food is available, I eat.

Patient No. 13; Gender: Female; Age: 60 Years; Health related problem: Asthma; Duration of Sickness: 5 years.

Annotations	Transcripts with only patient's narrative
Inconvenience	<p>My age may be 60 years. I am a widow. Son is in Army. Here, myself, daughter- in- law and my son's children stay.</p> <p>I take medicine because there is no option. Do not get sleep. I get some relief and next day same condition. I go to Primary health centre twice a month to get medicines. The primary health center is away from the village. I find it</p>

<p>Unavailability of doctor</p> <p>Seasonal variations</p> <p>Work related problems</p> <p>No care taker</p> <p>Lifestyle non-adherence to diet</p> <p>Not concerned about health</p> <p>No family responsibility</p>	<p>difficult to walk that distance. Problem to get medicines. Who will bring for me? Many a times, doctor is not available. Looking at case paper, nurse gives medicine. In winter and rainy season, my condition becomes worse. I am unable to do any agricultural work. My family members are not bothered about me. I am deserted by my family. I eat the food, which is served to me. I do not know, whether I am following diet.</p> <p>In this condition, I do not want to live longer.</p> <p>I don't have any responsibilities.</p>
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Patient No. 14; Gender: Male; Age: 70 Years; Health related problem: Cancer;  
Duration of Sickness: 2 years.

Annotations	Transcripts with only patient's narrative
<p>Unavailability of doctor</p> <p>Medication non-adherence</p>	<p>I was a healthy person. During my entire life, hardly went to doctor. Sometimes I am sick with fever, cold, stomach upset, back pain etc. Last six months, I am having severe back pain; I went to the Primary Health center. Doctor is usually not available in the Primary health center. Nurse gives some medicine. They usually give medicine for three or four days. I</p>

No necessity of medicine	take medicine till I am ok. Usually I take medicine for a day. Once I feel better, I stop taking medicine. If you are fine, why take medicine for no reason? Why follow everything, whatever doctor says? I never follow, whatever doctor tells. Too many medicines are not good for health.
Unaware about the disease	Now I am helpless, this pain is unbearable. I was taken to a doctor at Belgaum. Blood tests, x-rays and scanning were done.
Discontinuation of treatment	I do not know what is wrong with me. I have lost the hope, because I feel I will not recover from this sickness.
Unaffordability	I am a pensioner. Very less amount. Daughter pays doctor's fees but no cure. What is the use? I feel bad, disappointed. I have discontinued the treatment.  Doctor has told to eat everything, but I do not feel eating.

Patient No. 15; Gender: Male; Age: 60 Years; Health related problem: Lung cancer;

Duration of Sickness: 4 years.

Annotations	Transcripts with only patient's narrative
Non-professional	I may be 59-60 years old. I have two sons and

consultation	one daughter. One son and daughter are married.
Positive outcome	I always consult a doctor who is practicing at my village. People say he is not a doctor. I am not bothered. We get good outcome with his medicines. He knows every person from our village. There is credit facility also. Doctor told me smoking and consuming alcohol is not good for health. This even I know. My bad habits are creating problems at home, so I want to control alcohol consumption but I will not give up smoking.
Satisfied with doctor's quality	
Tobacco and alcohol consumption	
Willingness to give up alcohol consumption but not smoking	
Social support	I take medicines whichever is given by my son and wife.
Regimen difficulty	I am illiterate; I do not understand what doctor told about medicines. I do not know which medicine to take. Doctor has told me to eat less pungent and less spicy food. I cannot change my food habits. I like spicy and very pungent food.
Lifestyle non-adherence to diet	
Unaffordability	Do not smoke, no alcohol, no good food, then how to survive? At present, I am feeling ok. Doctor told to show a big doctor from the city. I do not have that much money. Going to city means, I will have to spend for transport, food,

<p>Medicines are costly</p> <p>Medication non-adherence</p> <p>Non-availability of medicines</p> <p>Work related problems</p> <p>Financial burden</p>	<p>doctor's fees, tests and buying medicines. Therefore I am postponing going to city doctor.</p> <p>My son- in law came to know about my sickness and took me to the city doctor. Tests and x-rays were taken. He told my son-in law something, which I did not understand. I came to know something is seriously wrong. Now treatment is given for a month. I am back to my village. I get temporary relief with medicines.</p> <p>Son was saying, medicines are very costly, therefore, whatever medicines has been purchased and available, is given to me and not all. No pharmacy in the village. I was working on daily wages. I go to work, whenever I feel ok. If my health condition is very bad, then only, I avoid going to work. If I am unable to work fast, employer shouts. He has instructed me, not to come for work, in case I am unable to work. My family is facing lot of financial problems because of my sickness. I feel bad, because of sickness, son is not marrying. I requested my son to stop the treatment. If I die early, my family will be relieved from tension and my son may marry or he will be overage for the marriage.</p>
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Patient No. 16; Gender: Female; Age: 65 Years; Health related problem: Arthritis, High Blood Pressure and cataract; Duration of Sickness: More than 5 years- Arthritis, Blood pressure-2 years, Cataract-1 year.

Annotations	Transcripts with only patient's narrative
No social support other than spouse	I and my husband both are senior citizens, we stay in our village. Children are married. Sons are working and staying in cities. Husband gets pension and one son supports financially. We are the caretakers for each other and nobody else.
Medication non-adherence Multiple medicines	Last 4-5 years I am taking treatment for arthritis from a specialist. He prescribed lot of medicines, half of which I took. Showed me some exercises and told to go for walk for at least 30 minutes a day. Not to sit down by folding legs. In villages, majority of
Lifestyle non-adherence to exercise	the house-keeping work is done by sitting down, which I cannot avoid. We spend around Rs.1200.
Work related problems	No cure. I went for walk for two days. In villages, how it is.
Unpleasant enquiries	People started asking me, why, what and so on. I was annoyed. Therefore, I stopped.
No necessity of exercise	I feel whatever housework I do is enough. Exercises are not required. Doctor told that I have to take
Medication non-adherence No necessity of taking	medicines for the rest of my life and there is no permanent cure. Then why take medicine? I skip the

<p>medicines</p> <p>Skip the doses of medicine</p> <p>Medicines are costly</p> <p>No concern for health</p> <p>Forget to take medicine</p> <p>No positive outcome</p> <p>Medication adherence</p> <p>Short term treatment</p> <p>Lifestyle non-adherence to rest</p> <p>Demand for additional services at primary health center</p>	<p>doses of medicine. Medicines are costly. Whenever, knees pain, I take medicine for some days, if that medicine is available or I go to the local Primary health center. The doctor or nurse, whoever is available, checks and gives medicine. I manage with this medicine. Whenever my husband goes to city, brings medicines.</p> <p>I am not much bothered about my health. Mostly I forget to take medicine. That is ok. Whenever medicine is over, husband brings from the primary health center. My knees pain very badly. Day by day it is becoming worse.</p> <p>Last week, cataract operation was done in one eye. Now I can see properly. Good service but canteen should have been there. I took medicines, because it was for only for some days. Husband does not know cooking. Doctor told not to cook at least for 15 days on Chula because of smoke. Neighbors gave food for eight days. After 8 days I started cooking. Doctor had also instructed not to watch TV and avoid direct sunlight for some days that I followed.</p> <p>Eye checkup, sugar level check up should be there at Primary health centers at the villages. Villagers cannot afford to go to city hospitals.</p>
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Patient No. 17; Gender: Female; Age: 43 Years; Health related problem: Psychiatric;

Duration of Sickness: More than 4 years.

Annotations	Transcripts with only patient's narrative
<p>No care taker</p> <p>Lack of social support</p> <p>Frustration</p> <p>Fed up of sickness</p> <p>Home remedies</p> <p>Consult many doctors</p> <p>Social stigma</p> <p>Unaffordability</p> <p>Buy but do not take medicine</p> <p>Medication non-adherence</p> <p>Side effects</p> <p>Work related problems</p> <p>Lifestyle non-adherence to exercise</p> <p>Social stigma</p> <p>Treatment non-adherence</p>	<p>I stay with my parents and sister. They do not like me. They do not support me. I want to work. Nobody is employing me.</p> <p>I am fed up of this sickness. For years, I am doing home remedies as well as I take medication from local doctor, but of no use. He does not even listen to me; I do not take his medicine. Since neighbors were enquiring, mummy stopped my treatment. Now we go to Bambolim hospital. Sometimes I am hospitalized. I consult many doctors. I have no money to buy medicine. Sometimes I buy the medicine but I do not take it. I avoid taking medicine because I feel sleepy the entire day.</p> <p>My parents are not allowing me to go for work but I have to do all the house-keeping work, even if I am not well. I do not want to take treatment and live here. I want to stay in hostel.</p> <p>Doctor told to do yoga .Such difficult, my god. I do not remember those exercises. Even if I try something, body pains, I do not like, and will</p>

Spiritual healing	<p>not do. I am completely alright but my mother feels I am sick. I do not want others to about my sickness. Forcibly, my mother takes me to the doctor. I do not follow the doctor's instructions.</p> <p>I go for spiritual healing.</p>
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Patient No. 18; Gender: Male; Age: 48 Years; Health related problem: Nephrological Problem; Duration of Sickness: 1 year.

Annotations	Transcripts with only patient's narrative
Work related problem	I have wife and three children. Few months back daughter got married. I am a single earning member in a family of five members. I am a tour operator. I go to office every day, even on Sundays.
Self medication	I used to get abdominal pain and problem in passing urine. I did not tell it to family members.
Poor group advice	Season time, so avoided going to the doctor.
Medication adherence	Took medicines as suggested by friends, drank beer every day. It did not help.
Convenience	I went to a local doctor. Took medicines but I was postponing diagnostic tests. Finally, I had to do tests. It was diagnosed as kidney stone and related problem.
Referral	
Satisfied with staff	One of our relative is a doctor at KLE Hospital,

<p>quality</p> <p>High medical expenditure</p> <p>Good work culture</p> <p>Lifestyle non-adherence to diet and rest</p> <p>Forget to take medicine</p> <p>Positive outcome</p>	<p>Belgaum. I was shifted to Belgaum. After two days I was operated. At KLE Hospital, everything is good. Location is convenient. Local transport also is there. Hospital staff is very cooperative. Service is expensive. For a good service and positive outcome, one has to spend. I do not know, I was well treated because of my relative working there or may be the work culture is good.</p> <p>I followed the diet for a very short period of time. My work is such, many a times I eat out. Therefore I cannot follow strict diet. I cannot afford to stay at home for rest.</p> <p>I forget to take medicines. Doctor has told me to take a tablet thrice a day, I take once or twice. But now I am completely alright. If I am unwell, I do not tell anybody at home.</p>
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## APPENDIX II

### THE LIST OF INDEPENDENT ITEMS AND DEPENDENT ITEMS

1. There is a long queue at the hospital/clinic to meet the doctor.
2. I perceive lot of risk in the treatment.
3. I am not concerned about my health.
4. The location of the Hospital/clinic is not convenient.
5. Medicines have side effects.
6. The responsibility of the entire family is on me.
7. I am bothered of social stigma
8. My doctor does not listen to me.
9. Hospital is not so good.
10. Exercising is boring.
11. I am more concerned about the health of others in the family.
12. I think everything is fine with me.
13. I feel diagnostic tests are unnecessary.
14. I feel I am cured.
15. I always consult more than one doctor.
16. I do not want to carry medicines to my place of work.
17. Hospital staff is not cooperative.
18. I want to keep my treatment a secret.
19. The hospital is not accessible by public transport.
20. I cannot leave the job, although sick.
21. My family members do not bother about me.
22. The hospital timings are not convenient.
23. I have to do the work, although sick.

24. The work culture of this hospital is not good.
25. Money is required for other pressing needs.
26. Regimen is not easy to follow.
27. Hospital is crowded.
28. The food habits are difficult to change.
29. Doctor does not know my health status.
30. Doctor does not instill confidence.
31. I have to work because people are dependent on me.
32. I am forgetful.
33. Food is tempting.
34. I have lot of tensions.
35. I do not want others to know about my sickness.
36. Regular exercising is not possible.
37. The doctor's charges are not affordable.
38. The diagnostic tests charges are not affordable.
39. I am fed up of taking treatment.
40. I depend on self medication.
41. I have more than one health problems.
42. I am not happy with the outcome of the treatment.
43. I do not get support from my family and friends.
44. I am confused about the doses of medicine.
45. I do not have a caretaker.
46. Hospital/clinic does not have the necessary health care facilities.
47. Medicines are costly.
48. The doctor did not explain the dangers of treatment non-adherence.

## THE LIST OF DEPENDENT ITEMS

1. I do not like to go to the doctor.
2. I have discontinued the treatment.
3. I take medicines prescribed for others.
4. I take a higher dose of medicine.
5. I eat whatever I want.
6. I do not buy the medicines.
7. I cannot stop consuming alcohol.
8. I cannot give up eating gutka.
9. I am not following scheduled visits to the doctor.
10. I take lower doses of medicine than those prescribed by the doctor.
11. I am not exercising as instructed by the doctor.
12. I did not do diagnostic tests as prescribed by the doctor.
13. I postpone the tests.
14. I go to the doctor whenever I am very sick.
15. I avoid taking medicine.
16. I brought medicine, but do not take it.
17. I skip the doses of medicine.
18. I am not taking rest as advised by the doctor.
19. I do not fill the prescription in time.
20. I do not take the medicines prescribed.
21. I am not following the diet as recommended by the doctor.
22. I do not exercise regularly.

## APPENDIX III

### INTER RATER AGREEMENT

#### EXPERT RATING DOCUMENT FOR INDEPENDENT ITEMS

Kindly categorize each item into a category closest in meaning by putting(X) mark in the appropriate box.

**Research area:** Determinants of chronic diseases treatment non-adherence among consumers of health care services.

The brief meaning of the determinants of treatment non-adherence:

#### 1. **Treatment non-adherence**

Treatment non-adherence is referred to as all degrees of patient non-conformity to prescribed medication and/or lifestyle modification related recommendation by the doctor.

#### 2. **Work compulsions** – Compulsions to continue work, although sick.

#### 3. **Social stigma**- Social stigma of disease and fear of disclosure about the sickness and treatment.

#### 4. **Dissatisfaction with Staff quality** – Patients' dissatisfaction with hospital staff responsiveness, empathy and assurance.

#### 5. **Frustration** – Perception of negative consequences of the medical treatment, inability to remember and the feeling of disappointment from nonattainment of clinical outcome.

#### 6. **Regimen difficulty**- Inability to understand and follow up of the treatment regimen.

#### 7. **Unaffordability** - Inability to make payments towards purchase of medicines,

doctor's consultation fees and charges for diagnoses tests.

8. **Lack of External support**- The activity of not providing financial and/ or other support by the family members, relatives and friends.
9. **Inconvenience** – Inaccessibility in seeking required health care facility and unavailability of required health care related facilities at the hospital/ clinic.



Expert Rating Document For Independent Items										
Sr.no	Statements	1	2	3	4	5	6	7	8	9
1	The doctor does not instill confidence									
2	I do not get support from my family and friends									
3	I am not concerned about my health									
4	The doctor does not know my health status									
5	The hospital/ clinic's location is not convenient									
6	I am bothered about social stigma									
7	The doctor did not explain the dangers of non-adherence									
8	Required health care facilities are not provided at the hospital/clinic									
9	The doctor's charges are not affordable									
10	I want to keep my treatment a secret									
11	The hospital/ clinic is not accessible by public transport									
12	I cannot leave the job, although sick									
13	I do not have a care taker									
14	The work culture of this hospital is not good									
15	The treatment regimen was not easy to follow									
16	I am confused about the doses of medicines									

17	The doctor does not listen to me carefully									
18	I have to work because there are people dependent on me									
19	I am forgetful									
20	I don't want others to know about my sickness									
21	Hospital /clinic staff is not cooperative									
22	The diagnosis test charges are not affordable									
23	There is a long queue in the clinic/hospital to meet the doctor									
24	I perceive lot of risk in the treatment									
25	I am fed up of taking treatment									
26	I have to go to work, although sick									
27	Medicines are costly									

1. Work compulsions, 2. Unaffordability, 3. Dissatisfaction with staff quality,

Lack of external support, 5. Frustration, 6. Inconvenience, 7. Social stigma

8. Regimen difficulty, 9. None of the category

### **EXPERT RATING DOCUMENT FOR DEPENDENT ITEMS**

Kindly categorize each item into a category closest in meaning by putting (X) mark in the appropriate box.

**Research area:** Determinants of chronic diseases treatment non-adherence among consumers of health care services.

The brief meaning of the dimensions of treatment non-adherence:

**Medication non-adherence-** Medication non-adherence is referred to as all degrees of patient discontinuation of the treatment, not filling the prescription, non-conformity to medication as prescribed by the doctor and /or not following up scheduled visits to the doctor, and not doing diagnostic tests as instructed by the doctor.

**Lifestyle modification non-adherence** – Lifestyle modification non-adherence is referred to as all degrees of patient non-conformity to the exercises, diet and rest as advised by the doctor.

STATEMENTS	Medication Non- adherence	Lifestyle modification Non- adherence	None of the category
I have discontinued the treatment			
I am not doing follow up visits as advised by the doctor			
I take lower dose of medicine than prescribed by the doctor			
I did not do diagnostic tests as prescribed by the doctor			
I am not exercising as advised by the doctor			
I am not taking rest as advised by the doctor			
I avoid taking medicine			
I am not following the diet as prescribed by the doctor			
I skip the doses of medicine			
I do not fill the prescription in time			

Table: Expert rating agreement as per Fleiss kappa

	Independent items	F1	F2	F3	F4	F5	F6	F7	F8	F9	
S No.	Statement	W C	SS	DSQ	F	RD	U	LES	I	NC	Pi
1	The doctor does not instill confidence			8						1	0.777
2	I do not get support from my family and friends							9			1
3	I am not concerned about my health				9						1
4	The doctor does not know my health status			9							1
5	The hospital/ clinic's location is not convenient								9		1
6	I am bothered about social stigma		9								1
7	The doctor did not explain the dangers of non-adherence			7		2					0.611
8	Required health care facilities are not provided at the hospital/clinic								8	1	0.777
9	The doctor's charges are not affordable						9				1
10	I want to keep my treatment a secret		9								1

11	The hospital/ clinic is not accessible by public transport							9		1
12	I cannot leave the job, although sick	9								1
13	I do not have a care taker			1			8			0.777
14	The work culture of this hospital is not good		7						2	0.611
15	The treatment regimen was not easy to follow				9					1
16	I am confused about the doses of medicines			1	7				1	0.583
17	The doctor does not listen to me carefully		7	1					1	0.583
18	I have to work because there are people dependent on me	9								1
19	I am forgetful			6					3	0.5
20	I don't want others to know about my sickness		8	1						0.777
21	Hospital /clinic staff is not cooperative		9							1
22	The diagnosis test charges are not					9				1

	affordable										
23	There is a long queue in the clinic/hospital to meet the doctor				6					3	0.5
24	I perceive lot of risk in the treatment				1					8	0.777
25	I am fed up of taking treatment				8					1	0.777
26	I have to go to work, although sick	9									1
27	Medicines are costly						9				1
		27	26	47	34	18	27	17	26	21	23.05
	27 X 9 = 243										
	27/ 243, 26/243	.11 1	.106	.193	.139	.074	.111	.069	.106	.086	
	.111 square	.01 23	.011 4	.0374	.0195	.0054	.0123	.0048	.0114	.0074	0.1219
	23.050/ 27 = .8537										
	.8537 - .1219 =.7318										
	1 - .1219 = .8781										
	k = .7318/.8781 = .833										

WC-Work compulsions, U-Unaffordability, DSQ-Disatisfaction with Staff Quality,LES-  
Lack of External Support, F-Frustration, I-Inconvenience, SS-Social Sigma, RD-Regimen  
Difficulty NC-None of the Category, k= kappa

Table: Expert rating agreement as per Fleiss kappa

S.no	Statement	MNA	LMNA	NOC	Pi
1	I have discontinued the treatment	4	1	0	0.6
2	I am not following up visit as advised by the doctor	4	1	0	0.6
3	I take lower dose of medicine than prescribed by the doctor	5	0	0	1
4	I did not do the diagnostic tests as prescribed by the doctor	4	1	0	0.6
5	I am not exercising as instructed by the doctor	0	5	0	1
6	I am not taking rest as advised by the doctor	0	5	0	1
7	I avoid taking medicine	4	1	0	0.6
8	I am not following the diet recommended by the doctor	1	4	0	0.6
9	I skip the doses	5	0	0	1
10	I do not take the medicines prescribed	5	0	0	1
		32	18	0	8



	$10 \times 5 = 50$				
	$32/50, 18/50$	0.64	0.36	0	
	$0.64 \text{ square}, 0.36 \text{ square} =$	0.4096	0.1296	0	0.5392
	$8/10 = .8$				
	$0.8 - 0.5392 = .2608$				
	$1 - .5392 = .4608$				
	$k = 0.2608 / 0.4608 = 0.57$				

## APPENDIX IV

### CONTENT VALIDITY

#### EXPERT RATING DOCUMENT FOR INDEPENDENT ITEMS

This questionnaire aims to identify the determinants of patient non-adherence to chronic illness treatment. Kindly rate each of the items from the questionnaire, on a scale of 1-4 on the basis of **Relevance, Clarity and Simplicity**.

The description of the rating scale is as follows:

<b>Relevance</b>	<b>Clarity</b>	<b>Simplicity</b>
1-Not relevant	1-Not clear	1-Not simple
2- Item needs some revision	2- Item needs some revision	2- Item needs some revision
3 – Relevant but needs minor revision	3 –clear but needs minor revision	3 – Simple but needs minor revision
4- Very relevant	4- Very clear	4- Very simple

Sr.no	Statements	Relevance	Clarity	Simplicity
	<b>WORK COMPULSIONS</b>			
1	I cannot leave the job, although sick			
2	I have to work because there are people dependent on me			
3	I have to do the work, although sick			
	<b>UNAFFORDABILITY</b>			
4	The doctor's charges are not justifiable			
5	The diagnosis test charges are not affordable			
6	Medicines are costly			
	<b>DISSATISFACTION WITH STAFF QUALITY</b>			
7	The doctor does not instill confidence			
8	The doctor does not know my health status			
9	The doctor did not explain the dangers of non-adherence			
10	The work culture of this hospital is not good			
11	Hospital /clinic staff is not cooperative			
12	The doctor did not listen to me carefully			
	<b>LACK OF EXTERNAL SUPPORT</b>			
13	I do not have a care taker			
14	I do not get support from my family and friends			
	<b>FRUSTRATION</b>			

15	I am forgetful			
16	I am not concerned about my health			
17	There is a long queue at the clinic/hospital to meet the doctor			
18	I perceive a lot of risk in the treatment			
19	I am fed up of taking the treatment			
	<b>INCONVENIENCE</b>			
20	The required health care facilities are not provided at the hospital/clinic			
21	The hospital/clinic is not accessible by public transport			
22	The hospital/clinic's location is not convenient			
	<b>SOCIAL STIGMA</b>			
23	I am bothered about social stigma			
24	I want to keep my treatment a secret			
25	I don't want others to know about my sickness			
	<b>REGIMEN DIFFICULTY</b>			
26	The treatment regimen was not easy to follow			
27	I am confused about the doses of medicines			

## EXPERT RATING FOR DEPENDENT ITEMS

This questionnaire aims to identify the determinants of patient non-adherence to chronic illness treatment. Kindly rate each of the items from the questionnaire, on a scale of 1-4 on the basis of **Relevance, Clarity and Simplicity**.

The description of the rating scale is as follows:

<b>Relevance</b>	<b>Clarity</b>	<b>Simplicity</b>
1-Not relevant	1-Not clear	1-Not simple
2- Item needs some revision	2- Item needs some revision	2- Item needs some revision
3 – Relevant but needs minor revision	3 –Clear but needs minor revision	3 – Simple but needs minor revision
4- Very relevant	4- Very clear	4- Very simple

Sr.no	Statement	Relevance	Clarity	Simplicity
	<b>MEDICATION NON-ADHERENCE</b>			
1	I have discontinued the treatment			
2	I am not following up the visit as advised by the doctor			
3	I take a lower dose of medicine than prescribed by the doctor			
4	I did not do the diagnostic tests as prescribed by the doctor			

5	I avoid taking medicine			
6	I skip the doses			
7	I do not fill the prescription in time			
	<b>LIFESTYLE NON-ADHERENCE</b>			
8	I am not following the diet recommended by the doctor			
9	I am not taking rest as advised by the doctor			
10	I am not exercising as instructed by the doctor			

MNA-Medication non-adherence, LMNA-Lifestyle Modification Non-adherence, NOC-None of the Category, k=Kappa

Table: Relevance rating of independent items by experts and calculation of I-CVI and S-CVI								
<b>Content Validity Index for Relevance</b>								
S.No	Statements	R1	R2	R3	R4	R5	R6	I-CVI
	<b>WORK COMPULSIONS</b>							
1	I cannot leave the job, although sick	4	4	4	4	4	4	1.000
2	I have to work because there are people dependent on me	3	4	4	4	2	4	0.833
3	I have to do the work, although sick	4	4	4	4	4	4	1.000
	<b>UNAFFORDABILITY</b>							
4	The doctor's charges are not affordable	3	4	4	4	4	4	1.000
5	The diagnostic test charges are not affordable	3	4	4	4	4	4	1.000
6	Medicines are costly	4	4	4	4	4	4	1.000
	<b>DISSATISFACTION WITH STAFF QUALITY</b>							
7	The doctor does not instill confidence	3	4	3	3	3	1	0.833
8	The doctor does not know my health status	3	3	4	3	4	4	1.000
9	The doctor did not explain the dangers of non-adherence	4	4	4	4	4	4	1.000
10	The work culture of this hospital is not good	3	1	4	3	4	3	0.833
11	Hospital /clinic staff is not cooperative	4	1	4	4	2	4	0.667
12	The doctor does not listen to me carefully	4	3	4	3	4	4	1.000
	<b>LACK OF EXTERNAL SUPPORT</b>							
13	I do not have a care taker	4	4	4	4	4	4	1.000
14	I do not get support from my family and friends	3	4	4	3	2	4	0.833

	<b>FRUSTRATION</b>							
15	I am forgetful	2	4	4	4	4	4	0.833
16	I am not concerned about my health	2	4	4	3	4	4	0.833
17	There is a long queue in the clinic/hospital to meet the doctor	3	4	4	4	3	4	1.000
18	I perceive lot of risk in the treatment	3	3	4	4	4	3	1.000
19	I am fed up of taking treatment	3	4	4	4	4	4	1.000
	<b>INCONVENIENCE</b>							
20	Required health care facilities are not provided at the hospital/clinic	2	4	4	3	3	4	0.833
21	The hospital/ clinic is not accessible by public transport	4	4	4	3	4	4	0.833
22	The hospital/ clinic's location is not convenient	4	4	4	3	3	4	1.000
	<b>SOCIAL STIGMA</b>							
23	I am bothered about social stigma	3	4	4	4	1	1	0.667
24	I want to keep my treatment a secret	3	1	4	4	4	1	0.667
25	I don't want others to know about my sickness	3	4	4	4	3	1	0.833
	<b>REGIMEN DIFFICULTY</b>							
26	The treatment regimen was not easy to follow	3	4	4	3	3	4	1.000
27	I am confused about the doses of medicines	4	4	4	4	3	4	1.000
							Total	24.498
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS							24.498/ 27
								0.907



Table: Clarity rating of independent items by experts and calculation of I-CVI and S-CVI								
	<b>Content Validity Index for Clarity</b>							
Sr.no	Statements	R1	R2	R3	R4	R5	R6	I-CVI
	<b>WORK COMPULSIONS</b>							
1	I cannot leave the job, although sick	4	4	4	4	3	4	1.000
2	I have to work because there are people dependent on me	4	4	4	4	3	4	1.000
3	I have to do to work, although sick	4	4	4	4	4	4	1.000
	<b>UNAFFORDABILITY</b>							
4	The doctor's charges are not affordable	3	4	3	4	4	4	1.000
5	The diagnostic test charges are not affordable	3	4	4	4	4	4	1.000
6	Medicines are costly	4	4	4	4	4	4	1.000
	<b>DISSATISFACTION WITH STAFF QUALITY</b>							
7	The doctor did not instill confidence	2	4	3	3	3	3	0.833
8	The doctor does not know my health status	1	4	4	3	4	3	0.833
9	The doctor did not explain the dangers of non-adherence	4	4	4	4	3	4	1.000
10	The work culture of this hospital is not good	3	4	3	3	4	3	1.000
11	Hospital /clinic staff is not cooperative	4	4	4	4	3	4	1.000
12	The doctor did not listen to me carefully	4	4	4	3	4	4	1.000
	<b>LACK OF EXTERNAL SUPPORT</b>							
13	I do not have a care taker	4	4	4	4	4	4	1.000
14	I do not get support from my family and friends	3	4	4	3	4	3	1.000
	<b>FRUSTRATION</b>							

15	I am forgetful	4	4	4	4	2	4	0.833
16	I am not concerned about my health	2	3	4	3	4	3	0.833
17	There is a long queue in the clinic/hospital to meet the doctor	4	3	4	4	4	4	1.000
18	I perceive lot of risk in the treatment	3	3	4	4	3	4	1.000
19	I am fed up of taking treatment	4	4	3	4	4	4	1.000
	<b>INCONVENIENCE</b>							
20	The required health care facilities are not provided at the hospital /clinic	4	4	4	3	3	3	1.000
21	The hospital /clinic is not accessible by public transport	4	4	4	3	4	3	1.000
22	The hospital /clinic's location is not convenient	4	4	4	3	4	4	1.000
	<b>SOCIAL STIGMA</b>							
23	I am bothered about social stigma	4	4	3	4	1	4	0.833
24	I want to keep my treatment a secret	4	4	4	4	4	4	1.000
25	I don't want others to know about my sickness	4	4	4	4	3	3	1.000
	<b>REGIMEN DIFFICULTY</b>							
26	The treatment regimen was easy to follow	4	4	3	3	4	3	1.000
27	I am confused about the doses of medicines	4	4	4	4	4	4	1.000
							Total	26.165
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS						S-CVI	26.165/27
								0.969

Table: Simplicity rating of independent items by experts and calculation of I-CVI and S-CVI

	<b>Content Validity Index for Simplicity</b>	R1	R2	R3	R4	R5	R6	
S.N	Statements							I-CVI
	<b>WORK COMPULSIONS</b>							
1	I cannot leave the job, although sick	4	4	4	4	4	4	1.000
2	I have to work because there are people dependent on me	4	4	4	4	3	4	1.000
3	I have to do the work, although sick	4	4	4	4	4	4	1.000
	<b>UNAFFORDABILIT Y</b>							
4	The doctor's charges are not justifiable	3	4	4	4	4	4	1.000
5	The diagnosis test charges are not affordable	3	4	4	4	4	4	1.000
6	Medicines are costly	4	4	4	4	4	4	1.000
	<b>DISSATISFACTION WITH STAFF</b>							

	<b>QUALITY</b>							
7	The doctor does not instill confidence	3	4	4	3	3	3	1.000
8	The doctor does not know my health status	2	4	4	3	3	3	0.833
9	The doctor did not explain the dangers of non-adherence	4	4	4	4	4	4	1.000
10	The work culture of this hospital is good	3	4	4	3	4	3	1.000
11	Hospital /clinic staff is not cooperative	4	4	4	4	3	4	1.000
12	The doctor did not listen to me carefully	4	4	4	3	4	4	1.000
	<b>LACK OF EXTERNAL SUPPORT</b>							
13	I do not have a care taker	4	4	4	4	4	4	1.000
14	I do not get support from my family and friends	3	4	4	3	4	4	1.000
	<b>FRUSTRATION</b>							
15	I am forgetful	4	4	4	4	2	4	0.833
16	I am not concerned	4	4	4	3	4	1	0.833

	about my health							
17	There is a long queue in the clinic/hospital to meet the doctor	4	4	4	4	4	4	1.000
18	I perceive lot of risk in the treatment	4	4	4	4	3	2	0.833
19	I am fed up of taking treatment	4	4	4	4	4	4	1.000
	<b>INCONVENIENCE</b>							
20	The required health care facilities are not provided at the hospital/clinic	4	4	4	3	3	4	1.000
21	The hospital/clinic is not accessible by public transport	4	4	4	3	4	1	0.833
22	The hospital/clinic's location is not convenient	4	4	4	3	3	4	1.000
	<b>SOCIAL STIGMA</b>							
23	I am bothered about social stigma	4	4	4	4	1	2	0.833
24	I want to keep my treatment a secret	4	4	4	4	4	4	1.000
25	I don't want others to	4	4	4	4	3	3	1.000

	know about my sickness							
	<b>REGIMEN DIFFICULTY</b>							
26	The treatment regimen was not easy to follow	4	4	4	3	3	3	1.000
27	I am confused about the doses of medicines	4	4	4	4	4	4	1.000
							TOTAL	25.998
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS						S-CVI=	25.998/ 27
								0.963

Table: Relevance rating of dependent items by experts and calculation of I-CVI and S-CVI

<b>Content Validity for Relevance</b>								
Sr. No.	Statement	R1	R2	R3	R4	R5	R6	I-CVI
	<b>MEDICATION NON-ADHERENCE</b>							
1	I have discontinued the treatment	4	4	4	4	4	4	1.000
2	I am not following	4	4	4	4	4	3	0.833

	scheduled visits as advised by the doctor							
3	I take lower dose of medicine than prescribed by the doctor	3	1	4	4	3	4	0.833
4	I did not do the diagnostic tests as prescribed by the doctor	4	4	4	4	4	4	1.000
5	I avoid taking medicine	4	1	4	4	3	3	0.833
6	I skip the doses	4	4	4	4	3	4	0.833
7	I do not fill the prescription in time	4	1	4	4	4	4	0.833
	<b>LIFESTYLE NON-ADHERENCE</b>							
8	I am not following the diet recommended by the doctor	4	1	4	4	4	4	0.833
9	I am not taking rest as advised by the doctor	4	4	4	4	4	4	1.000

10	I am not exercising as instructed by the doctor	4	4	4	4	4	4	1.000
							Total	8.998
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS						S- CVI =	0.8998
								0.9

Table: Clarity rating of dependent items by experts and calculation of I-CVI and S-CVI

<b>Content Validity for Clarity</b>								
N	Statement	R1	R2	R3	R4	R5	R6	I-CVI
	<b>MEDICATION NON-ADHERENCE</b>							
	I have discontinued the treatment	4	4	4	4	4	4	1.000
	I am not doing follow up visit as advised by the doctor	4	4	4	4	4	4	1.000
	I take lower dose of medicine than prescribed by the doctor	4	4	4	4	4	4	1.000
	I did not do the	4	4	4	4	4	4	1.000



	diagnostic tests as prescribed by the doctor							
	I avoid taking medicine	4	4	4	4	4	4	1.000
	I skip the doses	4	4	4	4	4	4	1.000
	I do not fill the prescription in time	3	4	4	4	4	4	1.000
	<b>LIFESTYLE NON-ADHERENCE</b>							
	I am not following the diet recommended by the doctor	4	4	4	4	4	4	1.000
	I am not taking rest as advised by the doctor	4	4	4	4	4	4	1.000
0)	I am not exercising as instructed by the doctor	4	4	4	4	4	4	1.000
							Total	10.000
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS						S-CVI =10 /10	1.00

Table: Simplicity rating of dependent items by experts and calculation of I-CVI and S-CVI

Content Validity for Simplicity								
Sr.n o	Statement	R1	R2	R3	R4	R5	R6	I-CVI
	<b>MEDICATION NON-ADHERENCE</b>							
1	I have discontinued the treatment	4	4	4	4	4	4	1.000
2	I am not doing follow up visit as advised by the doctor	4	4	4	4	4	4	1.000
3	I take lower dose of medicine than prescribed by the doctor	4	4	4	4	4	4	1.000
4	I did not do the diagnostic tests as prescribed by the doctor	4	4	4	4	4	4	1.000
5	I avoid taking medicine	4	4	4	4	4	4	1.000
6	I skip the doses	4	4	4	4	4	4	1.000
7	I do not fill the prescription in time	4	4	4	4	4	4	1.000
	<b>LIFESTYLE NON-ADHERENCE</b>							
8	I am not following the diet recommended by the doctor	4	4	4	4	4	4	1.000
9	I am not taking rest as advised by the doctor	4	4	4	4	4	4	1.000

10	I am not exercising as instructed by the doctor	4	4	4	4	4	4	1.000
							Total 1	10.000
	S-CVI= TOTAL OF I-CVI / NO. OF STATEMENTS						S- CVI =1	

## APPENDIX V

### SCALES (DOCDTNAS and CDTNAS)

This questionnaire aims to identify the determinants of treatment non-adherence among patients with chronic conditions. The survey results will help the patients, health care providers, pharmacists and health care policy makers. Kindly note that the information you share with the researcher will be treated as confidential and will be used only for academic purpose.

#### Part A

Please read each statement and give your feedback against each statement. Consider your recent medical treatment and please respond by circling the appropriate response that best describes your situation: SD=Strongly disagree, D= Disagree, U= Undecided A= Agree, SA= Strongly agree.

**This part of the questionnaire inquires about the determinants of treatment non-adherence (DOCDTNAS)**

S. N.	Statements	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	The doctor does not instill confidence	SD	D	U	A	SA
2	I do not get support from my family and friends	SD	D	U	A	SA
3	I am deeply concerned about my health	SD	D	U	A	SA

4	The doctor knows my health status	SD	D	U	A	SA
5	The hospital/clinic's location is not convenient	SD	D	U	A	SA
6	I am bothered about social stigma	SD	D	U	A	SA
7	The doctor did not explain the dangers of non-adherence	SD	D	U	A	SA
8	The hospital/clinic has all up to-date health care facilities	SD	D	U	A	SA
9	The doctor's charges are not affordable	SD	D	U	A	SA
10	I want to keep my treatment a secret	SD	D	U	A	SA
11	The hospital/clinic is not accessible by public transport	SD	D	U	A	SA
12	I cannot leave the job, although sick	SD	D	U	A	SA
13	I do not have a caretaker	SD	D	U	A	SA
14	The work culture of this hospital/clinic is good	SD	D	U	A	SA
15	The treatment regimen was not easy to follow	SD	D	U	A	SA
16	I am confused about the doses of medicines	SD	D	U	A	SA
17	The doctor does not listen to me carefully	SD	D	U	A	SA
18	I have to work because there are people dependent on me	SD	D	U	A	SA
19	I am forgetful	SD	D	U	A	SA

20	I don't want others to know about my sickness	SD	D	U	A	SA
21	The Hospital/clinic staff are not cooperative	SD	D	U	A	SA
22	The diagnostic test charges are not affordable	SD	D	U	A	SA
23	There is a long queue in the clinic/hospital to meet the doctor	SD	D	U	A	SA
24	I perceive a lot of risk in the treatment	SD	D	U	A	SA
25	I am fed up of taking treatment	SD	D	U	A	SA
26	I have to do the work , although sick	SD	D	U	A	SA
27	Medicines are costly	SD	D	U	A	SA

### Part B

**This part of the questionnaire inquires about the forms of patient**

#### **Non-adherent behavior (CDTNAS)**

1	I have discontinued the treatment	SD	D	U	A	SA
2	I am not doing follow up visit as advised by the doctor	SD	D	U	A	SA
3	I take lower doses of medicine than those	SD	D	U	A	SA

	prescribed by the doctor					
4	I did not do the diagnostic tests as prescribed by the doctor	SD	D	U	A	SA
5	I am not exercising as instructed by the doctor	SD	D	U	A	SA
6	I am not taking rest as advised by the doctor	SD	D	U	A	SA
7	I avoid taking medicine	SD	D	U	A	SA
8	I am not following the diet recommended by the doctor	SD	D	U	A	SA
9	I skip the doses	SD	D	U	A	SA
10	I do not fill the prescription in time	SD	D	U	A	SA

### Part C

**Kindly give your personal details by circling the appropriate number**

Gender	Male	1
	Female	2
Marital Status	Married	1
	Unmarried	2
	Widowed	3
Number of Members in the family	One	1
	Two	2
	Three	3

	Four	4
	Five and above	5
Education	Illiterate	1
	Primary level (up to 7 <sup>th</sup> Std)	2
	Secondary level ( up to 12 <sup>th</sup> Standard)	3
	Graduation	4
	Post graduation	5
Occupation	Agriculture	1
	Service	2
	Business	3
	Unemployed	4
	House wife	5
	Retired	6
For which chronic disease are you taking medical treatment?	Cancer	1
	Asthma	2
	Orthopedic (Bones related)	3
	Diabetes	4
	Cardiovascular (Heart related)	5
	Nephrological (Kidney related)	6
What is the duration of your treatment?	Less than one year	1
	1 year and less than 2 years	2



	2 years and less than 3 years	3
	3 years and less than 4 years	4
	4 years and above	5
Which system of healthcare facility do you avail of?	Allopathic	1
	Ayurvedic	2
Which type of health care facility do you avail of?	Public Hospital/ Health Centre	1
	Private clinic/ Hospital	2

1. Age: \_\_\_\_\_ Years 2. Monthly Income of the family (Rs.): \_\_\_\_\_

3. Medical expenditure per month (Rs.): \_\_\_\_\_ 4. State \_\_\_\_\_

## APPENDIX VI

### Item-Total Statistics of the Scales (DOCDTNAS and CDTNAS)

Table A6.1 Item-Total Statistics (DOCDTNAS)

	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Cronbach' s alpha if item deleted
The doctor does not instill confidence	83.8038	161.920	.008	.755
I do not get support from my family and friends	85.3236	155.445	.176	.749
Rc- I am deeply concerned about my health	85.6451	160.840	.026	.757
Rc-The doctor knows my health status	85.8163	159.004	.141	.749
The hospital/clinic's location is not convenient	83.7578	150.991	.380	.737
I am bothered about social stigma	85.1795	149.030	.336	.738
The doctor did not explain the dangers of non-adherence	85.6284	156.209	.173	.748
Rc-The hospital/clinic has all up-to-date health care	84.3382	154.676	.187	.748

facilities				
The doctor's charges are not affordable	84.6827	151.054	.273	.743
I want to keep my treatment a secret	85.1712	147.912	.341	.738
The hospital/clinic is not accessible by public transport	84.0355	144.281	.488	.728
I cannot leave the job, although sick	84.4697	156.425	.159	.749
I do not have a caretaker	85.0084	155.385	.194	.747
Rc-The work culture of this hospital/clinic is good	85.1879	159.776	.052	.756
The treatment regimen was not easy to follow	85.1858	151.491	.307	.741
I am confused about the doses of medicines	85.1628	149.660	.362	.737
The doctor does not listen to me carefully	85.6347	152.174	.303	.741
I have to work because there are people dependent on me	83.9896	152.061	.267	.743
I am forgetful	84.4322	154.246	.267	.743
I do not want others to know about my sickness	85.1879	147.592	.374	.736

The hospital/clinic staff are not cooperative	85.0626	151.452	.302	.741
The diagnostic tests charges are not affordable	83.9791	145.899	.443	.731
There is a long queue in the clinic/hospital to meet the doctor	83.6221	154.612	.324	.741
I perceive a lot of risk in the treatment	84.5720	148.793	.319	.740
I am fed up of taking treatment	83.8643	151.473	.361	.738
I have to work, although sick	83.8184	149.379	.384	.736
Medicines are costly	83.4864	152.928	.416	.737

**Valid Cases: 479    Alpha: .750    Items: 27**

Table A6.2 Item-Total Statistics (CDTNAS)

	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Cronbach's alpha if item deleted
I have discontinued the treatment	27.27	74.447	.376	.864
I am not doing follow-up	26.19	64.391	.612	.847

visits as advised by the doctor				
I take lower doses of medicine than those prescribed by the doctor	26.03	62.572	.715	.837
I did not do the diagnostic tests as prescribed by the doctor	25.91	63.977	.633	.845
I am not exercising as instructed by the doctor	25.30	71.436	.372	.865
I am not taking rest as advised by the doctor	25.72	73.426	.295	.870
I avoid taking medicine	26.52	62.844	.719	.837
I am not following the diet recommended by the doctor	25.53	68.505	.506	.855
I skip the doses of medicine	26.49	61.589	.759	.833
I do not fill the prescription in time	26.64	63.349	.711	.838

**Valid Cases: 479    Alpha: .863    Items: 10**

**APPENDIX VII**

**CONSENT FORM**

I Mr./Ms. \_\_\_\_\_ give my consent to participate in the survey, 'Determinants of patient non-adherence to chronic illness treatment'.

Signature: \_\_\_\_\_

Date:

**Thank you very much for completing the questionnaire**

## APPENDIX VIII

### COPY OF LETTER SEEKING PERMISSION TO CONDUCT SURVEY

Mrs. Vidya R. Dalvi

Associate professor in Commerce

Govt. College of Arts, Science and Commerce

Quepem, Goa

Date

To

\_\_\_\_\_

\_\_\_\_\_

Sub: Permission to conduct patient survey

Sir/Madam,

I am a research scholar, registered for Ph D. in Management, Department of Management Studies, Goa University, Goa. The research work aims to investigate determinants of chronic disease treatment non-adherence from patient's perspectives. Kindly grant me permission to conduct survey among chronic patients seeking treatment at your health care facility. The information shared will be treated as confidential and will be used only for the academic purposes. Please find enclosed a copy of the questionnaire.

Thank you in anticipation.

Yours faithfully

Mrs. Vidya R. Dalvi

Enc- Questionnaire



## APPENDIX

### PUBLICATIONS BASED ON THE RESEARCH

Mekoth N., George B.P., Dalvi V., Rajanala N., and Nizomadinov K., (2012). Service quality in the public sector hospitals: a study in India. *Hospital topics: Research and perspectives on Health care*, 90(1), 16-22. ISSN: 0018-5868 print/ 1939-9278 online.

Dalvi V. and Mekoth N. (2013). Health care cost and patient adherence: an exploratory study. *Bhruti-Journal of Business and Finance*, Vol.3: 38-44. ISSN: 2321-7685.

Mekoth N. and Dalvi V. (2015). Does quality of health care service determine patient adherence? Evidence from primary healthcare sector in India. *Hospital Topics: Research and perspectives on Health care*, 93:9, 60-68. ISSN: 0018-5868 (print) 1939-9278 (online)

Dalvi V. and Mekoth N. (2015). Determinants of non-adherence to chronic diseases treatment in Goa. Chapter in a book titled as, "*Goa: Looking Back, Looking Ahead*" Published by Govt. College of Arts, Science and Commerce, Quepem. ISBN awaited

Mekoth N. and Dalvi V. (2015), Development and validation of a self-reported, structured measure of non-adherence to chronic disease treatment. *Vision India: the road ahead – Conference proceedings –Two day National conference, 27-28 January, 2015*. ISBN: 978-81-930826-0-7. Published by Valia College, Mumbai.

Dalvi V. and Mekoth N. (2015), Treatment non-adherence: a challenge to health care systems, National Conference, 1<sup>st</sup> October, 2015, MAPS College, Mangalore.