The Medication Mismanagement System:
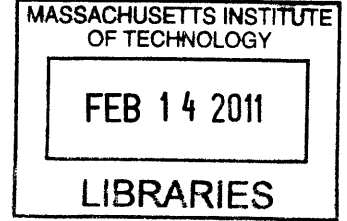## Causes, Evidence of User Innovation, and a View Towards a Product/Service Solution for the Elderly

By

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Dedication

Thank you,

Mom, for my outgoing nature.

Dad, for my love of learning.

Amanda, for keeping me young.

Sue, for our wonderful little home.

And to all of the brilliant people I have met along the way at MIT and Lifeline.

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1 Introduction and Overview

What could be easier than taking a pill? The doctor prescribes it, the pharmacist provides it and the patient swallows it with a glass of water twice a day for a cure; a very straightforward system of cause and effect. Unfortunately, statistics show that 66% of all Americans fail to take any of their prescription medicines (American Heart Association, 2009) and as a result many of the medical innovations that have increased life expectancy by 47 years since 1900 (Wan He, 2005) remain left unclaimed.

So why than do Seniors, facing the pain of arthritis or the impending certainty of death from congestive heart failure, refuse to take their pills? The first half of this thesis seeks an answer to this question while debunking the view that this is a simple problem of ignorance or laziness on the part of the patient. In place of this oversimplified view, the problem of "medication management" is defined and cast in an in-depth and nuanced way that includes issues involving the patient, their caregiver, the disease state, social circumstances and financial constraints.

The second half of this thesis focuses on possible solutions. While rethinking the entire medication system can result in great gains, the innovations discussed (both lead user and off-the-shelf innovations) all work within the current medication system and are addressable by product/service designers. By adhering to these two constraints the resulting solutions remain quickly implementable, cost effective and relevant to industry. In the end we find that end users have created a series of innovations and product modifications that address the physical and cognitive barriers they face, while product

manufactures are innovating products and services that address the motivational issues users face.

The Problem: Medication Mismanagement (Chapter Two)

The scale and consequences of patients not properly taking their medications is both widespread and detrimental. Chapter Two begins by outlining the size of the problem and demonstrates that NOT taking your medication is often the unfortunate case. Proving the adage, "an ounce of prevention is worth a pound of cure" the result of having to treat the consequences of missed medication adds $290 billion annually (New England Healthcare Institute, 2009) into the healthcare systems. Clearly this is a problem deserving more attention.

Chapter two then continues by adopting the term "medication management" as the most generic definition of the problem (compliance, adherence, persistence, etc. all being subcategories). This term is favored as "management" implies the ongoing control over a process rather than the other terms that shift the focus on a onetime end result. From this first pass we begin to see the complexity inherent in the problem.

Overview of the Senior Population (Chapter Three)

Chapter three takes a step back from the specifics of medication management and provides a detailed overview of the Senior population. This portrait is explored from three different angles; their demographics (the hard numbers), their circumstances (common chronic conditions), and their lives (market segmentation based on worldview). By the end of this chapter we reveal that not only are Seniors the fastest growing demographic group, they exert the largest impact on the medical system, suffer

from the most chronic conditions, take the most medications, run into the most problems (social, physical and cognitive) and, therefore, have the greatest need for a workable solution.

Causes of Medication Mismanagement for Seniors (Chapter Four)

Using both medication mismanagement and Seniors a backdrop, Chapter four sets out to provided a detailed framework for understanding the causes of the problem and sheds some light on why Seniors facing almost certain negative health consequences would refuse to take his or her pills. Firstly, a simple (and commonly used) five step model of the problem is defined. It is shown that, while this model is straightforward, it does not adequately explain the source of the problem and does not suggest the points of intervention with enough leverage to make a lasting impact. Moving beyond this model, the Complex Systems Model is defined from the point of view of the Senior population with relevant statistical information. In this model proper medication management is treated as an emergent quality of five interacting dimensions: "Economic and Social", "Healthcare System", "Patient", "Condition" and "Therapy". Each is discussed at length and the chapter concludes with a survey of patients that confirms the issues outlined.

The Solutions: Product/Service Innovation Focused (Chapter Five)

Chapter Five transitions the discussion from the problem space of medication mismanagement to the solution space of product/service innovation. While rethinking the entire medication system - what roles it gives doctors, pharmacists, and nurses, how it chooses to see and interact with patients, or the incentives it provides patients and

caregivers – would result in great gains, it remains beyond the scope of this thesis and most companies interested in finding solutions. Instead, Chapter Five calls out those parts of problem that will benefit most from solutions in the realm of product/service design and shows why influencing behavior though better design has the highest potential to help Seniors quickly.

Lead User Innovation (Chapter Six)

Chapter Six provides an overview of a number of different studies (focus groups, online interviews, and in home ethnography) carried out with Seniors and other groups facing medication management issues (parents, the blind, etc). These studies were mined for this thesis to show how these groups, in an attempt to make due, are modifying off-the-shelf tools and systems and creating their own innovative solutions. Using the Fogg Behavioral Model we uncover and catalogue a number of systems that reduce cost, overcome physical disabilities, and motivate people through times of denial or depression. By seeing the end user as a source of innovation and not just as a consumer, this chapter recasts these modifications as potential areas of research and development that can lead to successful commercial ventures.

Product/Service Innovation (Chapter Seven)

Chapter Seven explores how traditional device manufacturers and entrepreneurs are addressing the problems of medication management. These off-the-shelf solutions are introduced and critiqued against the Persuasive Technology Framework (Fogg, Persuasive Technology, 2002) that explains how computers can be instrumental in fostering and sustaining behavior change using a set of seven tools (reduction,

tunneling, tailoring, suggestion, self-monitoring, surveillance, conditioning). Three products that cover the spread of solutions available to Seniors today are discussed; a low tech approach (The Pill Box), a high tech approach with complementary monitoring service (The Philips Medication Dispenser) and a mobile software service (The Caregiver Iphone App).

Conclusion (Chapter Eight)

In the final chapter, with the complexity of the medication management problem understood and how this problem has driven users and manufactures alike to create innovations, limitation and next steps are pointed out. End users (seniors, caregivers, and other suffers of chronic diseases) have mostly explored solutions that focus on improving the physical and cognitive effort required to take the medication. While manufacturers, on the other hand, are starting to create devices and/or services that aim to shape and trigger behavior by using the techniques of persuasive technologies. While the exact design solutions are not clear, the suggested next step is to use the frameworks presented to continue researching, innovating and evaluating new solutions and to expand the scope of solutions to include a wider range of participants (doctors, nurses, pharmacists and other actors) whose behaviors also has a role in medication management.

2 The Problem: Medication Mismanagement

"Drugs don't work in patients who don't take them."

- C. Everett Koop, MD, 13th Surgeon General of the United States

2.1 Scale and Consequences

In the United States, 90% of older adults use one or more prescription medications per week (Gurwitz JH, 2003), while 32 million Americans take three or more medications daily (American Heart Association, 2009). Add it all up and you get an industry that dispenses 2.7 billion prescriptions a year, with $110 billion in annual sales (American Heart Association, 2009). The full story shows a lot happens between your doctor appointment and your morning pills.

The American Heart Association, as part of their "Live and Learn" program, published the following list of alarming statistics:

- 66% of all Americans fail to take any of their prescription medicines

- 29% of Americans stop taking their medicine before it runs out

- 22% of Americans take less of the medication than is prescribed on the label

- 59% of those on five or more medications are taking them improperly

- 50% or more people with chronic diseases don't follow their physician's medication guidance

- The average length of stay in hospitals due to medication noncompliance is 4.2 days

And it gets worse. In one study (Andreas Storm, 2008) comprised of hospital outpatients, 31% of patients who visited their doctor complaining of a problem NEVER

made it to the pharmacist to acquire the solution they asked for. While those with short-term diseases (infections and mycoses) fared better than those suffering from chronic diseases (psoriasis and eczema), non-cooperation was commonplace for both groups. As the study continued, it was determined that 50% of patients failed to renew their prescription a second time and 10% of patients never showed up for treatment again. The net result is that roughly 70% of patients cannot be trusted to follow doctor's orders.

So we see, despite the seeming ubiquity of medicine in our lives and the full acceptance of easy health through pill popping, the fact remains that many people fail to take their medication and the consequences of this inaction are severe. The New England Healthcare Institute estimates if a solution presented itself healthcare expenditures could reduce by $290 billion annually (New England Healthcare Institute, 2009). Similarly, the American Heart Association estimated hospital admissions could be reduced by 10% and the 23% of nursing home admissions resulting from patients failing to take their prescription medications accurately could be avoided. If only we could get people to take their medicine.

2.2 Common Definitions

As the statistics show, the phenomenon of people failing to take their medicine is wide-spread. As such, a variety of terminology has been created to define the problem. The phrases non-adherence or non-compliance, often used interchangeably and ambiguously, refers to someone not taking their medication for any reason, at any time. For the purposes of clarity this paper will use the following more clearly defined set of definitions.

- **(Miss) Management** – This is the term I have adopted to act as the most generic definition of the problem (compliance, adherence, persistence, etc. all being subcategories). I also prefer this term because management implies the ongoing control over a process rather than the other terms which shift the focus on an end result.

- **(Non) Compliance** – the amount which a person's actions follow the recommendations of their doctor. Compliance can include lifestyle changes and behavior changes in addition to the prescription regime.

- **(Non) Attendance** – the amount which a patient sees their doctor as scheduled.

- **Primary (Non) Adherence** – the act of filling the first prescription and starting treatment.

- **(Non) Acceptance** – the act of refilling the prescription and remaining on treatment a second time.

- **(Non) Persistence** – the act of being compliant till the end of treatment.

- **Secondary (Non) Adherence** – Either willfully or inadvertently taking the correct or incorrect dose of medication. Reasons include,
  - Missing a dose
  - Having more of a drug than prescribed
  - Having a dose at the incorrect time
  - Having a medication not prescribed to you
  - Having a dose with banned foods, drinks, and other drugs
  - Having expired medications
  - Keeping medications in the wrong environment
  (ASCP Foundation and American Society on Aging, 2006)

Using these definitions, the complexity required for full compliance begins to reveal itself. Compliance is a function of multiple doctors visits, many trips to the pharmacy, and following detailed instructions regarding dose, frequency, timing, etc. Furthermore, this activity is frequently managed over an extended period of time that can last days, weeks, or even a lifetime depending on particular diseases. We also see that while someone may think they are taking their medication, and thus would technically count themselves as adherent, they may be unintentionally doing something wrong as described in the category of secondary adherence. These subtle problems – which can potentially have catastrophic consequences – are often missed by the treating physician and thus not counted in many studies on the subject.

3 Overview of the Senior Population

3.1 Their Numbers: Demographics

Pick just about any age group, ethnicity, medical condition or social group and you will find numerous examples of medication non-adherence. The problem is universal. However, the senior demographic and their relationship to medication is particularly interesting to study (and is the main focus of this thesis) as this group exerts the largest impact on the medical systems, suffers from the most chronic conditions, takes the most medications, run into the most problems (physical, social and cognitive) and, therefore, have the greatest need for a workable solution.

The National Institute on Aging and the U.S Census Bureau tell a detailed story of aging in America (Wan He, 2005). In review, The Current Population Report counts 18.3 million people between the ages of 65 – 74, 12.9 million aged 75 -84 and 4.7 million people over 85 years old. These three groups, collectively referred to as Seniors, represent 12% of the total US population and this percentage is about to explode with the addition of the aging Baby Boomers. Projections for 2030 place this oldest segment at 72 million people or 20% of the US population.

The key driver to the increase in the number of seniors relative to other age demographics is a dramatic increase in life expectancy. In 1900 average life expectancy was only 47.3 years! A hundred years later people gained 34.6 years onto the end of their life. In addition, the number of centenarians increased from 37,000 in 1990 to 50,000 in 2000. Great advances in the treatment of many chronic conditions such as

heart disease (bypass surgery) and cancer (earlier screening, better radiation and chemotherapy treatments) all contributed to the improvement of this number.
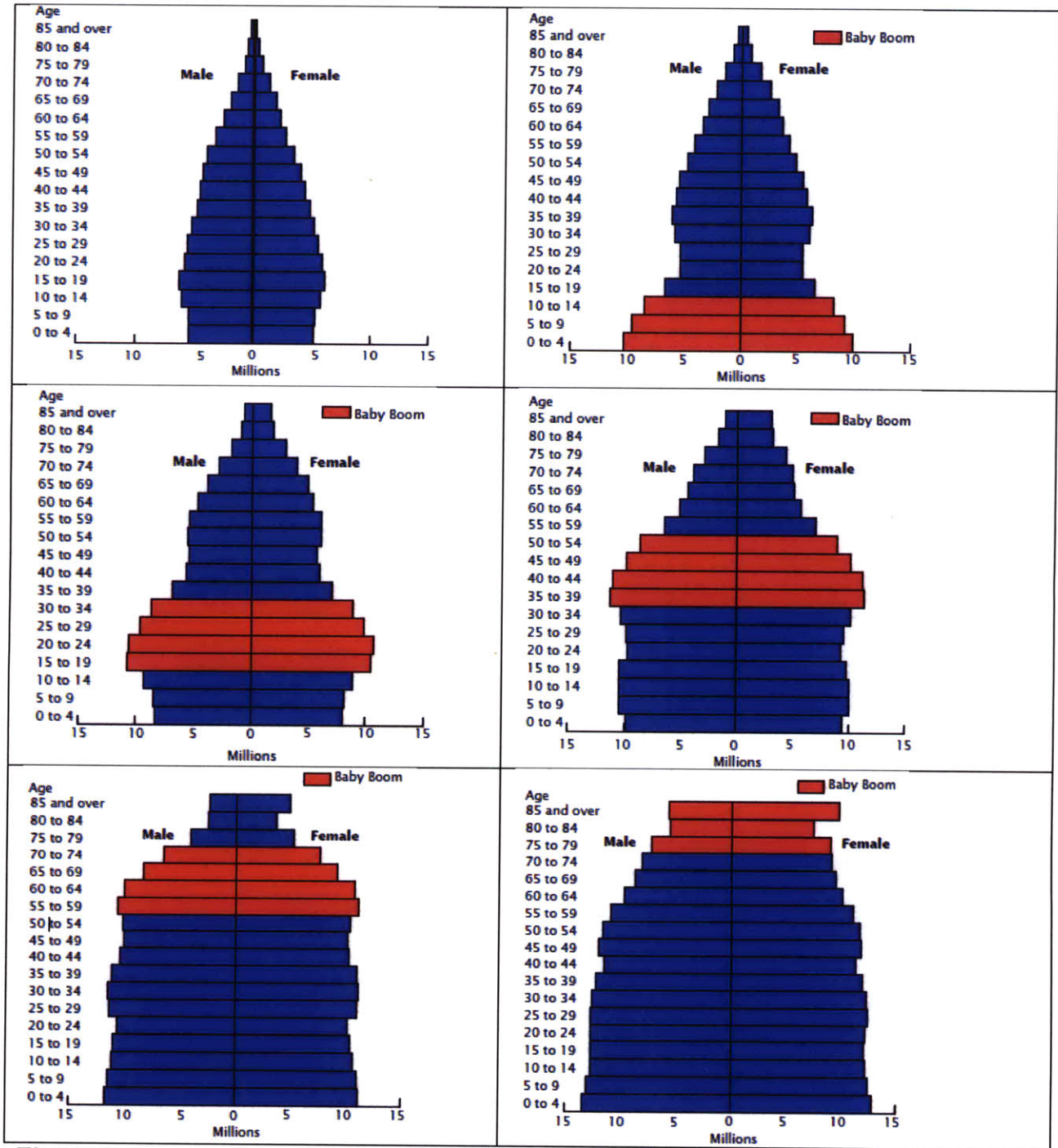
Figure 1: Pop by Age and Sex: 1940, 1960, 1980, 2000, 2020, 2040(L->R)

3.2 Their Circumstances: Chronic Conditions

When people live longer they have more time to get sick. This demographic transition has led to an increased prevalence of chronic illnesses, which make them a particularly relevant population segment to study regarding the problem of medication mismanagement. Pneumonia (inflammation of the lungs), COPD (decrease elasticity of the lungs), Emphysema (obstruction in the lunges), Angina (heart pain cause by inefficient coronary arteries), Myocardial Infarction (coronary artery blockage), Parkinson's Disease (lack of dopamine in the brain), Osteoarthritis (worn cartilage), Rheumatoid Arthritis (whole body cartilage degradation), Gout (excessive liver production), Diabetes (insulin resistance), depression (continually feeling down), are all common inflictions that require a lot of medication, usually for extended periods of time. 80% of seniors have at least one chronic health condition and 50 percent have at least two. (Wan He, 2005)Not surprisingly, as a result Seniors consume more prescription medications than any other age group, with rates three times higher per capita than the general population. This amounts to 50% of all prescription medication taken in the world (World Health Organization, 2003).

Condition	Age 65+	Age 75+
Arthritis	46.9%	47.4%
Hypertension	34.0%	34.2%
Hearing Impairment	26.8%	31.8%
Cataracts	15.5%	21.5%
Heart Disease	14.2%	15.7%
Sinusitis, chronic	14.1%	13.5%
Diabetes mellitus	9.5%	8.9%
Tinnitus	8.4%	7.9%
Cardiac arrhythmia	8.3%	9.7%
Visual impairment	7.7%	9.9%
Allergic Rhinits	7.5%	6.2%
Bronchitis, chronic	5.7%	5.1%
Constipation, frequent	5.1%	7.6%
Glaucoma	5.0%	7.3%
Asthma	4.7%	4.2%
Thyroid disorders	4.5%	4.3%
Emphysema	4.3%	3.8%
Gout	3.5%	3.8%
Ulcer	3.0%	2.3%
Migraine Headache	2.0%	1.6%
Anemia	1.9%	2.3%
Psoriasis	1.4%	1.2%
Speech impairment	0.8%	0.5%
Seizure disorder	0.5%	0.5%

Figure 2: Common Chronic Conditions Among the Elderly in the United States (The ASCP Professional Affairs Department, 1996)

"Crabbit Old Woman" By Phyllis McCormack

What do you see, what do you see?

Are you thinking, when you look at me-

A crabbit old woman, not very wise,

Uncertain of habit, with far-away eyes,

Who dribbles her food and makes no reply

When you say in a loud voice, I do wish you'd try.

Who seems not to notice the things that you do

And forever is loosing a stocking or shoe.

Who, unresisting or not; lets you do as you will

With bathing and feeding the long day is fill.

Is that what you're thinking, Is that what you see?

Then open your eyes, nurse, you're looking at me.

I'll tell you who I am as I sit here so still!

As I rise at your bidding, as I eat at your will.

I'm a small child of 10 with a father and mother,

Brothers and sisters, who loved one another-

A young girl of 16 with wings on her feet,

Dreaming that soon now a lover she'll meet,

A bride soon at 20- my heart gives a leap,

Remembering the vows that I promised to keep.

At 25 now I have young of my own

Who need me to build a secure happy home;

A woman of 30, my young now grow fast,

Bound to each other with ties that should last;

At 40, my young sons have grown and are gone,

But my man's beside me to see I don't mourn;

At 50 once more babies play around my knee,

Again we know children, my loved one and me.

Dark days are upon me, my husband is dead,

I look at the future, I shudder with dread,

For my young are all rearing young of their own.

And I think of the years and the love that I've known;

I'm an old woman now and nature is cruel-

Tis her jest to make old age look like a fool.

The body is crumbled, grace and vigor depart,

There is now a stone where I once had a heart,

But inside this old carcass, a young girl still dwells,

And now and again my battered heart swells,

I remember the joy, I remember the pain,

And I'm loving and living life over again.

I think of the years all too few- gone too fast.

And accept the stark fact that nothing can last-

So open your eyes, nurse, open and see,

Not a crabbit old woman, look closer-

See Me.

3.3 Their Lives: Market Segmentations

A nurse found this poem, as internet legend has it, while she packed Phyllis McCormack's belonging shortly after she passed away in a nursing home in Ireland. While its origins remain under debate, the poem's message is clear: regardless of appearances, always keep in mind the person and not just the outward appearance of the person under your care.

While the US Census report accurately portrays the collective story of the rise of the senior class, it fails to shed light on the personal motivation and challenges they face. As we will see later in this paper, both the large demographic trends and the intimate details of seniors lives (motivations, inspirations, determents, etc) equal shape the mismanagement problem. What the census data fails to show is that not all seniors are alike, they cannot be stuffed into a single category, and any solution that treats them as a single group will fail.

George Moschis wrote one particularly useful framework that gives a view into the personal motivation of seniors in his book, "Gerontographics" (Moschis, 1996). Dr. Moschis segmented the elderly population into four groups (Healthy Hermits, Healthy Indulgers, Ailing Out-goers, and Frail Recluses) not based upon their age but rather by their social outlook and the state of health (SEE FIGURE). He found that products and service needed to be marketed and designed uniquely for each of the four types.
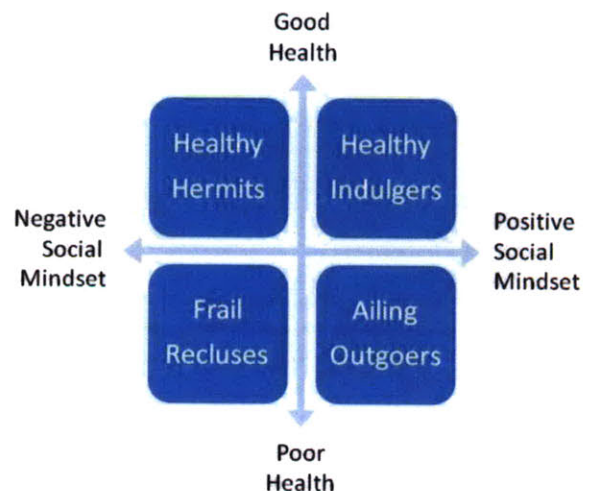
Figure 3: The Moschis Segmentation

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4 Causes of Medication Mismanagement for Seniors

It seems unthinkable that Seniors facing the pain of arthritis or the impending certainty of death from congestive heart failure would refuse to take his or her pills. What could be easier than taking a pill? The doctor prescribes it, the pharmacist provides it and the patient takes it with a glass of water twice a day; a very straightforward system of cause and effect.

Amazing advances have re-defined medicine in the last 30 years. Diseases that once were a death sentence are now curable. Until the 1970's, heart disease generally went undiagnosed until it announced itself suddenly as a heart attack, often killing its victim. The revolutions of heart bypass surgery and statins have transformed heart disease today into a treatable chronic illness and not a deadly acute illness.

So what is keeping people from taking advantages of these medical breakthroughs?

4.1 The Simple View of the Problem

The Center for Technology and Aging (Center for Technology and Aging, 2009) perfectly illustrates the prevailing view of medication use. In their five-step model, each step is carried out in sequence in a never-ending loop. First, the doctor assesses the patient's needs, which are accurately articulated by the patient and understood by the doctor. The doctor then translates the patients' assessment of symptoms into the proper medical treatment and prescribes the appropriate drugs. The medication is then dispensed by the pharmacist, picked up by the patient and the instructions for use are conveyed. The patient goes home, takes the dose at the right time, in the right amount, and for the right length of time. The treatment is monitored and the doctor adjusts the

medication as needed based on check up visits. The cycle repeats until a cure is reached.

Medication Use Process

Assess → Prescribe → Dispense → Administer → Monitor →

Figure 4: The Five Step Model of Medication Compliance (Center for Technology and Aging, 2009)

In this linear view, the system is straightforward, effective, and simple to fix if things go awry. For example, if the person doesn't take their medication it is usually their own fault. Or if the treatment isn't effective than the medication simply needs to be switched for another, problem solved. The problem with this model is that it is too simple to accurately handle the various complexities that often arise. In addition, there are too few points to intervene if the need arises, and the points of intervention the model does suggest don't have enough leverage to make a lasting impact.

This lack of leverage is shown further in the paper as the author suggests solutions to common problems encountered in each step. For example, under the 'Assess' step the goals listed are, "Patient history includes a complete and accurate medication list" and "patient needs are accurately conveyed and understood". The solutions are then given as, "Medication List Software" and "Personal Health Record". What the auther fails to see is, the existance of a Personal Health Record by itsel is not going to ensure that patient needs "are acuratly conveyed and understood" because the root cause of

information being misconveyed or misunderstood are not in the technologies but rather, in the people using the technologies and what biases and goals they bring to the table.

4.2 The Complex Systems View of the Problem

Contrary to this simplified view of the medication system, which places the blame of non-adherence entirely on the mistakes of individuals (patients, physicians, pharmacists, etc), the World Health Organization (WHO) developed a more holistic approach. The WHO conducted a detailed review (World Health Organization, 2003) of the problem of medication management in relation to long term-therapies and suggested that the problem is driven by the design of the system as a whole, not one segment of participants. In fact, patients, who find themselves at the end of the chain, not only *shouldn't* be blamed for non-adherence, but often are doing their best to comply, despite appearances to the contrary. Their ability to comply is impacted by the workings of the entire medication system in which they are participating.

The problems of non-compliance, non-adherence, and non-persistence are emergent qualities of the system and do not trace back to a single doctor in the system not doing their job or to a single, stubborn patient unwilling to take their medications. No one person is to blame. The framework suggested by the WHO divides the medication system into five dimensions: "Economic and Social", "Healthcare System", "Patient", "Condition" and "Therapy"– all of which interact to create a complex, chaotic system. Navigating such a complex system with multiple dimensions becomes critically important for many seniors for whom proper medication management is a life-sustaining activity. In the next sections each of these dimensions is discussed with relevant statistical information added regarding Seniors.

4.2.1 Economic Dimensions

The simple truth is that prescription medicine is not cheap and Seniors often lack the financial resources to meet all of their medication needs. For example, the median annual income for disabled Seniors living alone at home was only $14,160, with a total wealth of $47,913 (this figure mostly represents equity in their primary residence) and only $7,908 in financial assets available to them to meet their expenses for the rest of their lives (Richard Johnson, 2006).

Despite the fact that many Seniors are ill-equipped financially to obtain their own medications, help from outside resources is also limited. Medicaid does not provide benefits to Seniors unless they meet stringent qualification standards of low or no income. As a result, in 2002 only 15.5 percent of frail Seniors and 27.3 percent of Seniors with severe disabilities had Medicaid coverage (Richard Johnson, 2006),

Given the low fixed incomes and lack of Medicaid coverage, medication often competes for resources as Seniors choose between medicine and food, medicine and heat, or medicine and clothing. These competing interests often keep seniors from taking less than the recommend dosage, skipping dosages, or not buying the medication to begin with.
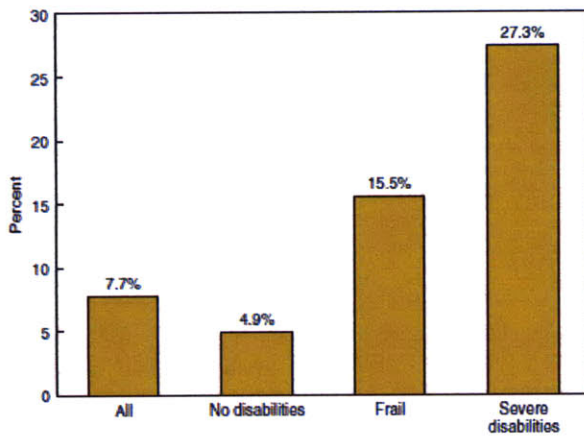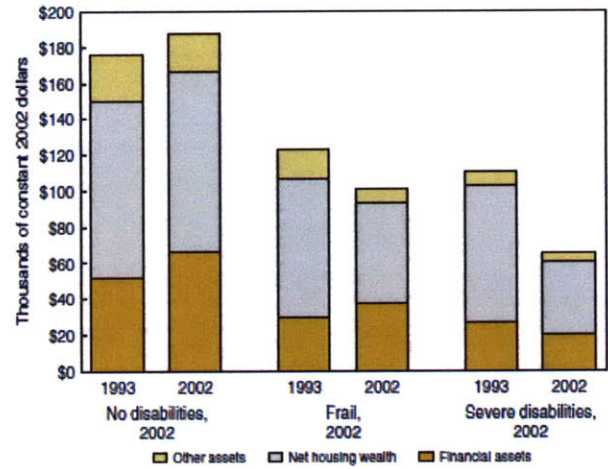
Figure 5: Medicare Coverage and Household Wealth Census Figures

4.2.2 Social Dimensions

Humans are social creatures and as such, their beliefs, decisions, and mental frameworks are shaped and informed by the social norms and institutions around them. If one were to take a step back and look at the problem from an even higher level, they would see that the problem of medication management and its root cause are influenced by a number of social factors.   One such driver is education.   Poor educational systems yield high illiteracy rates which impact Seniors ability to learn proper medication management since they may not be able to read directions given to them by providers or instructions for use printed on the bottle.   In many cases a contributing factor includes lack of adequate social services that either cannot or do not provide education or additional support to the senior population.   In some cases, support is provided but with a lack any cultural sensitivity.

Other social factors impacting medication non-adherence can include unstable living conditions, family dysfunction, or poor environmental conditions. One can imagine it being difficult to adhere to a regimented dosing schedule under changing life conditions or the emotional and psychological stress brought on by family problems. Environments with outside distractions and stress can create a culture which leaves Seniors' prone to an inability to focus on and take responsibility for their own personal care.

(Number of people aged 85 and over per 100 people aged 50 to 64)
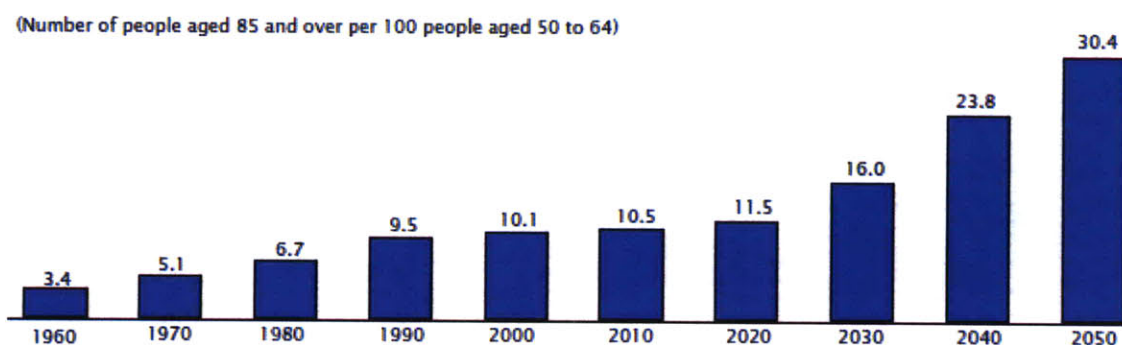
Figure 6: Parent Support Ratios (Wan He, 2005)

The other social dimension to medication adherence is the availability of support (physical, mental, emotional, etc) from family. We all need help, especially when tackling an illness, and seniors are no different. Unfortunately, many demographic trends work against Seniors getting the help they need (see Figure 2 above). While 88.5 percent of seniors got married at some point during their life and stayed married (3 percent of seniors never married and 8.4 then went on to divorce), the sad truth is 31.6 percent of seniors are widowed (Richard Johnson, 2006). This of course leaves them without much of the family support they have leaned on during most of their adult lives.

With their spouse no longer around, many Seniors then rely on the support of their adult children. However, the availability of this support group is also limited. The figure below

depicts parent support ratios, a measure of the ratio of caregivers (people aged 50-64) to seniors (65+). In 1990, there were 9.5 seniors for every 100 hundred caregivers. Today, those same 100 caregivers have to give support to 10.5 seniors (Wan He, 2005). This is a direct result of the aging Baby Boomer demographic trend.

While the majority of support for Seniors comes from a spouse or adult child (as shown in Figure 3 below), many seniors who do not have this option must rely on other relatives or friends and neighbors. As more seniors are widowed and as the parent support ratio decreases, one could assume that Seniors are less able to find and receive the support they truly need to attain full medication adherence.
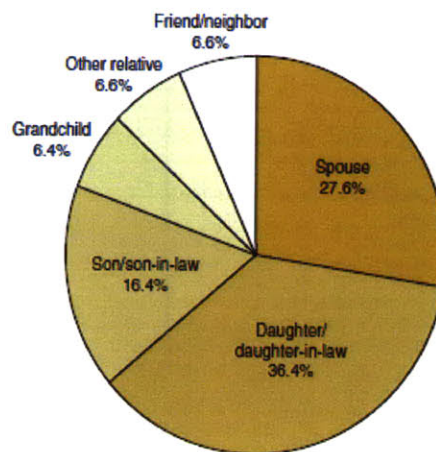
Figure 7: Relationship of Caregiver to Frail Senior (Richard Johnson, 2006)

Even with the full support of a fully competent caregiver, compliance can be less than perfect. Although statistics are not available, the difficulty of being a caregiver is staggering. Daughters give on average 98 hours a month caring for their frail senior, while spouses provide 153 per month. If the senior is severely disabled this number can jump as high as 236 hours per month! (Richard Johnson, 2006). These hours not

only rival a full time job (or beyond) but they also are carried out in addition to a full time job. Given this workload, and the fact that medication adherence is only a small part of the activity caregivers undertake daily, it is easy to see how the mere presence of a caregiver isn't enough to solve the adherence problem. Not only must the caregiver be present, but also focused enough to assure proper medication.

4.2.3 Healthcare System Dimensions

At the start of any medication regime is the prescription. A prescription written by a doctor. A doctor who, like the patient she is treating, comes with her own set of cultural, physical and emotional biases. These biases drive her ability to relate to her patients and her ability to provide the appropriate care for each Seniors' complex and unique set of needs. In addition, this doctor was educated in system that values a certain removed approach to care, that teaches a language focused on treating symptoms and not on the human consequences of the treatment. Thus, the healthcare system provides its own dimensions that can affect medication adherence. It has a number of glaring holes: lack of a comprehensive and cohesive medical record, poor feedback about a patients disease progression (apart from what the Senior can or can't articulate during an examination), lack of training about noncompliance, and lack of knowledge of how to address the cultural and behavioral aspects of patient care.

While this description is far complete, it is easy to see how, to many Seniors, the health care system is a daunting obstacle with high drug costs and copayments, long wait times and limited time spent with doctor to answer questions, and multiple doctors, all with different communication and interpersonal styles.

4.2.4 Patient-Related Dimensions (Physical and Mental)

Currently the health care system works from the basic assumption that the patient is sufficiently motivated to follow their medication regime. However, this is not always the case and there are many patient-related factors (often outside of anyone's direct control) that impact non-adherence.

Within the Senior population living outside of nursing homes, it should come as no surprise that physical disability is common. In 2002, 26.5 percent of these Seniors had disabilities so debilitating that they severely impacted their ability to perform at least one activity of daily living (i.e., those skills that one must be able to perform to live alone) (Richard Johnson, 2006).

It seems obvious that to properly take one's medication, first and foremost, one needs the physical ability to do so. Visual Impairment of various forms -poor vision, macular degeneration, cataracts or blindness - hinder or prevent Seniors from properly reading instructions for dosage, proper scheduling, or warnings of side effects. Hearing impairment can prevent Seniors from properly understanding verbal directions, while cognitive impairment may make it difficult to comprehend or remember what they were told to do by the physician. In addition, the design of many medication's packaging and collateral materials is not created following proper human factors guidelines. Labels are too small to read and child proof tops require too much hand strength and dexterity. The end result is that Seniors, even those that want to be compliant, find it difficult or impossible to physically do so.

Apart from the physical factors of aging, a Patient also carries with them a body of knowledge regarding their dieses which influences their attitudes, beliefs, perception and expectations regarding that disease and use of medication.

At a rational level, knowledge of the disease - how it impacts their body or how it progresses over time - along with a knowledge of the medication – how to properly take it and how it impacts their disease - shapes the decision to adhere to the medication. Misinformation or a misunderstanding of the available information can lead not only to the wrong regime being followed (for example, taking pills every 8 hours instead of 12) but at a deeper level the attitudes and beliefs they hold also hold influence and cause them to make seemingly irrational unhealthy choices.

All medical professionals come to the table with a vast amount of education that allows them to process the complexity of the human body. Seniors on the other hand do not share that same level of proficiency. Looking at the education levels of Seniors we find that 22.8 percent of frail seniors (those who have trouble with three or more Activities of Daily Living (ADLS) never attended high school, 16.9 percent dropped out of high school, 37.9 percent finished high school, 14.6 percent never finished college and only 11.9 percent finished collage (Richard Johnson, 2006). Given this relatively low level of education, it can be concluded that many Seniors don't have the same ability to comprehend the intricate details of their illness that younger generations do.

Given their education level or their ability to understand the technical aspects of their medication regime, the list of attitudes and beliefs that Seniors hold towards their disease and medication is as varied and unique as their situation. For some, their

disease is perceived as shameful or stigmatizing, which leads to a denial of their condition and non-acceptance of its' health implications. For others, the stress of the disease is too much, creating a sense of hopelessness and causing them to harbor negative feelings towards themselves, their treatment, or their doctors. And for some Seniors, their beliefs lead to the fear that their medications will result in chemical dependence, high medical bills, or wild side effects. All of these factors can result in non-compliance.

This isn't to say that these fears are unfounded or without truth, but rather that even when presented with accurate information regarding proper usage or likely side effects, the information provided by doctors is not always taken at face value and is filtered through one's world view. These filters drive "negative views about medicines as a whole and suspicions that doctors over-prescribe medicines...[and] a broader "world view" characterized by suspicions of chemicals in food and the environment and of science, medicine and technology" (World Health Organization, 2003). Humans are complex social creatures, driven by complex social and emotional pressures that often lead them to make (from the outsiders view point) unhealthy decisions.

In the end, all of these beliefs and anxieties become self-fulfilling and lead to a loss of motivation in managing their treatment and missed visits to their doctors for check ins or missed refills of their prescriptions. Clearly, a lot goes through someone's mind as they bring the pill from the bottle to their mouth.

4.2.5 Condition-Related Dimensions

Just as every Senior is different, so too are the diseases they suffer from; how they feel, the severity of the symptoms, the long-term consequences of their disease, and the influence of their side effects all present in unique ways. Some diseases are insufferable (chronic back pain) while others lay dormant and imperceptible for years (Hypertensions). Another dimension of the disease is the varying degrees of treatment needed. One on end of the spectrum, treatment can be a daily pill. On the other end, it can be a total commitment to a new life style and diet (obesity, for example). Also, the high prevalence of functional impairments, depression, cognitive decline and dementia in Seniors put them at further disadvantage compared to others (who already are at risk for forgetting to take their medication) suffering from chronic dieses.

4.2.6 Therapy-Related Dimensions

Proper treatment often encompasses more than taking medication. Medication is only one part of the total therapy that may also include lifestyle changes (increased exercise or a change in diet, for example). The duration of these changes (sometimes months and sometimes for the rest of their life), the immediacy of beneficial effects, the complexity of this new regime, the amount of external support and encouragement or the acquisition of new skills (for example, use of equipment) can all discourage compliance to the new therapeutic interventions and the medication alike. Why bother with the medicine if I am unwilling to go along with everything else?

In addition, Seniors often face multiple co-morbidities, resulting in polypharmacy (interactions between multiple drugs) and burdensome medication regimens. In one study, The Effect of Prescribed Daily Dose Frequency on Patient Medication

Compliance (Seth Eisen, 1990), one small variable (dose frequency) was shown to have a large influence on compliance rates. The medication compliance of 105 patients receiving antihypertensive medications was monitored and a three-time daily regimen was changed to on a once-daily regimen compliance improved from 59.0 percent to 83.6 percent! Even the seemingly trivial parts of the therapy can have a large impact on compliance.

4.2.7 Further Complications: Interactions

Like any sufficiently complex system, challenges emerge from the interaction of the parts. Clayton Christensen in his book, The Innovator's Prescription (Clayton Christenson, 2009), maps out a clear depiction how multiple dimensions of the diseases overlap and give each disease a unique profile - a combination of the immediacy of the consequence and the degree to which behavior change is required to address the
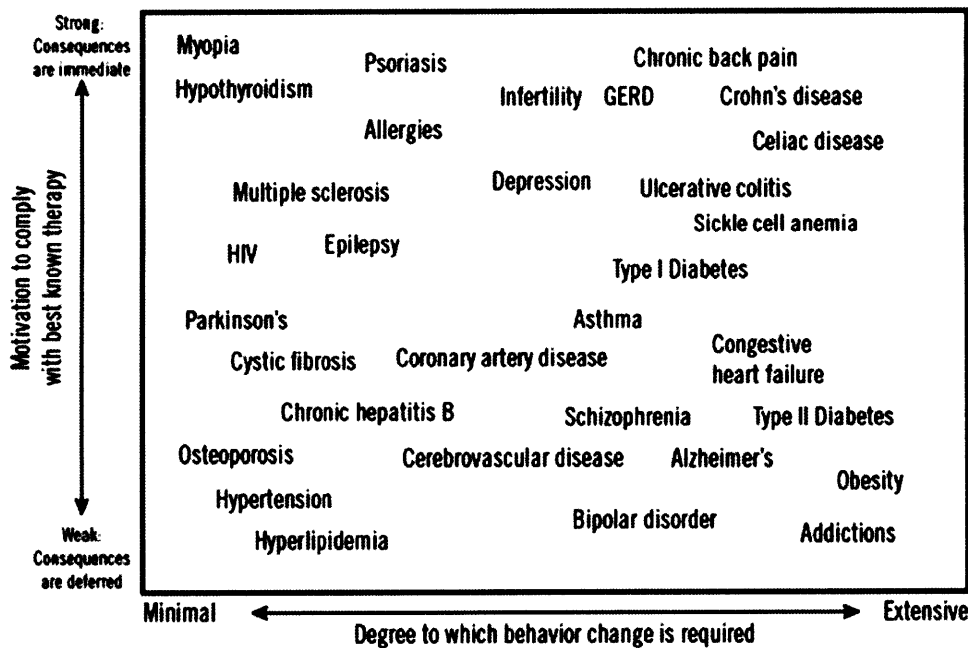
Figure 8: Disease Profile Map (Clayton Christenson, 2009)

condition – that presents unique treatment challenges for adherence.

The vertical access represents a qualitative measure of the immediacy of the consequences the disease has to the patient. The lower the disease is on the axis the more deferred the negative consequences. Hypertension, for example, often takes years before placing someone in the hospital making it easy to ignore and deny. Chronic back pain, on the other hand, placed at the top of the chart, brings pain so severe it cannot be ignored. The horizontal axis lines up the diseases from those that require minimal behavior changes to those that require extensive changes in daily routines or behaviors. The treatment for Hypertension is a cocktail of pills so it is placed to the left of Celiac disease that requires people to change their diet completely and stop eating any sort of wheat (no bread and no beer).

These examples show how often many of the causes of medication mismanagement – in this case, patient related factors and condition related factors - mix to create a complex landscape that shape the Seniors' level of risk perception and motivation to adhere or not. There are many other similar examples of the different interactions influencing one another thereby making the problem difficult to pin down.

4.3   A Case Study: Askapatient.com Opinion Poll

On the front page of the Website Askapatient.com, a website dedicated to medication topics, an opinion poll was posted asking, "If you didn't fill a prescription you received from your doctor, why not?" While not statistically valid with a total of 1032 votes it interesting to see how closely the answers match the framework presented above and provide a partial validations of the academic story outlined above. In other words, you do not have to look too far to find all of these issues bubbling up to the surface. The final tally and some chosen comments from participants are presented:

Felt better, didn't need it	13.2%
Worried about side effects	41.0%
Too expensive	16.9%
Decided it was not the right treatment for my symptoms	14.1%
Other	8.5%
Received free samples and just used those	4.3%
Used different treatment	2.0%

Posted Comments:

"Afraid of side effects"

"I did a research on it and discovered too many dangerous side effects not explained by doctor"

"I felt the doctor was medicating symptoms not treating the disease/condition."

"insurance won't cover"

"just wanted the narcotics not the steroids"

"Fear and stigma made me delay filling scrip for antidepressants."

"very skeptical"

"afraid to fill it"

"disease better than the cure"

"Without health insurance, the medicine is $165.00 per month, and my family "needs to have groceries."

"I was just talking about this today with a friend and taking something new is scary"

"took for 3 months and now, 3 months later, am still feeling like I'm going to explode"

"Finding other ways that are natural without side effects."

"Opted to give natural, alternative treatment a try instead-so glad I did!"

"just seem drug intolerant have side effects NO ONE has"

"Most doctors are just drug dealers for big pharma"

"wasn't given enough information and didn't like what I read about it"

"mail order drug company is difficult to deal with"

"i am not a guinea pig"

"I researched it and discussed it with doctor before not filling prescription."

5 The Solutions: Product/Service Innovation Focused

The staggering complexity of the medication management problem places a myriad of roadblocks at every turn. For some, the disease lacks the physical urgency to bother, for others the mental demand of juggling five different medicines is too much of a burden, while for others just opening the bottle hurts their arthritic fingers. But for most Seniors, if the truth is told, many of these problems present to some degree and mix into a potent cocktail. Given all of these disparate factors, the question arises: can one solution ever be developed? No, of course not. A single solution will never suffice.

However, a collection of innovations throughout the health system can lead to improvements. For example a well-designed device (to reduce the physical and cognitive burden), when used in tandem with a supportive online community (to reshape motives and urgency), supported by a doctor who can make informed decision based on usage patterns could sway things in a positive direction.

Put another way, medication management is not an end goal. Medication management is an emergent property that arises when all the stakeholders and parts of the system work together properly. It is like the performance of a sports car. A high-performance sports car has great handling, can grip tight corners at high speeds, and breaks on a dime. These abilities do not trace back to a single component. The cornering on a Ferrari going around a curve cannot solely be traced back to expensive tires, for example. Why? Because those same tires on an old station wagon won't give the same performance. The same is true of the engine, the brakes, or the turbo charger. In all

these cases, high performance is the result of many great components specifically designed and tuned to work together.

This concept of full optimization is familiar to the practice of systems engineering. Systems engineers design a system in which all part are optimized to work in conjunction with one another, versus each part being optimized individually and then joined to the system. This principle is highly applicable to the part of the health system involving medication management.

So what is the system that we, as product and service designer are looking to optimize? Is it the healthcare system? The medication system? While rethinking the entire medication system - what roles it gives doctors, pharmacists, and nurses, how it chooses to see and interact with patients, or the incentives it provides patients and caregivers – would result in great gains, it remains beyond the scope of this thesis. **Instead, this thesis will focus on those parts of problem that will benefit most from solutions in the realm of product/service design and innovation.**

Solutions of product innovation can be very powerful due to the ability of the product or service being innovated to affect human behavior change. How a Senior behaves when taking that pill, the behavior of the doctor when interacting with the patient to establish diagnosis and treatment regimen, the behavior of the pharmacist as they explain side effects and dosage instructions: these are just a few of the hundreds of behaviors carried out day-in and day-out by all the stakeholders in the system. Each set of behaviors are shaped by the system in which they are carried out – which is waiting to be influenced by better design. Better design can shift behavioral practices, and if these

practices can change within the existing system framework, large dividends are possible.

As stated earlier, medication management at its core is a problem of behavior. Therefore, it is possible to create a large impact through the implementation of behavior changes. And as we will see, design and innovation of the products and services within this system are an effective way in which to implement that change.

While behavior change can have a large impact on the medication system, it cannot fix the entire problem. For example, a sports car will never be a jet, no matter how much you optimize it. There are problems in the medication system that are not caused by behaviors. The high price of medicine is a real problem and finding ways to reduce this cost would invariably increase adherence. Public policy research and government subsidies could increase access to care. However, while these types of changes could bring about sweeping change, they also require a much higher level of societal involvement, cooperation, and resources. Influencing behavior though better design has the high potential of affecting positive change while requiring much less resourcing. Therefore, the focus of this thesis are those things that shape behavior and are addressable through design. It is suggested that the parts system most susceptible to influence deserve design focus, and these are the tools and technologies that work together to shape behavior.

6 Lead User Innovation

Despite all the missed doses, un-filled prescriptions, high prices of medicine, and lingering confusion walking out of the doctor's office, Seniors and their caregivers do their best to stay compliant by using and modifying the tools available to them. These modifications can teach product designers a thing or two. In fact, seeing the end user as a source of innovation and not just as a consumer is an established source of new product ideas.

Popularized by Eric Von Hippel at the Massachusetts Institute of Technology, the theory of user innovation, often also referred to as the lead-user approach to concept development, doesn't aim to ask consumers what they want, but instead looks at how they are changing existing products to meet their own needs. These customers, called "lead users", are for one reason or another ahead of the general market place and are innovating on their own behalf. By definition lead users are those people that "expect to receive a high benefit from a solution to their needs" and also "have needs that foreshadow general demand in the market place" (Hippel, 2006).

Seniors and their caregivers fit this description as they are forced to find solutions to the issue of poor medication management, which can in some cases be a matter of life or death. In these instances, the user does indeed expect to receive a high benefit from finding a solution.

User innovation has been found in many different sectors but it can also be found when studying various groups of people dealing with issues of medication management. Examples of user innovation within medication management have been distilled from a

variety of sources including focus groups, online discussion forums, and in home interviews (detailed below).

6.1 Fogg Behavior Model: A Framework for Categorizing Lead User Innovation

The Fogg Behavior Model (FBM), developed by a researcher from Stanford University named Dr. BJ Fogg, gives a framework upon which to build solutions (Fogg, 2009). The model's utility arises from the fact that it places the end goal – the new behavior - at the center of attention (explained below). Unlike other models that are complex and academic, this model is simple, effective, and useful as a tool to categorize the breadth of user innovation that Senior are creating to tame the complexity of the problems of medication management (as will be shown in the following section).

At the center of the model is the behavior we hope to adopt, known as the Target Behavior. Target behaviors are simple: They are best described as verb-noun constructs that articulate a baby step of intent. For example, 'Take pills', 'Go for a walk', or 'Mail bills' are all well-formulated Target Behaviors. Did they occur? Yes or No. Their interpretation is void of ambiguity. Unlike these simple Target Behaviors, complex behaviors such as "Staying healthy" or "Be a better person" are too broad to be useful. When dealing with a complex Target Behavior, it needs to be broken down into more quantifiable goals. "Stay healthy" could be broken down into the Target Behaviors, "Drink 8 glasses of water a day" and "Eat vegetables with dinner".

To carry out the Target Behavior, the FBM model requires three conditions be met simultaneously:

1. The person must be sufficiently motivated

2. The person must be sufficiently able

3. The person must be triggered to action

6.1.1 Condition One: Motivation

The first condition. motivation, qualitatively measures the desire needed for a person to carry out the Target Behavior. Obviously, not all Target Behaviors require the same amount of motivation. Some behaviors such as making a sandwich require a lot less motivation than making a three-course meal. The completion of a Target Behavior requires that the person has to exceed the motivation needed to complete this task. They must pass through what is called the 'motivation threshold' of the task.

Looking a layer deeper, motivation in the FBM framework has three sources of tension, called 'core motivators'. The model does not suggest how these motivators ultimately become embodied in a product or service but are listed as common strategies. They are as follows:

Pleasure/Pain – These two devices motivate in an immediate way by eliciting a primitive response. Spanking a child, giving a pet a treat, or feeling the rush of nicotine when smoking a cigarette are all examples of this style of motivation.

Hope/Fear – Hope is the expectation that things will improve in the future while fear is the expectation that they will deteriorate. People are motivated to use a parking meter for fear of a ticket, while people buy lottery tickets for hope of riches.

Social Acceptance/ Rejection – The desire to fit in by wearing the trendiest clothes, to not be embarrassed by saying something outlandish, or to be cheered on for scoring the winning goal all satisfy this motivation. Unlike the 'pleasure/pain' set of motivators, this type of motivation is long-term, influencing the person for a long time before the actual applause or rejection. One act of rejection can motivate certain behaviors for a lifetime.

6.1.2 Condition Two: Ability

The second threshold required to reach a target behavior is ability. One has to have the ability to carry out the steps required to accomplish the target behavior. Ability is addressable in two ways: one can either improve the user's skills or simplify the tasks required of the user. Unfortunately, as a designer, improving the users' physical or mental ability is beyond influence. If someone is blind, this disability is nonnegotiable and the system design has to utilize the abilities the user does have. Therefore, a system must be designed in such a way as to reduce the skills required to carry out the target behavior.

The FBM model defines six components that set the ability threshold of a system. Through the design of the system each of these six factors is set. The system is successful in carrying out the target behavior if the set point is within the ability level of the user. If any one of these factors is set to high, the system fails.

Time – Does the user have enough time to complete the tasks using the system? If, for example, the doctor's office asks me to wait an hour and half in the reception area and I only have an hour for lunch than the system is not simple and the system design failed.

Money – Regardless of how well every other dimension of the system works, if it costs more than the user is able to afford the system will fail.

Physical Effort – the effort required must be in line with the ability of the user. For example, if one wants to go to the top of a 100-story skyscraper but is not physically capable of climbing that many stairs, the system will fail. However, if an elevator is present, then the system will succeed.

Brain Cycles – Like physical effort, systems also require mental effort. Not only does the mental ability of users differ from person to person, but it also differs for a single person depending on what else they are also doing at the time. For example, one can easily send text messages on a cell phone. However, sending a text message while driving introduces many other mental tasks, making it is impossible to send the text safely.

Social Deviance – Does using the system go against engrained social norms? Dr. Fogg uses the following example: wearing pajamas to a city council meeting might require the least effort, but there's a social price to pay "which creates complications for that behavior" (Fogg, A Behavior Model for Persuasive Design, 2009).

Non-Routine – The more a new task or system fits into established routines, the simpler it is. Taking a pill at 3 in the afternoon is a lot simpler than taking a pill at 3 in the morning when most are routinely asleep.

The goal of the designer is reduce each of these variables as much as possible thereby keeping their design as usable as possible.

6.1.3 Condition Three: Triggers

Triggers are simple external actions that move someone to action. Alarms, reminders from friends, television commercials are all examples of triggers that move people to action.

6.2 Examples of Lead User Innovation

As part of ongoing internal Marketing research, the company Philips Lifeline has amassed many hours of market customer interviews, focus groups, and ethnographic studies. Transcripts of the focus groups and interviews, full length video of the ethnographic home visits, and final reports were all re-analyzed to specifically look for issues concerning medication management and examples of user innovation.

The first study (Philips Lifeline, December 2007) was comprised of 33 Seniors, ages 68-95 (5 men, 28 woman), all living independently in the Chicago area. The main topic of discovery in this study involved the daily routines of Seniors with a focus on their use of technology (phones, cars, computers, etc) to stay connected with their social network. Over the course of the study the researchers (myself included, in part) carried out twenty-one 45 minute face-to-face interviews and twelve in-depth ethnographic in-home interviews.

The second study (Philips Lifeline, December 2008) included twenty ethnographic interviews with Seniors (aged 75+ years of age) who use a cane or walker. The researchers (myself included, in part) focused on topics of daily life, home environment, and medical emergencies (past falls and other life threatening events, including medication management). In addition, this study included a single focus group with

twelve caregivers that discussed lessons learned and outcomes of the habits that had been formed.

A third study (Philips Lifeline, August 2008) used an online discussion forum, guided by a moderator, to carry out a five-day online focus group. Due to the extended format of this method, the moderator was able explore concepts in a through manner by giving participants many hours to think about and reflect upon their answers. A group of 12 caregivers and a second group of 13 Seniors (all 65+ years of age) participated. Both groups talked to discussion topics specifically focused on medication management and issues involving met/unmet needs, lifestyles and fears.

Finally, a small group of five Seniors at the Scandinavian Living Center in Newton Ma were interviewed in April 2010 to discuss if the findings of this thesis matched their experiences as a final informal check.

To cast an even wider net, thereby increasing the likelihood of finding a comprehensive set of user innovations, a number of alternative communities with an online presence and a need to manage medications were studied. The first alternative community was a group of parents of small children. This group approaches the problem of medication management in a more playful way that may be useful in other domains. A second group included people who were blind and/or deaf who, because of their disability, are forced to adapt many unique workarounds. Finally, the last group was comprised of the patients themselves. A number of social networking sites focused on patients – www.crazymeds.us, www.patientslikeme.com, www.crazyboards.org,

ask.metafilter.com – were searched for discussions related to user innovation and medication management.

As a way to structure the findings, the The Fogg Behavior Model and the tools defined (motivation, money, time, physical effort, brain cycles, social deviance and routine) are used to show were people are successfully finding ways to overcome the common challenges faced to reach their target goals.

6.2.1 Money: Innovations that Reduce the Cost to Manage Medications.

As previously discussed, many people on a fixed income or dealing with a long-term disability are forced to choose between their medication and other non-negotiable items such as rent, heat, or food. It is not surprising, then, to find a lot of discussion regarding ways to reduce the cost of taking medications. When implemented properly, these innovations of frugality can increase adherence.

For example, in a forum on CrazyMeds.com, a online discussion group for people suffering from various mental health issues, a member asked for an alternative to an expensive medication. Another member replied, "...cut a 12mg/24 patch in half to offset the gargantuan price of the drug. I've been cutting them in half for three months, and haven't noticed any change in efficacy vs. the 6mg/24 patches" (Serpens, 2008). This common technique of splitting doses (regardless of medication form) was discussed on many different forums, suggesting a widespread practice in today's society. One author (Oregon.gov), with the caveat that this is not appropriate for every drug, even went so far as to calculate the potential savings from using this technique with various medications (SEE Figure).

Drug	Clinical Uses	% Savings
Clonazepam (Klonopin)	Panic disorder; epilepsy	41
Doxazosin (Cardura)	Hypertension;	46
Citalopram (Celexa)	Depression	46
Atorvastatin (Lipitor)	High cholesterol	33
Paroxetine (Paxil)	Depression; anxiety	46
Pravastatin (Pravachol)	High cholesterol	23
Nefazodone (Serzone)	Depression	49
Sildenafil (Viagra)	Impotence	50
Lisinopril (Zestril)	CHF; hypertension	38

Figure 9: Table Depicting Drug Cost Savings From Splitting Dosages

Another commonly discussed technique to save money is to ask for free samples from your doctor. "Do try and ask your doctor for samples. Remind them frequently, if necessary...sometimes my doc can find decent amounts of samples in the hospital storeroom" (Sum, 2010). Doctors who realize the financial dilemma many of their patients face keep a stockpile of samples for these instances. While not always sustainable, the provided samples allow people to get people through financial rough patches.

While most of these solutions are focused on personal techniques of frugality, one solution discovered on the website Seniorscrips.com evolved into something more substantial. SeniorScrips a non-profit membership cooperative, allows Seniors to partially subsidize the cost of their medication by pooling their monthly dues. According to information found on the internet, SeniorScrips was "established by seniors, for seniors aged 55 and over". A user innovation that, unfortunately, no longer seems to be active.

While none of these innovations constitute a readymade product or service, they do point to a series of unmet needs. Specifically, the high cost of medication leaves many implications for drug companies and could lead them to consider how to best restructure or develop alternative business models to reach those less fortunate. Pills or patches could be designed to encourage being split in half, for example. Or programs could be created to give away medication to Seniors in order to raise awareness and build a stronger brand image. Smarter pricing could increase adoption and profits. There are implications for the public sector as well: Governments could take the lead from SeniorScrips and create additional co-ops.

6.2.2 Physical Effort – Innovations that Overcome Physical Disabilities

Given the almost universal prevalence of physical disabilities in the elderly population, even small physical obstacles can stop the best intentioned Senior in their tracks. Pill bottles with childproof tops were the major complaint from people with low strength and dexterity from arthritis or otherwise. One solution found to this problem is to have someone transfer the pills into an easier-to-open container or plastic zip lock bag or to just leave the cap off the bottle altogether. One especially creative woman used a wine bottle opener to bore a hole in the top of the bottle allowing her to dispense a single pill at time. (Philips Lifeline, December 2007) Where there is a will there is a way!

Small print provided another common obstacle. Small font sizes dominate instructions for use and warnings on the bottle, making it all but impossible to know how or when to take new medicines. During in-home visits, magnifying lenses and bright lights are commonly found located strategically where needed most often (Figure 10). To provide

additional help, many caregivers would rewrite the labels in large script to keep medications from being mixed up.
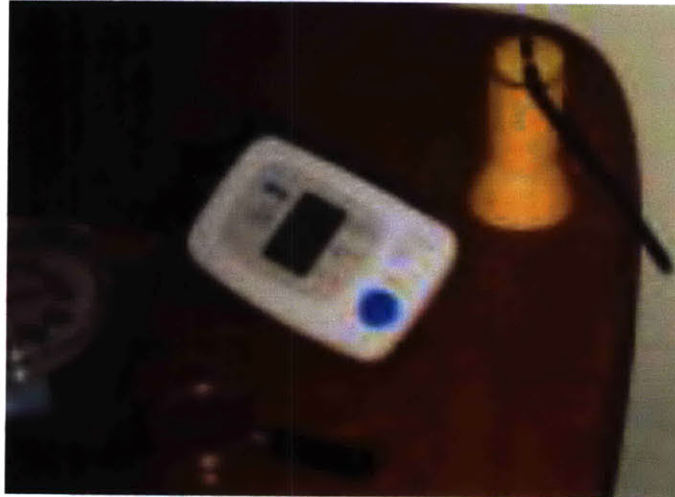
Figure 10: A Flashlight and Magnifying Glass are Kept on a Bedside Table (Philips Lifeline, December 2007)

Additional solutions to physical challenges were discovered while reviewing websites for the blind. Many blind people were found to create clever systems to keep track of their medication. They often rely on the size, shape, texture, smell, or sound the pills make when rattled to identify one medication from the other. As one writer put it, "thankfully, imagination and ingenuity are limitless, and blind people continue to find ways to manage their medications safely and independently through a variety of low vision, no vision, low-tech, and high-tech options" (Ley, 2010).

The National Federation for the Blind's website contains a number of examples of user innovation. For those with low vision, placing markings on medicine bottles that can be read right side up or upside down can differentiate two medications packaged in

identical bottles (SEE FIGURE). This practice can also work for those with no sight by using a puffy fabric marker that leaves a raised surface.

Figure 11: A Pill Bottle Is Marked With Easily Identified Symbol

Additional information can be coded onto a medicine bottle with a simple system of markings. For example, one convention discussed is to use a single dot for medications taken once a day, a dot and a line for medications taken every day morning and night, and an single line for medications taken only at night. More elaborate systems are also possible that indicate both dosage and timing. Other systems include using rubber bands or hair elastics wrapped around bottles (one band per pill). People have even been found to glue small pieces of foam or cloth on their bottles for the same purpose of coding.

For pill bottle manufactures, the path to delivering better solutions through design is clear: at the very least containers, need to be easier to open and balance the need to keep medication out of the hands of children and into the hands of seniors. While

bottles are the current ubiquitous choice, the use of plastic zip-lock bags suggests this may be a better alternative. In addition, there is the opportunity for the bottle to be more than a storage container. With the clever use of shape, weight, texture, or color, the bottle could be designed to help the user easily differentiate medications and identify the required dosage and/or timing. Pharmacist could place morning medications in blue bottles, day medications in yellow bottles, and evening medication in grey bottles for example. A solution could also come from a different point in the medication system: drug stores and pharmacies could sell texture kits to be applied on bottles to help caregivers implement this coding. While the exact design isn't clear, the need for such solutions is evident.

6.2.3 Brain Cycles – Innovations that Overcome Cognitive impairments

Everyone has trouble remembering to take their medication from time to time. This forgetfulness is even more common amongst the elderly, who face cognitive decline either naturally or because of the early-stage progression of a cognitive disease. Thus, cognitive decline in the elderly population often amounts to more than the occasional lapse in memory. For this reason, many Seniors know they need to rely on a number of techniques to trigger their memory.

Seniors frequently adopt timers found in other devices to trigger them to take their medication. They frequently use timers in watches, bedside alarm clocks, and even in cell phones. While this method can work, it seems limited by the devices' ability and ease to program more than a single reminder a day.

For more complicated and frequent reminders, Seniors often build strict routines around their medication regimes and place triggers appropriately. They create mental rules around always incorporating taking their medications with other engrained routines, such as eating, making coffee, or brushing their teeth. Then, they often place their medicine in a spot appropriate to that activity to serve as a visual cue. Several examples of this are as follows:

- "The best thing for me is to keep to a routine. Medications in the same place and in a 7-day container. If my routine is broken [due to] travel, company, whatever... I make an effort to keep to the routine I have established" (Philips Lifeline, August 2008). – Senior

- "...he keeps his medication in the fridge with a laminated reminder on the fridge...as he is the cook in the house he is at the fridge before meals...it seems to have worked for him." (Philips Lifeline, August 2008) - Senior

- "I brush my teeth religiously in the morning. I used to tack the empty blue sleeve to the mirror; it would always catch my eye in the morning and I would remember to take them!!!!!!!!!! TRY THAT ONE!!!!!!!!!!" (LovemyKids, 2009) - LoveMyKids forum participant.

Perhaps the most common technique to reduce the cognitive burden placed on the Senior is to shift it to the caregiver. In this capacity, caregivers act as lead users too. Within the caregiver community there are many examples of the same innovations that Seniors adopted. For example, caregivers often add labels to the medication bottles to make them easier to read or color-code bottles to differentiate them from one another. They also preload pill boxes, write detailed notes with dosage and

timing instructions, and set alarms to trigger their Senior to take the medication. They even place the medication in strategic locations near the fridge, sink, or other commonly-traveled destinations. Caregivers also often to a lot of "checking in" (either in person or by phone) on their Senior to make sure the medication was taken.

- *"I basically write on the bottles, numbers to tell her and me which pills go first and in which order. It helps me keep organized because I just go straight to the bottles and I know which one is next and what it is for"* (Philips Lifeline, August 2008). *– Caregiver*

- *"I write the name of the drug and what it is for on the outside of the bottle in Spanish for her to understand better"* (Philips Lifeline, August 2008) *- Caregiver*

These insights are useful to the product designer as they think about how technological solutions can be employed, not only to keep from interfering with set routines, but also to interface with and build off of them. For example, prescriptions could come with Post-It notes or refrigerator magnets printed with the time and dosage information allowing Senior to easily place these trigger around their home. Alarms could be triggered not just by time but by the location of the Senior (i.e., the alarm could be set to go off when the Senior approaches the medication or when there is a commercial break during a television show).

All of these examples show that while a final design may not be established, there are clearly areas where lead user innovation in this space is calling for solutions that work

within the Senior's schedule and provide appropriate triggers. These are key elements needed in any successful commercial product designed for this space.

6.2.4 Motivation - Innovations that Encourage Patient Engagement

While clearly a major cause of non-adherence, motivation is one area where few solutions created by Seniors were identified. Instead, motivation was an area addressed more by the caregivers. In one-on-one interviews, many caregivers talked about constantly reminding and "nagging" their Senior to take their medications. While sometimes motivating, it seems this strategy fails to address the deeper emotional issues (denial, ignorance, peer support, etc.) that drive adherence over the long term.

One motivational innovation used by parents with young children is to create a reward for medication adherence, either by flavoring medication or by mixing it with candy or other desirable foods. And sometimes, taking the medication is coupled with a separate reward. Examples consist of the following:

- "...crush tablets up in chocolate, that chocolate is very good at covering up the taste of the meds...crush the tablets and mix them in Sprite...the carbonation would dissolve them and the Sprite would cover up the taste..." (How do you get your kids to take medicine?, 2001)

- "...Have you tried full-on bribery? Start small, so you have something to build up to...like maybe a sticker on a chart every time she takes her medicine [without] having a fit or throwing up. Then maybe after 5 stickers, she gets to pick a treat out of a special treat basket filled w/ cheap trinkets that you only take out for "medicine rewards" (How do you get your kids to take medicine?, 2001)

More mature versions of both of these solutions can also be used for Seniors. Perhaps a drug manufacturer would find success creating a chocolate covered Alzheimer's pill. Or pharmacies or doctor's offices could create "cash back rewards" given once a Senior has filled three prescriptions in a row, for example.

Despite the lack of Senior-created innovation in the area of motivation, one area outside the world of medication management offers examples of motivational success. Social networking is making a clear impact for the sufferers of chronic diseases. In this domain, the lead users are all chronic disease suffers. This population is generally younger than the Senior population and generally ahead of Seniors in terms of the use of technology for social purposes. There are many numbers of websites that provide an online forum for these patients to discuss relevant issues and work out solutions together. Two sites in particular provide good examples of how each facilitates user-created solutions to the problem of motivation.

One strong barrier to medication management is the acknowledgement of the consequences of disease. Those in denial are not motivated to equip themselves to deal with the challenges of their affliction because they have not yet even acknowledged those challenges. The following exchange on an online forum for sufferers of diabetes, diabeticconnect.com, takes the topic of denial head on...

- "im in denial!!!! i have diabetes and im in denial. im married and my wife and i just had a baby but it still doesn't make me go to the doctor or check my sugar nor does it make me stop eating out. i need help! im only 27 years old!"

    - April 8 at 12:38 am, by gharah

- "Hey there friend. Be patient. It will take time to find what works, but after some time it'll be automatic. Trust me, you won't starve, and you'll learn to enjoy meals again that will not be killing you. For me, and example would be a simple thing like hamburgers. It's not the hamburgers for me, it's the "buns". They push my numbers up. Orowheat makes a bun that is whole wheat and thin. Not quite the same, but they will hold a burger!! It makes a big difference not to have to eat a burger with a fork. Stevia powder is great to put in coffee or tea, and life goes on!! Congrats on your new addition in your family. Remember your new child when you start going into denial. It's just another adjustment to life."

  - firstflight800 April 11 at 3:04 pm

The posts then go on, offering support, guidance, and solutions that others have found or created that work for them. In the span of a single post we see that the hope/fear, pleasure/pain, social acceptance/rejection, modes of motivation are all discussed and utilized. This type of advice is beyond what is available in published literature from more traditional sources, such as self-help books or informational pamphlets at the doctors' office.

This trend of non-expert, user-created advice is also the framework behind the website askapatient.com. Askapatient.com collects patients' firsthand accounts of their experiences using medications. The site allows them to share what works, what doesn't, and what side effects may result. These reports are often more vivid and forthcoming than standard pamphlets and doctors recommendations.

- "My 84 year old husband was taking Coumadin for three years. He experienced a very minor fall in our driveway which resulted in ...his death from "spinal cord hemorrhage". It was worse than the stroke he had hoped to avoid. We were never advised about this risk! This "worst-case" scenario regarding the use of Coumadin should be made better known by the pharmaceutical industry. Think twice before taking it. " –Male, 84

- "I was put on this stuff [Coumadin] with no @^!^%@ instructions, except don't eat salads. That was it. I fell and my leg swelled up like a balloon...I has lost so much blood into my leg my blood pressure had dropped to 75/45. I had blood transfusions and spent 3 days in the hospital...Until I read the posts on this site I never connected my severe tiredness to the Coumadin - I thought it was my heart medicine." Male Age 73

Motivation increases as people are validated by finding similarities between what they are experiencing and what others are reporting. This helps them take charge of their medications regimes and empowers them to talk to their physician to find the best solutions for their situation. Not only are these websites a great source of market research, there is an opportunity to take them out of the fringe and into the mainstream with endorsements and financial support from drugstores (Walmart, for example), pharmaceutical companies, hospitals, and the like.

7 Product/Service Innovation

In addition to the examples of user innovation shown above, traditional device manufacturers and entrepreneurs have also found inspiration to create innovations that address the problems of medication management. In the next sections, these off-the-shelf solutions will be introduced and critiqued against the Persuasive Technology framework that is also outline below.

Obviously, there are many more examples off off-the-shelf technologies than can reasonably be discussed, so three solutions have been chosen that cover the spread of solutions available to Seniors today; a low tech approach (The Pill Box), a high tech approach with complementary monitoring service (The Philips Medication Dispenser) and a mobile software service (The Caregiver Iphone App).

7.1 Persuasive Technologies: A Framework for Categorizing Product Innovation

In a second body of work by BJ Fogg, "Persuasive Technologies: Using Computers to Change What We Think and Do", a theory is presented that explains how computers can be instrumental in fostering and sustaining behavior change. Computers, can not only be more persistent than humans (aka the nagging caregiver) but they also can act on large amounts of data, scale to help many people at once and shift from one form of communication to another (graphics, sounds, text, etc). In the following section the seven techniques commonly used by Persuasive Technologies are outline to that despite the fact that humans are complex social beings, technologies employing these simple means can hold influence over their behavior.

7.1.1 Tunneling

Tunneling techniques take you by the hand and guide you through a process. Tunneling techniques force the user to adapt the system designers' set of assumptions and goals. This can, on the one hand, simplify the behavior making it effortless but, on the other hand, it can create frustration if the user doesn't share these assumptions and goals.

Automated voice systems are a common implementation of this technique. When you place a call to your bank and an automated voice asks you to, "Press 1 for Billing. Press 2 for Invoice Inquires. Press 3 to hear the hours of operation." you are using a tunneling system. The system takes you systematically to your final destination, step by step. If you wanted Billing, Invoicing or the hours of operation, great. What if you want to talk to an operator?

7.1.2 Tailoring

Like a tailor, making a suit to your exact measurements, tailoring is a technique that aims to present information that is unique to you and your circumstances to increase the likeliness that you will chose to change your behaviors and attitudes.

This form of technological persuasion has increased dramatically on the internet. Today, many websites take a users' special circumstances into consideration when offering advice. Google has created an advertising empire by serving up advertising tailored to a user's latest search term. For example, a search for the "Boston Red Sox" returns sponsored links for two separate stores selling Red Sox merchandise (Figure 12).
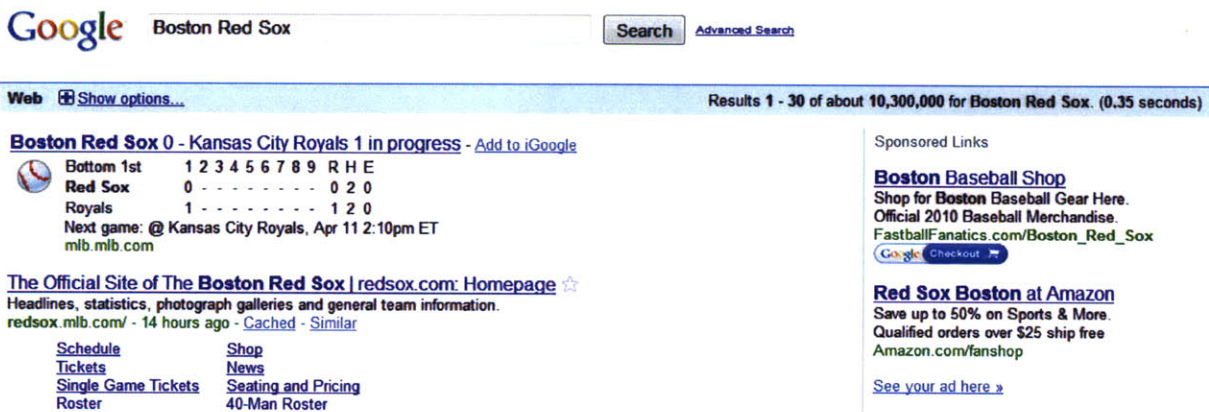
Google   Boston Red Sox   Search   Advanced Search

Web   ⊞ Show options...   Results 1 - 30 of about 10,300,000 for Boston Red Sox. (0.35 seconds)

Boston Red Sox 0 - Kansas City Royals 1 in progress - Add to iGoogle
Bottom 1st   1 2 3 4 5 6 7 8 9 R H E
Red Sox   0 - - - - - - - - 0 2 0
Royals   1 - - - - - - - - 1 2 0
Next game: @ Kansas City Royals, Apr 11 2:10pm ET
mlb.mlb.com

The Official Site of The **Boston Red Sox** | redsox.com: Homepage ☆
Headlines, statistics, photograph galleries and general team information.
redsox.mlb.com/ - 14 hours ago - Cached - Similar
    Schedule   Shop
    Tickets   News
    Single Game Tickets   Seating and Pricing
    Roster   40-Man Roster

Sponsored Links

Boston Baseball Shop
Shop for **Boston** Baseball Gear Here.
Official 2010 Baseball Merchandise.
FastballFanatics.com/Boston_Red_Sox
Google Checkout

Red Sox Boston at Amazon
Save up to 50% on Sports & More.
Qualified orders over $25 ship free
Amazon.com/fanshop

See your ad here »

Figure 12 Google Search Screen

7.1.3 Suggestion

Suggestion takes advantage of the fact that information becomes more relevant when served at the right moment. For this to be possible, the technology itself needs awareness of the user's context and actions. A big billboard placed next to a highway (full of captivated drivers in deadlocked traffic) that reads, "If you lived here you would be home now" is a cleaver low-tech example of suggestion. The sign placed next to the menu in McDonalds which reads "Would you like to Go Large?" is a another example of this type of motivation.

While the examples provided here are straightforward, what constitutes good timing or the opportune moment is complex. BJ Fogg writes, "Timing involves many elements in the environment (ranging from the physical setting to the social context) as well as the transient disposition of the person being persuaded (such as mood, feelings of self worth, and feeling of connectedness to others)" (Fogg, Persuasive Technology, 2002).

When technologies only see one aspect of timing, their suggestions very quickly go from useful to annoying.

7.1.4 Self-monitoring

The advent of inexpensive microcontrollers and sensors (accelerometers, gyroscopes, etc.) has made monitoring a reality using mobile devices. Self-monitoring helps people reach their goals by easily tracking progress and learning about their performance. The Nike+ device places a pedometer in the sole of a running shoe to collect running data to enable a feedback system and data collection via one's ipod (SEE FIGURE).

Figure 13: Nike+ - Example of Self Monitoring Technologies (Nike+ Ipod)

7.1.5 Surveillance

Unlike automatic self-monitoring, surveillance is classic example of persuasive technologies. For years, factory workers have punched in and out of their shifts at the

beginning and end of each work day. The punching machine is a way for managers to watch over workers and their habits. Security cameras in malls, electronic monitoring of email at work, and speed traps on the highway are other examples of surveillance.

One distinction to note is that for a technology to be persuasive using surveillance it must be overt. In other words, the person under surveillance must be aware that someone is watching them. If the surveillance is covert and they are not aware of it, then they don't have an opportunity to adopt their behavior. Covert surveillance is called spying.

One potential drawback to the surveillance form of persuasion (and it depends on your long-term goals) is that its effectiveness is not long lasting. For example, you may drive under the speed limit until you hit a speed trap, but once you pass it's easy to assume another one further down the road is unlikely so you accelerate.

7.1.6 Conditioning

Conditioning uses positive reinforcement to guide complex behaviors. The use of a point system in video games is a common method of conditioning. The points act as an artificial reward for a behavior the game designer hopes to encourage that otherwise lacked the proper motivation.

American Airlines' frequent flyer miles program is another example of this type of motivation. This system rewards travel by offering miles that serve as a discount on future travel. These miles are only redeemable with American Airlines (unlike cash which is redeemable everywhere), thus encouraging the behavior of loyalty by encouraging future travel with this particular airline.
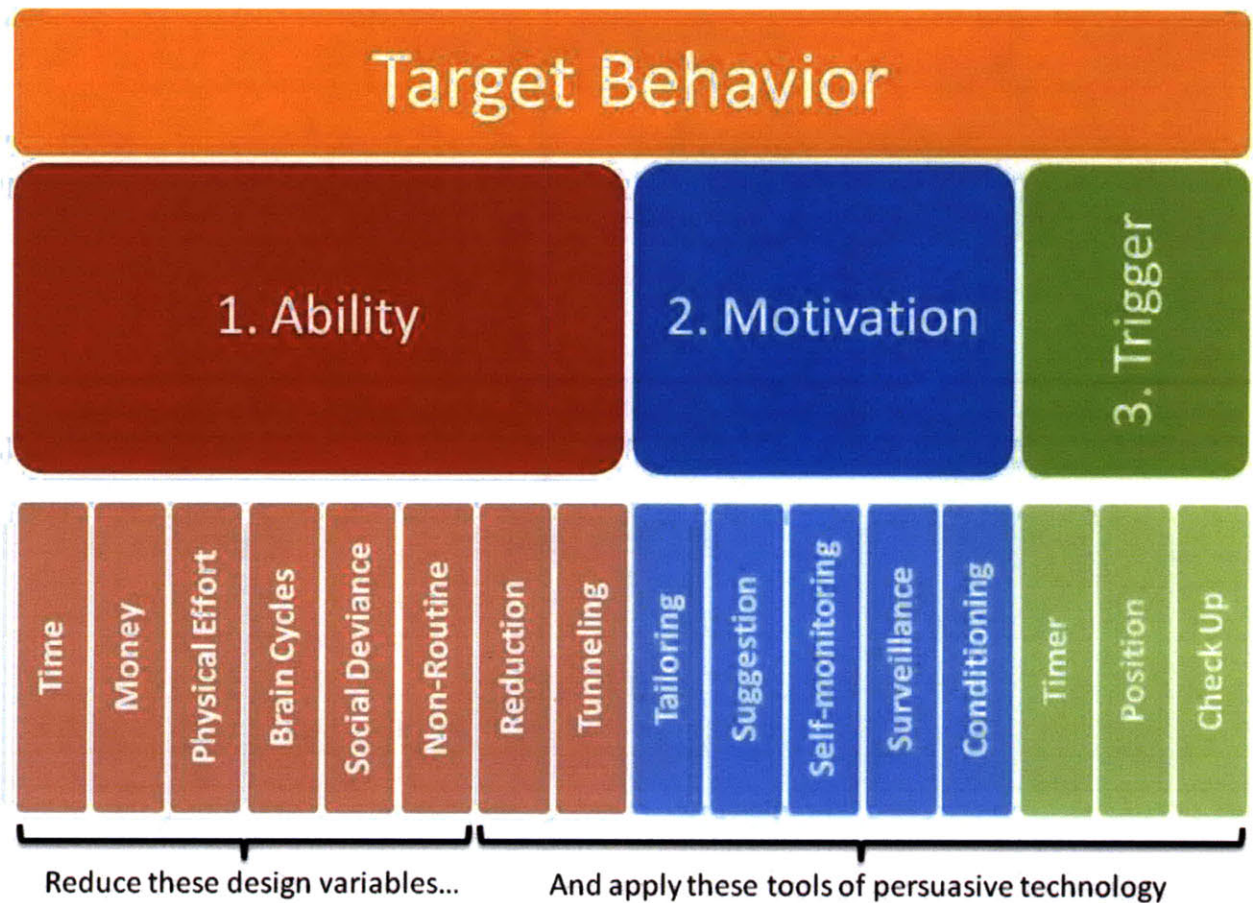
Figure 14: Overview of Design Frameworks (Fogg Behavior Model and Persuasive Technologies)

7.2   The Product/Service Innovation Landscape

7.2.1   The Pillbox Overview

Image Source: (Amazon)

This ubiquitous low-tech solution composed of a number of plastic compartments organizes a series of dosages by time of day. Each compartment, generally marked with timing information, holds a few pills at most. The varieties of pillboxes range from small travel sizes with a single dose to a large home version that holds a week's or more worth of medications. Days are often broken down by AM/PM, Morning/Afternoon/Evening, or even hour. The user presorts their medication into the individual compartments and takes them as directed.

The defining characteristic of this solution is its simplicity. This simplicity not only keeps the device very affordable, often costing less than ten dollars, but it is also straightforward and intuitive to use. The small size makes it easy to travel with and move around the house. The fonts on the boxes are often large and in high contrast, making it good for people with less than perfect vision.

The Pillbox: Strengths as a Persuasive Technology

The pillbox takes advantage of Tunneling (guiding users through the required steps) as its primary technique of technological persuasion. Once loaded (assuming it was done correctly), the Senior no longer has to think about what specific medications to take since this information is encoded in the pillbox itself. For example, when Monday night arrives, the Senior simple needs to take the medications in the Monday night slot.

As a secondary technique of technological persuasion, pillboxes, when loaded by a caregiver, utilize Reduction (making things easier by simplifying the steps) by offloading the burden and complexity of figuring out medication routines from the Senior onto the caregiver. Caregivers can do this days or weeks in advance, making the activity an effective use of their time. In addition, by looking to see which compartments are emptied, the caregiver or Seniors can check for adherence. As one Senior put it, *"...the pill containers are a Godsend. If you couldn't remember whether or not you took your medications, just look in your pill case"* (Philips Lifeline, August 2008).

Pillbox: Weaknesses as a Persuasive Technology

Unfortunately, simplicity is also the pillbox's biggest weakness. It is unable to keep up with the complicated prescriptions regimes many Seniors face. The pillbox fails to guide users through many important aspects of their medication regimes. Which medication to take with food? Or which to take on an empty stomach? What about medicines in non-pill form? What to do if a dose is missed? These are all questions the pillbox is unable to help answer. Furthermore, the pillbox doesn't address any of the motivational challenges and it lacks any triggers to remind seniors of the correct time to take a pill.

These are key issues inherent in medication management. So, while the pillbox is an excellent solution for people with certain prescription regimes, it leaves a lot to be desired.

7.2.2 The Philips Medication Dispenser Overview
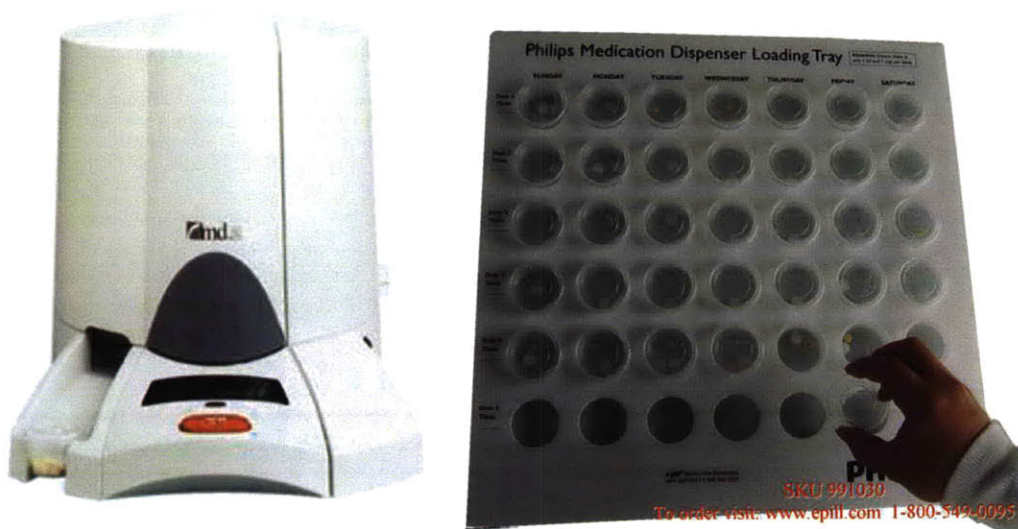
Image Source: (Philips Lifeline, August 2008)

The Philips Medication Dispenser (PMD) is an electronic device capable of holding 60 small cups of medication. The device is preloaded and locked with the individual cups and the schedule is programmed in. At the appropriate time, the unit flashes and speaks to grab the Seniors' attention. Then, the Senior needs only to press the button on the front of the unit to dispense the appropriate cup. The device is also capable of calling the Philips call center in the event the Senior does not dispense the medication. The call center can then call the Senior or their caregiver to provide another reminder that the medication has yet to be taken. Additionally, the device can also send alerts to indicate a refill is needed.

Setup of the PMD requires the use of a large cardboard grid that lays out the cups by day and time and allows the user to systematically fill the cups before loading them into

the device (see images above). This scheduling grid mimics the shape and function of a large box and minimizes the complexity of setup – how?

Because of the service features associated with the PMD, there is monthly service fee.

The PMD: Strengths as a Persuasive Technology

As mentioned above, the PMD is loaded in the same manner as a pillbox. As a result, it has all of the same benefits as pillbox: it tunnels the Senior so they no longer have to think about what or when specific medications need to be taken, it shifts the burden of medication management onto the caregiver, and it can be set up in advance to save the caregiver time. Also, because it can be locked by the caregiver, it can secure medications from others. This can be useful when medications dispensed are controlled substances and the device is used in a group setting where multiple persons have access.

But unlike a pillbox, the PMD adds a strong conditioning and triggering element by alerting seniors to the need to take the medication at the correct time. For example, pushing the red button is a conditioned action that becomes second nature over time. The triggering element of the PMD is so useful because Seniors often lose track of time (not just what time of day but even what day it is). The PMD keeps track of medication timing and triggers the Senior to take their medication when needed.

In addition, the PMD adds value beyond the pillbox by incorporating the features of its call center service. The service provides a strong motivational component by acting as a means of surveillance. Because information about the Senior is known to the call center, their response can be tailored to the particular needs of that Senior. For

example, the Senior's chronic conditions are known and can be relayed to emergency personnel

The PMD: Weaknesses as a Persuasive Technology

While the PMD does utilize many techniques of Persuasive Technologies (Tunneling, Tailoring, Surveillance, Conditioning and Triggering) it could be improved by adding additional features that strengthen these techniques. For example, the device could include a motion sensor that reminds them when their next dosage is when they move near the device. Or the device could keep track of what medications are being stored and a service could be included to send reports to be used during doctors' visits.
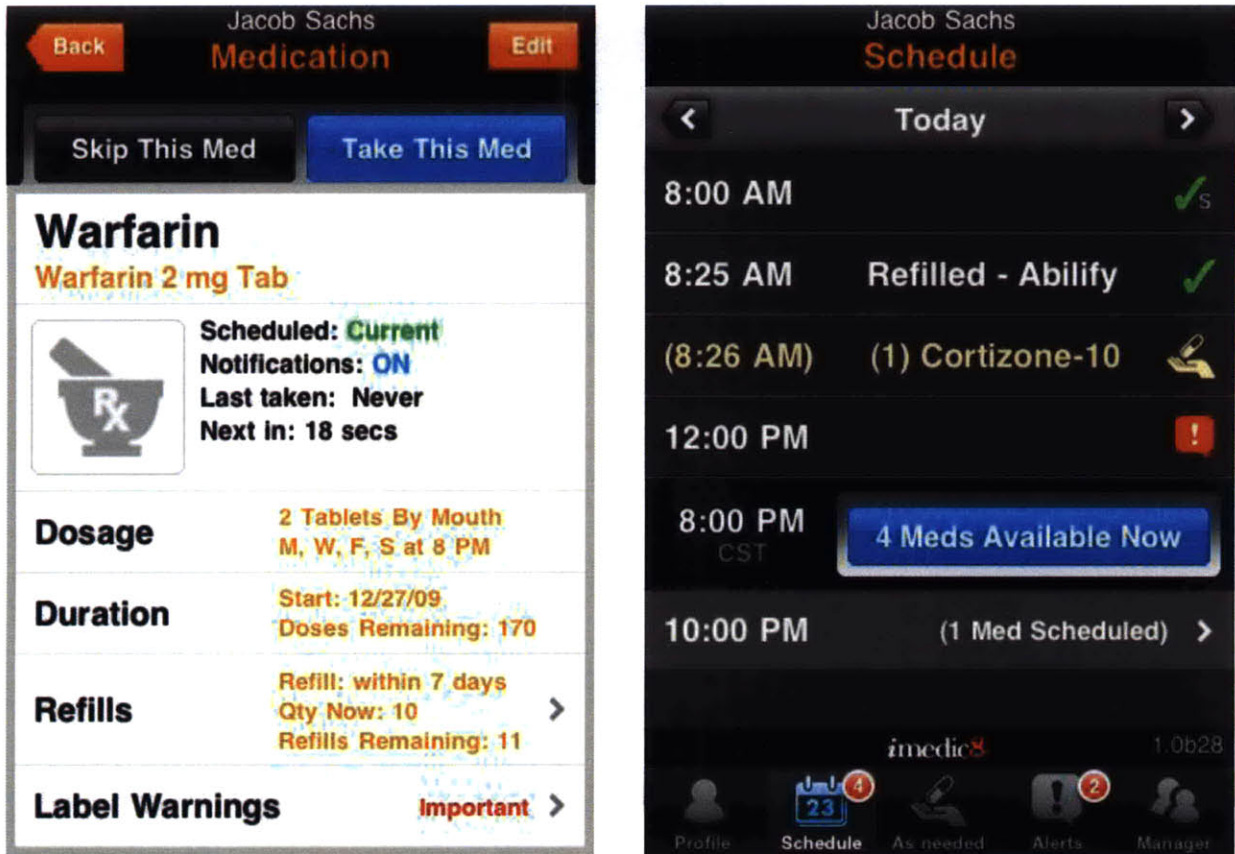
7.2.3 The Caregiver Iphone App Overview

Image Source: (Avimd, 2009)

The Caregiver Iphone App, the most reviewed Iphone app for medication management, is aimed at both patients and caregivers and offers them a number of features to stay complaint. Apart from the cost of the Iphone itself the App costs $4.99. Multiple profiles can be created so that caregivers can track multiple parents and themselves if needed. The user inputs both when to take their medications but they also input what specific medications to take at that time. The app has access to a comprehensive medication database that it draws from to provide pertinent usage information (specific instruction for use) and warnings. Using this information the App is able to build a detailed schedule that tracks what specific medications need to be taken, when they need to be

taken, the duration of treatment, when refills are needed and how many doses are left. Finally, it provides alarms to alert a user when it's time to take a dose. The user can confirm that a medication was or wasn't taken and a log of this information is kept that can be shared with a doctor.

"Finally...an important app!!!! As a physician it is finally great to find an app that has real usefulness in the care of my patients. They can track their own meds, or the meds of others in the family they care for. I expect compliance to improve, and patients can anticipate their needs by calling the office at the right times for refills. Also patients can review their meds during their office visits in a reliable way. I think this app is brilliant." by avimd (Avimd, 2009)

The Caregiver Iphone App: Strengths as a Persuasive Technology

The Caregiver Iphone App unique strength as a persuasive technology, is its ability to pull information from the internet to provide the user information (aka tailoring) about the specific medication they are taking. The appropriate warning, dosage and other special instructions (to take with a empty stomach, for example). The app also self-monitors the user and generates a log of their usage, users can even skip a dose if they want. so they can then provide accurate information to their doctors at the time of their visit.

The Caregiver Iphone App: Weaknesses as a Persuasive Technology

Where the Caregiver iPhone App Falls short is in the physical aspects of medication management. It does not help with the actual sorting and handling tasks. However, this solution could be paired with a pillbox nicely and if both were setup by a caregiver the pair could cover many of the aspects of persuasive technologies.

8 Conclusion

From the above analysis we see that complexity of the medication management problem has driven users and manufactures alike to create innovations. End users (seniors, caregivers, and other suffers of chronic diseases) have mostly explored solutions that focus on improving the physical and cognitive effort required to take the medication. They have also found interesting workarounds to pay less for their medications. Manufacturers, on the other hand, are starting to create devices and/or services that aim to shape and trigger behavior by using the techniques of persuasive technologies.

While all of the innovation discussed is moving in the right direction, a number of next steps to create a more comprehensive set of solutions is possible. For one, Seniors were chosen as the primary "lead user" in these studies, however, the same physical and cognitive problems that drove them to innovate also kept them from realizing more involved solutions. I did not find, for example, seniors creating their own Iphone apps. For this reason, using these same methodologies of interviews and ethnographic studies, could be applied to other population of heavy medication users who are not suffering from the same physical and cognitive impairments as Seniors. This study also focused on the problems most frequently encountered from the patient's point of view, however, the other stakeholders in the system (doctors, nurses, pharmacists) could also be studied to see what lead user innovation they have developed.

Device manufactures also still have a lot of room to explore innovation in the realm of persuasive technologies. While they are utilizing many of the techniques (triggers,

reduction, tunneling and self monitoring) they could increase the features on their products to add redundancy and to accommodate more types of people. For example, triggers that use sound, light and vibration could be used by the deaf or blind. Secondly, some techniques of persuasive technology were not well utilized. For example, conditioning (providing external positive reinforcement) could be used in the dispenser to create a point system making it more like a video game to encourage engagement.

While the exact design solutions are not clear, I hope this thesis has demonstrated not only the need for improved product and services for medication management, but has also has provided a set of frameworks to guide designers as they research, innovate and evaluate new solutions.

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