

**PUBLIC PERSPECTIVES ON COST-RELATED NON-
ADHERENCE AMONG PATIENTS**

A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE
WITH SPECIALIZATION IN PHARMACY ADMINISTRATION
TO THE FACULTY OF THE ARNOLD & MARIE SCHWARTZ
COLLEGE OF PHARMACY AND HEALTH SCIENCES
LONG ISLAND UNIVERSITY


BROOKLYN, NEW YORK

BY

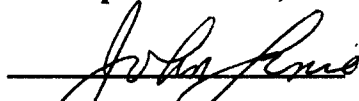
MERENA NANAVATY

MARCH 25th, 2014


Sponsoring Committee:



Dr. Bupendra Shah, Chair



Dr. John Louie, Committee Member



Prof. Fernando Gonzalez, Committee Member



Dr. Rutesh Dave, Division Director



Martin Brown, Associate Dean

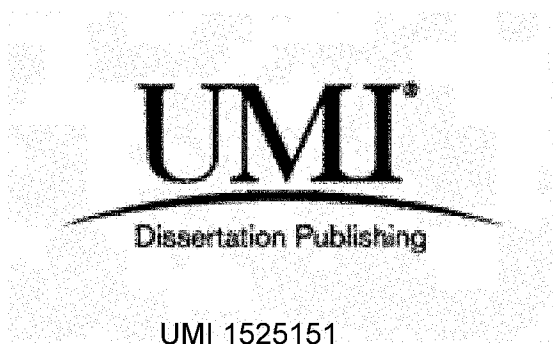
UMI Number: 1525151

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

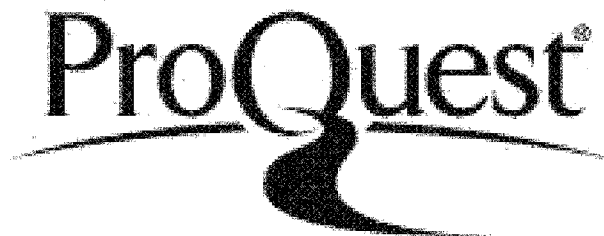
In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



Published by ProQuest LLC 2014. Copyright in the Dissertation held by the Author.

Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code.



ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

ABSTRACT

Objectives: Cost-related non-adherence is a highly prevalent phenomenon among patients; however, there is a current lack of studies that provide an insight into this issue using primary data. The objective of this study was to explore public perspectives of cost related non-adherence and the factors associated with it.

Methodology: Using a cross sectional design, four focus groups were conducted with students of Long Island University, Brooklyn. The conceptual framework obtained from two previously published studies was used to frame the questions used for the discussion as well as to rank factors quantitatively during the focus group. Data obtained was analyzed using MS Excel.

Results: Using data from 36 consenting participants, it was concluded that the public believes that cost as an important reason causing medication non-adherence in patients. Additionally, the factors 'out-of-pocket costs' and 'prescription coverage' were ranked 'extremely important factors' by more than half of the participants.

Conclusions: The study helped understand the phenomenon from the most important perspective, that of the public. Based on the importance of factors associated with cost-related non-adherence, recommendations are made for effective strategies to ameliorate the high rates on non-adherence among patients.

ACKNOWLEDGEMENTS

This thesis has been the most valuable part of my program here at Long Island University, Brooklyn. It has not only made me realize where my interests lie, but it also has taught me the dedication and perseverance that goes in to research.

For the successful completion of my thesis, there are a number of people I would like to thank. I would like to express my deepest gratitude to Dr. Bupendra Shah, with whose encouragement, support and immense knowledge, this study has now reached fruition. A heartfelt thank you to Dr. John Lonie and Prof. Fernando Gonzalez, members of the supervisory committee, for their constant guidance, advice and time. I'd also like to thank Dr. Hamid Rahim, Prof. Naushad Islam, Mr. Patrick Campbell, Dr. Rutesh Dave, and Dr. Jun-Yen Yeh for their support towards my thesis.

This thesis was conducted while I interned part-time at a healthcare consulting company. To this end, I'm especially grateful to my Director, Mr. Chakkarin Burudpakdee, the President, Sandip Shah and all my colleagues, for valuing my limited time-schedule, and giving me the liberty to pursue my interests in the thesis while I interned part-time.

I'd like to express my gratitude to all the participants for sharing their time, opinions and thoughts. I'd also like to acknowledge the role my numerous friends and loved ones have played in the successful completion of my thesis. Nothing in life is ever complete without the love and support of my family; my father Sheryar Nanavaty, my mother Nancy Nanavaty, my sister Serena Nanavaty and my brother-in-law Radhakrishna Manohar.

TABLE OF CONTENTS

Contents	Page Number
Title page	i
Abstract	ii
Acknowledgements	iii
Table of contents	iv
List of tables	vi
List of appendix	vii
Chapters:	
I. Introduction	1
1.1 Healthcare expenditure	1
1.2 Patients' financial burden	2
1.3 Research question	2
II. Literature review	3
2.1 Conceptual framework	6
III. Methodology	8
3.1 Study design	8
3.2 Sample size calculation	10

3.3 Sampling method and enrollment	10
3.4 Data entry and analysis	10
3.5 Relevant documents and storage	11
IV. Results	12
4.1 Study sample	12
4.2 Study outcomes	12
V. Discussion	22
References	26
Curriculum vita	44

LIST OF TABLES

1	Ranking scale	16
2	Results for quantitative ranking of factors associated with CRN behaviors	16

LIST OF APPENDICES

30	Appendix A	Participation flyer
31	Appendix B	Consent form
34	Appendix C	Introduction and ground rules
36	Appendix D	Focus group questions
38	Appendix E	Handout for ranking factors associated with cost-related non-adherence

CHAPTER I

INTRODUCTION

1.1 Healthcare expenditures

The annual healthcare expenditure (HE) in the United States (US) has been growing more rapidly over the last 50 years. HE has tripled as a share of the gross domestic product (GDP); growing from a 5% to a whopping 15%.¹ The US Census indicates HE increased from \$27.3 billion in 1960 to approximately \$2.4 trillion in 2009. It is projected that HE is expected to rise faster than the national income.² While a majority of the healthcare costs are paid by insurance providers, one-fifth of it is paid by patients in the form of out-of-pocket expenses (OOP).³ Patient OOP contribution is increasing every year. Insurance companies are increasing premiums and OOP costs (through increased deductibles, coinsurance, and co-pays) and employers are shifting costs to employees by increasing employee premium contribution every year. For example, Towers Watson, a major American risk management consulting firm, reports that last year alone, companies increased the employee premium by 66% for employee-only and by 73% for employee and dependent coverage. This scenario only adds to the financial burden on individuals and families. With limited income, more health conditions, and growing expenses of medications, financial burden on patients and their families can have a tremendous impact on patients' medication-taking behavior.

1.2 Patients' financial burden

High insurance premiums and OOP costs tend to be a huge burden on not only the individual, but also on their respective families. The national economic crisis has further increased the burden on families and individuals.

A national survey conducted in 2009 among 27,302 participants pointed out that roughly half of the participants reported that medication cost hardships had become more frequent in 2008 than before the economic recession.⁴ Such cost hardships and financial burdens, influence patients' decision-making and worsens healthcare outcomes, often due to cost-related non-adherence (CRN).

1.3 Research question

The aim of our study is to examine public perspectives of factors affecting CRN using public perspectives. Specifically, this study aims to answer the following questions from a public perspective:

1. How do they view medication non-adherence?
2. What can be done to help patients reduce cost related non-adherence?
3. Which factors do the public believe play an important role in cost related non-adherence?
4. Which factors identified in earlier studies are important and what is the level of importance for each of these factors?
5. What is the effect of the recent economic recession on patients' ability to afford medications?

CHAPTER II

LITERATURE REVIEW

There's an abundance of literature providing rates of CRN among different sections of the society. For example, literature from the mid 2000s found that nearly one-third of older adults reported taking less medication than prescribed due to cost pressures.⁵⁻⁷

Research has shown how this section of the population that resort to CRN behaviors are at an increased risk of declining health.⁸ Studies that used administrative data and national surveys have reported that while affecting their health, CRN also increases patients' costs due to hospitalization, emergency room use etc. Even patients with chronic conditions like diabetes who encounter high financial burden have reported cutting back on their medication.⁹ These cost-related medication underuse behaviors result in increased incidence of serious adverse events as well as drastic increase in number of emergency room visits.¹⁰ One particular study reported that a major part of the study population, consisting of patients with cardiovascular diseases, encountered increased rates of angina and non-fatal strokes when resorting to CRN behaviors.¹¹ In addition to CRN behaviors, still some patients resort to cutting back on their basic needs in order to be able to pay for their prescriptions.^{12,13}

There is abundant literature that shows the direct relationship between financial pressures (such as low income, lack of drug coverage etc.) and CRN.¹⁴⁻¹⁸ Furthermore, Piette et al. (2011) used data from 27,302 patient surveys with the goal to explore how patients'

beliefs about the necessity of the medication and medication adverse effects influenced CRN. The study reported that 21% of economically vulnerable respondents (individuals with household incomes US\$25,000 or less and monthly OOP medication costs of at least US\$60) reported being adherent to their medications despite cost pressures; while 14% of high-income respondents (individuals with household incomes US\$125,000 or more and monthly OOP medication cost of less than US\$60) had reported to some form of CRN. Additionally, the patients also reported that the low perceived need for the medication and concerns about the adverse effects affected the CRN risk among both groups.¹⁹ Few studies exist that talk about the various other factors that contribute to CRN.

Understanding and assessing the effect of such factors on CRN is of importance when the factors are potentially modifiable to benefit patients' health and well-being. This concept had been studied by Piette et al (2006) with the aim to understand chronically ill patients' responses to medication cost pressures. Based on a literature review, the study presented a unique conceptual model that evaluated factors other than financial pressures, such as, health system factors, clinician factors, patient characteristics, prescription characteristics etc., and their influence on CRN. A few years later Zivin et al (2010) used Piette et al (2006)'s conceptual model in a study using a secondary database of nationally represented sample of older adults. Zivin et al (2010)'s study²⁰ used data from the 2004 Health and Retirement Study (HRS) and the 2005 HRS Prescription Drug Study, hence lacked data on certain domains of the original conceptual model such as clinician counseling and health system factors. However, the study introduced a few other factors such as the patients' burden of chronic illness, financial net worth, patient characteristics

such as education level, marital status, job status, patient lives alone and trust for insurance decisions.

Some of the factors assessed by Piette et al (2006) are described here. Using data from several studies obtained through a literature review, the study reported that sociodemographic factors played a role in increasing risk of CRN behaviors.

Sociodemographic factors such as race and age were reported to affect CRN behaviors due to differences in patients' perceived need for the medication, trust in the healthcare systems, and knowledge about financial assistance programs. In terms of the disease characteristics and their role in CRN, the study highlighted the common belief that patients value short-term medication benefits (for example, pain) over long-term benefits (for example, survival benefit of antihypertensive drugs). The study also presented studies that talked about the occurrence of a behavior where patients were more cost-sensitive to symptom-relieving medications (for example, antihistamines) than to medications treating high cholesterol, diabetes and hypertension. In regards to the relationship between the adverse effects of the medication and CRN, the study concluded that the likelihood of cost-related underuse is high when the medication is not only expensive, but also causes discomfort of varying levels.

In addition to the factors described by Piette et al (2006), Zivin et al (2010) highlighted the role of depression as a major factor causing CRN, irrespective of the existence of cost pressures. Contradictory to the findings of Piette et al (2006)'s study, Zivin et al (2010) found no association between burdens of chronic illnesses, such as diabetes, stroke, arthritis, cancer etc., and CRN.

Essentially, there are two conceptual models that have been used to study CRN and its factors. Most of factors are common between both the studies and have similar results; however, some factors had contrasting results, which needs further exploration.

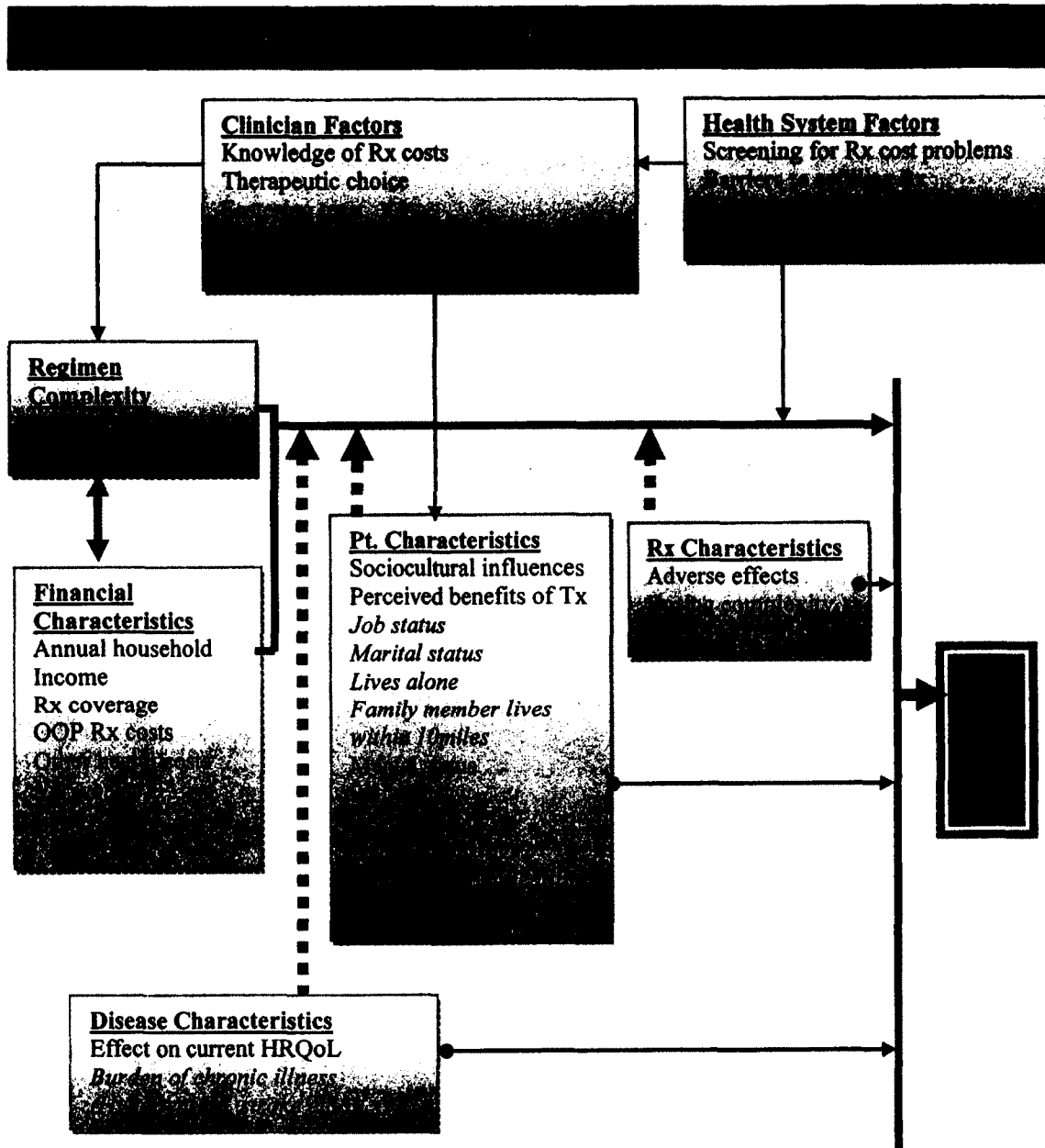
Additionally, since the studies were conducted using either a literature review or a secondary database methodology, they lack public perspectives on how the factors impact their CRN behaviors. Furthermore, both the studies failed to contextualize the effect of the geo-politico-economic environment (such as the 2008 recession) on CRN.

2.1 Conceptual framework

For the purpose of this study, Piette et al's original conceptual model was adopted as the foundation and Zivin et al's factors were added to develop the model given below.

The italicized factors represent the additional factors incorporated in Zivin et al's study. Piette et al's (2006) original model was based on literature review of research articles published between 1990 and 2004, while Zivin et al's (2010) was based on HRS data for the years 2004 and 2005.

Rx: Prescription, Tx: Treatment; HRQoL: Health-related quality of life, OOP: Out-of-pocket, CRN: Cost-related non-adherence
Thick solid line: Main effects of cost pressures on CRN; Thick dashed line: Moderating effects of other domains on patients' response to cost pressures; Thin solid line: Possible ways in which clinicians and health systems may buffer the effects of medication costs on patients' self-care and health status



CHAPTER III

METHODOLOGY

While previous researchers used published literature and secondary databases for their respective studies, we believe that CRN behaviors are a direct reflection of the patients' beliefs, thoughts, attitudes and characteristics. To gauge these beliefs, thoughts and attitudes, primary methods of data collection such as focus groups are considered to be ideal. It is a well known fact that surveys are a good tool to collect data about attitudes and attributes; however, in order to gain detailed information and understand these issues with a deep insight, we believe focus group discussions are ideal. Using focus groups as our tool, we intended to create a small and safe setting where individuals could express and share their thoughts and opinions while having them in a comfortable environment. The goal was to gain a deeper understanding of the factors that lead to CRN behaviors by helping participants thoughtfully answer questions in their own words and add dimensions and meaning to their thoughts and opinions.

3.1 Study design

A descriptive, cross-sectional study was utilized for the study. Flyers (Appendix A) inviting LIU Brooklyn campus students, 18 years or older in age were posted at different locations on campus, such as the fitness center, the three cafeterias, the library section, the student lounge area, the computer labs etc. These flyers (Appendix A) helped educate the readers on the nature and purpose of the study, the qualifying criteria for participants,

a schedule and location for the focus group discussion and contact details for more information. The flyer notified participants that the session would take place on the Brooklyn Campus and that refreshments would be served during the focus group sessions. The investigator made arrangements for a room on campus for each session at the scheduled date and time. Arrangements were made for the note-taker, Dr. Shah to take anonymous notes during each of the sessions.

At the commencement of each focus group session, each participant was handed a consent form (Appendix B) that they could sign or decline at their own will. The consenting participants were given a number badge, with the purpose of addressing them anonymously during the session and to tag their responses in the notes taken during the session. The moderator then thanked the participants for their time and welcomed them to the session. The moderator and note-taker introduced themselves and provided the audience with a brief introduction and ground rules (Appendix C) for the session. Following this was a round of discussion based on the questions (Appendix D) prepared by the moderator as well as probes based on the responses given by the participants. Participants were given a ranking document (Appendix E) that required them to review and rank a list of factors identified from the past studies in terms of their importance towards contributing to CRN behaviors in patients. Throughout the discussion session, the note-taker was taking summary notes based on the opinions shared by participants. At the end of each discussion, participants were thanked and asked for comments and/or suggestions if any.

Immediately after the participants left the location of the focus group, the notes were labeled with the date, time and location of the session. For the purpose of including all relevant and useful opinions expressed during each focus group, all participants' comments were summarized systematically per question posed by the moderator. Notes were cleaned for grammatical and spelling errors and saved as a Microsoft Word file.

3.2 Sample size calculation

Recommended guidelines²¹ for effective focus groups suggest six to ten participants per session and recommend one to ten sessions as per complexity of the study. For our study, we aimed to conduct four sessions of approximately six to ten participants each, leading to a sample size of 24-40 individuals.

3.3 Sampling method and enrolment

A convenience sampling method was utilized for enrolling a convenient sample of students at Long Island University, Brooklyn. The investigator posted flyers (Appendix A) at different locations on campus at the Long Island University, Brooklyn, that briefed readers on the nature and purpose of the study, the qualifying criteria for participants, a schedule and location for the focus group discussion, and contact details for more information.

3.4 Data entry and analysis

MS-Excel was utilized to conduct qualitative as well as quantitative analysis of participant responses made during the focus group. All summary notes saved within the

MS-Excel worksheets for each session and were reviewed individually using thematic analysis. First, the investigator will reviewed the notes thoroughly to become familiar with the data, following which the investigator assigned initial codes to responses that were relevant to any of the research questions. Each statement recorded during the focus group was coded using open coding; following which data was searched and reviewed for themes and sub-themes. Each theme and sub-theme was then defined and given an appropriate name. Statements were tagged to each theme and sub-theme, if applicable. Using the identified themes and sub-themes, a report was constructed summing up the pattern of responses provided by the participants of the focus group.

3.5 Relevant documents and storage

All participants signed and returned their respective consent forms which will be stored under lock and key at the faculty sponsor's office in the Department of Social & Administrative Sciences, LIU Pharmacy at Long Island University in Brooklyn, NY and will be destroyed after 3 years of the completion of the study as per federal regulations. All consent forms and ranking documents were coded in order to maintain anonymity and to link the documents to the consent forms in case of withdrawal of consent.

CHAPTER IV

RESULTS

4.1 Study sample

In summary, four focus group sessions were conducted in a period of three weeks. A total of 37 participants were initially involved in the study (9 in the first and third focus groups, 6 in the second, and 13 in the fourth). However, one participant voluntarily withdrew soon after the second focus group session began, making 36 the total number of respondents for the qualitative section. In the quantitative section (factor ranking), two participants had ranked only one side of the two-sided sheet; their responses were disqualified. Hence, for the quantitative section, the number of respondents was 34. In case that the participant had marked off two ranks for one factor, an average was taken. All participants were students of Long Island University, Brooklyn. Majority of the participants were young adults (approximately 18-25 yrs) and were enrolled in a healthcare or science related programs.

4.2 Study outcomes

Focus group questions used during each of the sessions are listed in Appendix D. The summarized results for each of these outcomes are listed below.

Outcome 1: Public perspectives on medication non-adherence

To understand this outcome, a question *"In your opinion, why do patients fail to take their medications as prescribed?"* was asked and relevant probes were used.

A wide range of responses were obtained in this section of the focus group. The common themes recognized were cost-related issues, forgetting, psychological barriers, medication-related issues, medication procurement, and subjective reasons. Cost-related issues included insurance coverage/non-coverage, high costs of medication, and affordability of medication. One participant expanded on affordability stating, *"A procedure like a root canal is expensive in itself. As a student paying for the procedure itself, and then the medications involved in after-care is very expensive. In that situation, I tried to cut down on the number of times I took the medication."* A majority of patients in each focus group believed that medications are often expensive and could be the most common reason for medication non-adherence. Following cost-related issues, the most common theme was forgetting to take their medication. An interesting point made by a few of the participants was that this phenomenon is likely to be more common among the elderly. A few participants also believed that 'forgetting' was even more common when multiple medications are involved. Psychological barriers included reasons such as *"some patients dislike taking medications"*, *"some patients feel embarrassed to buy medications for sexually transmitted diseases like AIDS"* and *"some patients are scared of getting addicted to certain medications, such as pain medication."* The theme medication-related issues involved two major reasons including side-effects of the medication and complexity of the directions. Reasons such as inability to procure medications from the pharmacy among the elderly, and pharmacy hours not facilitating a

pick-up after work hours were tagged to a common theme 'medication procurement'.

Several responses were tagged with the theme 'subjective responses' including, patients' perceived importance/need for the medication, difficulty swallowing pills, and stopping the course of medication when patients feel better.

Outcome 2: Public perspectives on CRN

The question "*In your opinion, is affordability of medications a big reason why patients may not take their medications as prescribed?*" was used to understand public perspectives on CRN.

An interesting observation was made throughout this study. All participants (n=36) in each focus group believed that cost was the most common reason for medication non-adherence. When asked to rank the importance of cost-related issues in terms of their impact on medication non-adherence, all participants in each group ranked this factor at 7-9 on a scale of 1-10. While discussing CRN, many participants described a common phenomenon recognized as 'financial prioritization', where patients who are financially strained often have to make a choice between their mortgage, food and medical expenses.

Outcome 3: Public perspectives on factors contributing to CRN

The discussion for this section of the study began with the question "*How do you feel about the out-of-pocket costs of medications and its relationship to non-adherence?*", and later delved into other factors using several probes.

A majority of the participants believed that often times despite having insurance coverage; patients pay high OOP costs for certain conditions, which in term serve as deterrent to initial pick-up as well as refill of medications prescribed, leading to the most common form of CRN. Another important factor recognized by the participants was annual income. To explain this factor, one participant opined *"Somebody with that earns \$100,000 per year may not mind paying for a medication that costs \$25 but the same price may be too much for somebody that earns \$30,000 per year."* A few participants linked this factor to 'socioeconomic status'. The third most important factor recognized was attributes of the disease itself. Several participates believed that the severity of the disease had a directly proportional relationship to the willingness to pay for the medication despite cost. One participant expanded that *"I wouldn't be willing to pay thousands of dollars for a cough medication but for a disease as life-threatening as cancer, I would."* The final factor recognized by one participant was 'single versus family', explaining which the participant voiced that *"As a single person you sometimes have the money to pay for your medication, but if you have an entire family to support, you may not have the money to pay for your medication."*

Outcome 4: Public perspectives on the importance of factors listed in Piette et al's and Zivin et al's study and their impact on CRN

To gain an understanding on this outcome, patients were given a ranking sheet found in Appendix E and were asked to rank the listed factors in terms of their importance in CRN. The ranking scale used is listed in **Table 1**.

Table 1. Ranking scale

0	Not at all an important contributor to a patient's medication taking behavior
1	Slightly important contributor to a patient's medication taking behavior
2	Moderately important contributor to a patient's medication taking behavior
3	Very important contributor to a patient's medication taking behavior
4	Extremely important contributor to a patient's medication taking behavior

One participant circles two ranks on two occasions, in this case, an average of the two were used. Two ranking sheets had to be disqualified due to incomplete responses; the results for the remaining 34 ranking sheet can be found below in Table 2.

Table 2. Results for quantitative ranking of factors associated with CRN behaviors

Patient's out-of-pocket costs	0 (0.0)	0 (0.0)	3 (8.8)	8 (23.5)	23 (67.6)	3.58
Patient's prescription coverage	0 (0.0)	0 (0.0)	0 (0.0)	13 (38.2)	21 (61.8)	3.61

Patient's job status	0 (0.0)	0 (0.0)	4 (11.8)	10 (29.4)	20 (58.8)	3.47
Patient's annual household income	0 (0.0)	0 (0.0)	3 (8.8)	12 (35.3)	19 (55.9)	3.47
Patient's burden of chronic illness	0 (0.0)	0 (0.0)	3 (8.8)	12 (35.3)	19 (55.9)	3.47
Number of prescription	0 (0.0)	0 (0.0)	2 (5.9)	14 (41.2)	18 (52.9)	3.47
Patient's mental status	0 (0.0)	2 (5.9)	8 (23.5)	8 (23.5)	16 (47.6)	3.11
Patient's health literacy	1 (2.9)	2 (5.9)	3 (8.8)	12 (35.3)	16 (47.6)	3.17
Effect on patient's quality of life	0 (0.0)	1 (2.9)	4 (11.8)	13 (38.2)	16 (47.1)	3.29
Perceived need of the prescription	0 (0.0)	2 (5.9)	5 (14.7)	12 (35.3)	15 (44.1)	3.17
Frequency of refills	1 (2.9)	0 (0.0)	4 (11.8)	14 (41.2)	15 (44.1)	3.23
Adverse effects of the prescription	0 (0.0)	0 (0.0)	2 (5.9)	18 (52.9)	14 (41.2)	3.35

Other health costs	1 (2.9)	1 (2.9)	9 (26.5)	11 (32.4)	12 (35.3)	2.94
Patient's financial net worth	0 (0.0)	4 (11.8)	4 (11.8)	15 (44.1)	11 (32.4)	2.97
Perceived benefits of treatment	1 (2.9)	2 (5.9)	5.5 (16.2)	14.5 (42.6)	11 (32.4)	2.95
Patient's self-efficacy	2 (5.9)	4 (11.8)	5 (14.7)	12 (35.3)	11 (32.4)	2.76
Dosing complexity of the prescription	0 (0.0)	2 (5.9)	7 (20.6)	16 (47.6)	9 (26.5)	2.94
Patient barriers to applying for prescription benefits	0 (0.0)	2 (5.9)	11 (32.4)	13 (38.2)	8 (23.5)	2.79
Patient's trust in making decisions about health insurance	1 (2.9)	2 (5.9)	9.5 (27.9)	14.5 (42.6)	7 (20.6)	2.72
Referral to prescription cost assistance programs	0 (0.0)	3 (8.8)	12 (35.3)	13 (38.2)	6 (17.6)	2.64

Patient barriers to refilling prescription	1 (2.9)	0 (0.0)	13 (38.2)	14 (41.2)	6 (17.6)	2.70
Patient lives alone	5 (14.7)	5 (14.7)	13 (38.2)	6 (17.6)	5 (14.7)	2.05
Healthcare provider discussion about prescription cost	0 (0.0)	2 (5.9)	20 (58.8)	7 (20.6)	5 (14.7)	2.44
Healthcare provider screening for prescription cost problems	2 (5.9)	0 (0.0)	13 (38.2)	14 (41.2)	5 (14.7)	2.58
Prescriber incentives	1 (2.9)	5 (14.7)	12 (35.3)	11 (32.4)	5 (14.7)	2.41
Patient's marital status	7 (20.6)	12 (35.3)	8 (23.5)	3 (8.8)	4 (11.8)	1.55
Physician's knowledge of prescription costs	1 (2.9)	5 (14.7)	9 (26.5)	15 (44.1)	4 (11.8)	2.47
Physician's therapeutic choice	1 (2.9)	2 (5.9)	16 (47.6)	12 (35.3)	3 (8.8)	2.41

Physician fostering trust	0 (0.0)	5 (14.7)	14 (41.2)	12 (35.3)	3 (8.8)	2.38
Patient's sociocultural influences	2 (5.9)	2 (5.9)	12 (35.3)	15 (44.1)	3 (8.8)	2.44
Patient's family member lives within 10 miles	9 (26.5)	8 (23.5)	11 (32.4)	5 (14.7)	1 (2.9)	1.44

Outcome 5: Public perspectives on strategies that could help reduce CRN behaviors among patients

To gain an understanding of this outcome the following question was used. *"In your opinion, what can be done to help patients reduce cost-related non-adherence?"*

The common themes identified in this section of the focus group are cost assistance, patient education and counseling, and health insurance related approaches. Participants that voiced that cost assistance programs are the primary strategy to target believed that the occurrence of CRN behaviors could be possibly reduced by effective programs that help financially vulnerable population with expensive conditions by providing them with coupons, payment plans and discounted rates for medications. A majority of participants believed that a lot could be done at the healthcare provider level in terms of educating the patient about the cost of the medication while prescribing and screening the patient for

any potential cost-related issues. Participants also expressed the need for more awareness programs regarding prevention and well-being among at-risk population at local, state and national levels. One participant also considered the possibility of breaking down psychological barriers with effective counseling strategies that aimed at educating the patient regarding the benefits of medication and the importance of adherence. A few participants articulated the need for clarity in terms of coverage provided by health insurance companies. One participant expressed that patients often make uneducated decisions while choosing health plans, which leads to limited or no coverage in times of need, thereby causing a cost pressure on the patient.

Outcome 6: Public perspectives on the effect of the recent economic recession on patients' ability to afford medications

Patients were asked the question *"In your opinion, what has been the effect of the recent recession on patients' ability to afford medications?"* to be able to gauge public perspectives on the above mentioned outcome.

All participants (n=36) in all focus groups believed that the recent economic recession had a detrimental effect on patients' ability to pay for their medications in most parts of the society, especially the financially vulnerable population. Some participants also went as far as to say that *"Often times it is a choice people families have to make between food and medication"* which best describes the reality of the situation.

CHAPTER V

DISCUSSION

This study explored public perspectives on cost-related non-adherence and its various contributing factors. The presentation of primary data so obtained provides a unique overview and is useful in the conceptualization of novel and effective strategies to target the issue of cost-related non-adherence among patients. A number of the noteworthy findings are described below.

The general implication from the first two outcomes assessed is that the public acknowledges the existence of medication non-adherence and believes that it is caused by a mix of factors; cost-related issues being the number one factor. This cost pressure, the public expressed, is even more pronounced among patients from low-income families, unemployed/underemployed sections of the society (students) and the elderly population. The vocalization of 'financial prioritization' as a common occurrence highlights the extreme state of CRN as an issue where families often have to make a choice between "*mortgage, food and medical expenses*". This finding is important and resonates with Maslow's hierarchy of needs that explains that every person is able to move up from level one of physiological needs to level five of growth needs, however; it requires that he fulfils all this needs to reach level five. Shelter (mortgage), food and medical expenses (health) are essential components of the basic level of the hierarchy.

Among the factors identified in previously published studies, the most important factors identified by the study participants, in no particular order are: patient's annual household income, patient's prescription coverage, patient's OOP costs, patient's financial net worth, patient's sociocultural influences, patient's mental status, patient's health literacy, adverse effects of the prescription, dosing complexity of the prescription, perceived need of the prescription, physician's knowledge of prescription costs, healthcare provider discussion about prescription cost, number of prescriptions, frequency of refills, effect on patient's quality of life and patient's burden of chronic illness. Contradictory to the findings in Zivin et al's study, burden of chronic illness was ranked to be major contributor to CRN, with more than half of the respondents rating it as an "extremely important" factor. Among the 31 factors assessed, more than half of the participants ranked patient's annual household income, patient's prescription coverage, patients' OOP costs, patients' job status, number of refills and patient's burden of chronic illness as 'extremely important' contributors to CRN. The important implication of this finding is that future strategies aimed at improving cost-related medication adherence should focus on the patient populations with the above mentioned characteristics that make them vulnerable to CRN behaviors. An example of the utilization of this implication is the conceptualization of patient-centered adherence or compliance program strictly structured for patients with a targeted chronic illness promoting education and counselling. Another possible strategy could be reducing the number of refills required, thereby managing the CRN issue caused by excessive number of refills. Apart from the above mentioned factors, more than half of the participants believed that adverse events associated with the

medication were a 'very important' contributor to CRN behaviors among patients, which is in agreement with the findings of both Piette et al and Zivin et al's studies. To tackle this CRN-inducing behavior, strategies like detailed two-way discussion between the healthcare provider and the patient educating the patient about the adverse effects of the medication prior to initiation of treatment. Alternatively, best practises can be utilized at the point of prescription where the physician can prescribe a medication that falls within the scope of patients' tolerability of adverse effects. The uniqueness of this section of the study where quantitative ranking has been provided using public perspectives is that this data can be used directly by decision-makers at the time of conceptualization of adherence/compliance programs.

Focus groups are considered ideal in studies that are carried out with the aim of gaining an insight into beliefs, thoughts and attitudes about a certain issue. Guidelines²³ recommend 1-10 sessions with an average of 6-10 participants each depending on the complexity of the study. Our study involved a total of 36 participants from a total of four sessions. The study was conducted among students of Long Island University, Brooklyn, which is known for its heterogeneity makeup, thereby facilitating an ethnically diverse set of participants.

Although studies by Piette et al and Zivin et al provided readers with list of factors that impact CRN behaviors among patients, both studies were conducted using secondary data, namely, literature review and HRS data. However, providing a public perspective via primary data is essential to gain a comprehensive understanding of the issue.

Additionally, this study provides a quantitative overview on the importance of these factors and their contribution to CRN behaviors. In summary, this study provides a detailed qualitative as well quantitative overview on factors related to CRN from a public perspective; hence, this data could be utilized in the future to build the foundation for effective strategies aimed at increasing adherence among patients.

Despite the worthwhile findings, this study has certain limitations. The sample population included students of Long Island University, Brooklyn. Although this presents an ethnically diverse group of participants, the participants were in general young adults, whose thoughts, opinions and beliefs may differ from that of an adult population as well as elderly population. An attribute of young adults that may have contributed to findings of this study is the fact that the young adults that participated in this study lived in a city as cosmopolitan as New York City. Another attribute of the participants is their education level; all participants were either under-graduate level or graduate level students. For future studies, it would be interesting to compare the findings of this study and a similarly designed study in a rural and undereducated group of young adults. Additionally, future studies could also focus on a similarly designed study to be conducted in an elderly population to make comparisons in perspectives of CRN this study population versus an elderly population.

In summary, the findings of this study are based on perspectives of young adults, with undergraduate/graduate level education, living in a cosmopolitan city. It would be interesting to compare the results of this study with various other sections of the society.

REFERENCES

1. National Bureau of Economic Research Website. <http://www.nber.org/data/>.
2. Robert Wood Johnson Foundation, *High and rising health care costs: Demystifying U.S. health care spending*, October 2008.
3. Distribution of Healthcare Expenses, 1996. May 2000. *Medical Expenditure Panel Survey Highlights*. Rockville, MD: Agency for Healthcare Research and Quality. Pub. No. 00–0024.
4. J.D. Piette, A.M. Rosland, M.J. Silveira, R. Hayward and C.A. McHorney CA, “Medication cost problems among chronically ill adults in the US: did the financial crisis make a bad situation even worse?,” *Patient preference and adherence*. 2011, 5, 187.
5. S.B. Soumerai, M. Pierre-Jacques, F. Zhang, D. Ross-Degnan, A.S. Adams, J. Gurwitz, G. Adler, D.G. Safran, “Cost-related medication non-adherence among elderly and disabled Medicare beneficiaries,” *Arch Intern Med*. 2006, 166:1829–1835.
6. D.G. Safran, P. Neuman, C. Schoen, “Prescription drug coverage and seniors: how well are states closing the gap?,” *Health Aff*. 2002, W253–W268.
7. J.D. Piette, M. Heisler, TH. Wagner, “Cost-related medication underuse among chronically ill adults: the treatments people forgo, how often, and who is at risk,” *Am J Public Health*. 2004, 94:1782–1787.

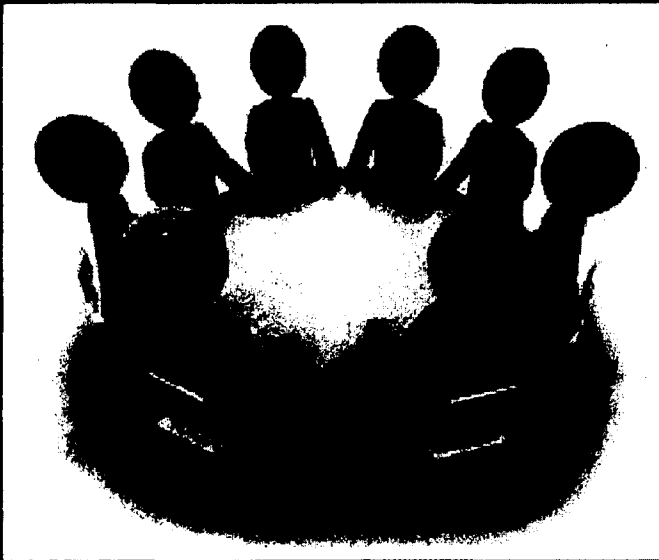
8. M. Heisler, K.M. Langa, E.L. Eby, A.M. Fendrick, M.U. Kabeto, J.D. Piette, "The health effects of restricting prescription medication use because of cost," *Med Care*. 2004,42:626–34.
9. J.E. Kurlander, E.A. Kerr, S. Krein S, M. Heisler and J.D. Piette, "Cost-Related Nonadherence to Medications Among Patients With Diabetes and Chronic Pain Factors beyond finances," *Diabetes Care*. 2009, 32(12), 2143-2148.
10. R. Tamblyn, R. Laprise, J.A. Hanley, M. Abrahamowicz, S. Scott, N. Mayo, J. Hurley, "Adverse events associated with prescription drug cost-sharing among poor and elderly persons," *JAMA*. 2001, 285(4), 421-429.
11. M. Heisler, K.M. Langa, E.L. Eby, A.M. Fendrick, M.U. Kabeto and J.D. Piette, "The health effects of restricting prescription medication use because of cost," *Medical care*. 2004, 42(7), 626-63.
12. M. Heisler, T. Wagner, J.D. Piette, "Patient strategies to cope with high prescription medication costs: who is cutting back on necessities, increasing debt, or underusing medications?," *J Behav Med*. 2005, 28:43–51.
13. J.M. Madden, A.J. Graves, F. Zhang, A.M. Adams, B.A. Briesacher, D. Ross-Degnan, J.H. Gurwitz, M. Pierre-Jacques, D.G. Safran, G.S. Adler, S.B. Soumerai , "Cost-related medication non-adherence and spending on basic needs following implementation of Medicare Part D," *JAMA*. 2008, 299:1922–1928.

14. I.B Wilson, W.H. Rogers, H. Chang, D.G. Safran, "Cost-related skipping of medications and other treatments among Medicare beneficiaries between 1998 and 2000. Results of a national study," J Gen Intern Med. 2005, 20:715–20.
15. W.F. Gellad, J.S. Haas, D.G. Safran, "Race/ethnicity and non-adherence to prescription medications among seniors: results of a national study," J Gen Intern Med. 2007, 22:1572–8.
16. M. Heisler, T.H. Wagner, J.D. Piette, "Patient strategies to cope with high prescription medication costs: who is cutting back on necessities, increasing debt, or underusing medications?," J Behav Med. 2005, 28:43–51.
17. J.D. Piette, M. Heisler, "Problems due to medication costs among VA and non-VA patients with chronic illnesses," Am J Manag Care. 2004, 10:861–8.
18. B.G. Saver, M.P. Doescher, J.E. Jackson, P. Fishman, "Seniors with chronic health conditions and prescription drugs: benefits, wealth, and health," Value Health. 2004, 7:133–43.
19. J.D. Piette, A. Beard, A.M. Rosland and C.A. McHorney, "Beliefs that influence cost-related medication non-adherence among the "haves" and "have nots" with chronic diseases," Patient preference and adherence. 2001, 5, 389.
20. K. Zivin, S. Ratliff, M. Heisler, K.M. Lnga, J.D. Piette, "Factors Influencing Cost-Related Nonadherence to Medication in Older Adults: A Conceptually Based Approach," Value in Health. 2010,13:4.

21. R.A. Powell and H.M. Single, "Focus groups," *International journal for quality in health care*. 1996, 8(5), 499-504.

APPENDIX A

Participation flyer



**VOLUNTEERS NEEDED FOR A FOCUS GROUP STUDY AT BROOKLYN
CAMPUS**

**STUDY TITLE: PUBLIC PERSPECTIVES ON COST-RELATED NON-
ADHERENCE AMONG PATIENTS**

Merena Nanavaty, a Pharmacy Administration student, and Dr. Shah, Department of Social and Administrative Sciences, would like to hear your viewpoints and perspectives on what factors influence cost-related non-adherence behaviors

If you are 18 years or older, a student of LIU and would like to participate in this study, please come to Room # __ at the __ building on mm/dd/yy. For more information email at merenashervar.nanavaty@my.liu.edu or bupendra.shah@liu.edu, or call us at 917-769-3535 or 718-780-4593 and we will answer all your questions.

Refreshments will be served

YOUR THOUGHTS AND OPINIONS MATTER TO US!

APPENDIX B

Consent form

LONG ISLAND UNIVERSITY (*Brooklyn Campus*)

Informed Consent Form for Human Research Subjects

I am being asked to volunteer in a research study called *Public perspectives on cost-related non-adherence among patients*, conducted by Merena Nanavaty, Graduate Student, Pharmaceutical Sciences, Long Island University under the guidance of Dr. Shah, Associate Professor, Pharmaceutical Sciences, Arnold and Marie Schwartz College of Pharmacy and Health Sciences, Long Island University. The purpose of the research is to study beliefs about the factors that cause medication non-adherence in patients and how it can be improved.

As a participant of this focus group, I will be asked questions in a group or individually in a session that may last around 60 minutes. The opinions I share in this focus group will provide insights in understanding factors that influence medication non-adherence by patients and in creating strategies to reduce medication non-adherence.

My identity as a participant in this study will remain confidential. My name will not be included in any forms, questionnaires, etc. This consent form is the only document identifying me as a participant in this study; it will be stored securely in lock and key in

the office of the faculty identified above at the College of Pharmacy, Long Island University available only to the investigators. Data collected will be destroyed at the end of a legally prescribed period of time of 3 years. Results will be reported only in the aggregate. If I am interested in seeing these results or if I have questions about the research, I may contact Ms. Merena Nanavaty at 917-769-3535/merenasheryar.nanavaty@liu.edu or the faculty advisor Dr. Bupendra Shah at 718-780-4593 or email him at bupendra.shah@liu.edu. If I have questions concerning my rights as a subject, I may contact the Executive Secretary of the Institutional Review Board, Ms. Kathryn Rockett at (516) 299-2523. My participation in this research is voluntary. Refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled, and I may discontinue participation at any time without penalty or loss of benefits to which I am otherwise entitled.

I have fully read the above text and have had the opportunity to ask questions about the purposes and procedures of this study. My signature acknowledges receipt of a copy of the consent form as well as my willingness to participate.

Typed/Printed Name of Participant

Signature of Participant,

Date

Merena Nanavaty

Signature of Investigator

Date

Dr. Bupendra Shah_____

Signature of Investigator

Date

APPENDIX C

Introduction and ground rules

1. Welcome

I thank each and every one of you for taking time out from your busy schedules and agreeing to be part of this focus group. We appreciate your willingness to participate.

2. Introductions

Moderator: Merena Nanavaty

Note-taker: Dr. Bupendra Shah

3. Purpose of the focus group

Moderator: As a part of my graduate program at Long Island University at Brooklyn, NY, I'm conducting a study to assess the different issues that patients might face as far as being adherent to their medication. For this, I need your input and want you to share your honest and open thoughts with us today. This should take around 60 minutes.

4. Ground rules

- a. We would like everyone to participate.
- b. There is no right or wrong answer. Every person's experiences and opinions are important. Speak up whether you agree or disagree. We want to hear a wide range of opinions.
- c. What is said in this room remains here. We want you to feel comfortable sharing when sensitive issues come up.

d. We will be taking notes because we want to capture everything you have to say.

However, we will not identify anyone by name in our notes and reports. You, your thoughts, and your opinions will remain anonymous.

APPENDIX D

Focus group questions

1. In your opinion, why do patients fail to take their medications as prescribed?
2. In your opinion, is affordability of medications a big reason why patients may not take their medications as prescribed? (Probes: Why are medications not affordable?)
3. How do you feel about the out-of-pocket costs of medications and its relationship to non-adherence?
 - a. At what \$ amount of total out-of-pocket costs would a patient consider not taking their medications? (Probes: One medication? Two medications? Per medication?)
 - i. Higher end of \$ amount?
 - ii. Lower end of \$ amount?
4. Each of you have been handed a document that consists of a list of factors that were studied by several researchers in the past for their association with cost-related non-adherence.
 - a. In your opinion, which of these factors are important contributors to cost-related non-adherence?
 - b. How would you rank the level of importance of these factors? (Please provide ranking for each factor on the document itself)

5. In your opinion, what can be done to help patients reduce cost-related non-adherence?

6. In your opinion, what has been the effect of the recent recession on patients' ability to afford medications?

a. Do you think cost-related non-adherence increased during the recession?

b. Do you know people who were adherent to their medications but started becoming non-adherent due to the effects of recession?

7. Any comments, suggestions?

APPENDIX E

Handout for ranking factors associated with cost-related non-adherence

Given below are names (in bold) of factors and their definitions (in parenthesis). Please read each factor and provide a rank using the following ranking scale:

0: Not at all an important contributor to a patient's medication-taking behavior

1 : Slightly important contributor to a patient's medication-taking behavior

2 : Moderately important contributor to a patient's medication-taking behavior

3 : Very important contributor to a patient's medication-taking behavior

4 : Extremely important contributor to a patient's medication-taking behavior

1	Patient's annual household income [Total yearly income of the household]	0	1	2	3	4
2	Patient's prescription coverage [Whether the patient has health insurance and the type of health insurance]	0	1	2	3	4
3	Patient's out-of-pocket costs [Medication costs paid by patients themselves out of pocket]	0	1	2	3	4

4	Other health costs [Costs associated with healthcare services such as lab tests, x-rays etc.]	0	1	2	3	4
5	Patient's financial net worth [A patient's total assets minus total liabilities]	0	1	2	3	4
6	Patient's sociocultural influences [How the cultural background and society the patient lives in affects their decision regarding their medication-taking behavior]	0	1	2	3	4
7	Perceived benefits of treatment [How well the patient thinks the medication benefits them]	0	1	2	3	4
8	Patient's job status [Whether the patient is employed or not]	0	1	2	3	4
9	Patient's marital status [Whether the patient is married or not]	0	1	2	3	4
10	Patient lives alone [Whether the patient lives alone or with a caregiver]	0	1	2	3	4
11	Patient's family member lives within 10 miles	0	1	2	3	4

	[Whether a family member(s) lives within 10 miles]				
12	Patient's mental status [How often the patient has felt depressed/anxious/happy recently]	0	1	2	3 4
13	Patient's self-efficacy [How confident the patient is about taking their medication(s) as prescribed]	0	1	2	3 4
14	Patient's health literacy [How well the patient is able to read understand and apply the information or instructions provided on prescription bottles and other informational materials]	0	1	2	3 4
15	Patient's trust in making decisions about health insurance [Whether the patient trusts others for making decisions about their health insurance such as MD, family, others]	0	1	2	3 4
16	Adverse effects of the prescription [Whether the patient has experienced side-effects or had bad experiences from taking the medication(s)]	0	1	2	3 4
17	Dosing complexity of the prescription [How many times a single medication has to be taken by the patient each day, for example, three times a day/ four times a day etc.]	0	1	2	3 4

18	Perceived need of the prescription [The extent to which the patient feels that it is necessary to take the medication(s) to feel better]	0	1	2	3	4
19	Physician's knowledge of Rx costs [To what extent the patient feels that his MD knows about the cost of the medication(s) being prescribed]	0	1	2	3	4
20	Physician's therapeutic choice [To what extent the patient feels that the MD chooses a medication(s) based on the best choice for improving the patient's condition(s)]	0	1	2	3	4
21	Physician fostering trust [To what extent the patient trusts that the MD will prescribe a medication(s) to improve their condition(s) regardless of costs]	0	1	2	3	4
22	Healthcare provider discussion about Rx cost [How often the patient's MD and pharmacist has talked to them about the cost of their medication(s)]	0	1	2	3	4
23	Referral to Rx cost assistance programs [How often the patient's MD and pharmacist has referred them to prescription cost assistance programs]	0	1	2	3	4

24	Number of Rx [The number of medication(s) the patient is taking for their condition(s)]	0	1	2	3	4
25	Frequency of refills [How often the patient needs to refill their medication(s)]	0	1	2	3	4
26	Healthcare provider screening for Rx cost problems [How often the patient's MD and pharmacist has examined the patient profile or asked the patient if they had any problem paying for their medication(s)]	0	1	2	3	4
27	Patient barriers to refilling Rx [How often the patient's MD and pharmacist has examined the patient profile or asked the patient if they had any problem refilling their medication(s)]	0	1	2	3	4
28	Patient barriers to applying for prescription benefits [How often the patient's MD and pharmacist has examined the patient profile or asked the patient if they had any problem applying for benefits to afford their medication(s)]	0	1	2	3	4
29	Prescriber incentives [How often the patient feels that their MD has prescribed them a medication(s) because of the benefits he/she receives from pharmaceutical companies]	0	1	2	3	4

30	Effect on patient's quality of life [How taking/not taking the medication would affect the patients' ability to engage in day-to-day activities]	0	1	2	3	4
31	Patient's burden of chronic illness [The extent to which the number of chronic conditions (such as hypertension, diabetes, stroke etc.) that would affect the patient's ability to take their medication(s)]	0	1	2	3	4

The total number of over-the-counter medications you have used in the past 30 days: _____

The total number of prescription medications used in the past 30 days: _____

CURRICULUM VITA

MERENA NANAVATY

196-20, 89th Ave, Queens, New York – 11423 • 917-769-3535 • merena.sn@gmail.com

Honors Graduate with research background in the Masters Program at Long Island University and one year part-time Internship experience in healthcare consulting, seeking a position to apply relevant skills and gain hands-on experience

Educational Background

- ❖ Master of Science in Pharmaceutical Administration Graduation May 2014
Long Island University – Brooklyn Campus, NY GPA: 3.85
- ❖ Bachelor of Pharmacy Sep 2006 – May 2010
Malla Reddy Institute of Pharmaceutical Sciences, India GPA: 3.9

Professional Experience

- ❖ Intern at Market Access Solutions LLC, NJ Oct 2012 – Dec 2013
 - Conducted two Systematic Literature Reviews in the Autoimmune disease area to be published in relevant journals and presented at International and European ISPOR Conferences
 - Conducted a Payer Segmentation and HTA Processes study in the EU5 market
 - Created a Core Value Prospectus in the Cardiovascular disease area
 - Contributed to a Global Value Dossier in the Bariatrics area
 - Conducted secondary research for the creation of a database in the Oncology area
 - Assisted with health economics and modeling research and analysis

- Prepared presentation decks for kick-off meetings, proposals and client reports
- Assisted with client communication, meeting scheduling and meeting minutes

- ❖ HeOR Assistant at Arnold Consultancy & Technology LLC, NY Aug 2011 – Dec 2011
 - Contributed to research for a Budget Impact Analysis and a Cost-effectiveness Analysis for an Oncology product in the Chinese market
 - Hands-on experience with TreeAge Pro and MS Excel based modeling
- ❖ Research Assistant at Long Island University, Brooklyn, NY Sept 2011 – May 2012
 - Assisted with literature reviews, data compilation, data entry, statistical analysis and presentation of reports
 - Served as Moderator/Facilitator for student focus groups

Technical Skills

- ❖ Microsoft Office, TreeAge, SPSS, SAS

Academic Research Experience

- ❖ Graduate Thesis
 - Public Perspectives on Cost-related Non-adherence
- ❖ Undergraduate Thesis
 - Synthesis of novel Benzimidazole derivatives for anti-helminthic and anti-bacterial activity

Honor/Certification/Membership

- ❖ The Rho Chi Honor Society
- ❖ Human Subjects Protection Training by NIH
- ❖ Consistent Undergraduate Honor Roll
- ❖ Member of ISPOR & ISPE