

# **MEDICAL AGEISM AGAINST YOUTH**

A Thesis Presented to the Department of Sociology  
In Partial Fulfillment of the Requirement for the Degree of  
Bachelor of Arts with Honors

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April 2010

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## **ACKNOWLEDGEMENTS**

I would like to thank my thesis advisor, Dr. Sarah Burgard, for making this thesis experience everything it was for me. I greatly appreciate all of her time spent not only in guiding my research, but also in defraying my concerns throughout the process. Always available for questions or a quick word of encouragement, I feel as though I would have never grown as much academically without such a strong advisor.

I would next like to thank my class advisor, Dr. Silvia Pedraza, and my second reader, Dr. Barbara Anderson, as well as my peer honors cohort for a challenging but rewarding three semesters. Collectively we explored the research process and bounced ideas off each other throughout the entire process. I know that some promising work and future researchers will come out of this class.

I would also like to thank all of my respondents. Not only did they answer my questions and share their stories with me, but many provided constructive feedback about my project and offered new venues to explore. I would like to thank those who passed on my information to other potential respondents. I would especially like to thank doctoral candidate Michelle Debbink for providing me with a crucial link to the medical school.

And last but not least, I would like to thank my mother, my sister, and my fiancé. They have been there since day one to listen to my research ideas and progress along the way. They have always supported me in my academic endeavors. Without them, I would not be graduating with honors from the University of Michigan.

## **ABSTRACT**

Society functions under the assumption that the elderly population is the segment of society that becomes ill. Countless studies have shed light on the mistreatment of the elderly in the medical field, and the medical community is also attuned to their greater illness burden (Rivlin 1994; Bowling 1999; Levin & Levin 1980). Yet, no one addresses the topic of ageism against the young. Young people are expected to be healthy. This study provides a qualitative analysis of interviews conducted with chronically ill youth and also with medical students sampled from a large research university population. This research shows that there are common issues, such as heavy reliance on age to categorize and diagnose, which could lead to misdiagnosis and difficulties in managing chronic conditions in younger patients. A better understanding of this segment of the young who are chronically ill and the challenges they face, as well as the difficulties the medical community faces in diagnosing and treating them, will be fruitful if it helps physicians and other health care providers to overcome an unintentional but institutional bias against the young. These findings are also useful for doing away with the perception that a young and ill person is an anomaly. This creates the opportunity for medical practitioners to provide informed and receptive care in order to reduce misdiagnosis or inappropriate care or treatment plans.

**Key words:** chronic illness, youth, medical education, institutional ageism, age

## **I. INTRODUCTION**

In the fall of 2006, I was experiencing major health problems. At first, I took my lingering symptoms lightly, because I thought that it was impossible for a freshman in college to be seriously ill. I interpreted my fainting spells as stress-related or the consequence of catching the flu from living in the dorms. A few days later, I ended up in the hospital having emergency surgery to implant a pacemaker. As with all medical devices, pacemakers come with promotional and educational materials. Every single image in these materials had an elderly person doing an older age-appropriate activity, such as a grandmother gardening. Even a book to help my little sister understand what I was going through had only illustrations of the elderly. Doctors and nurses would themselves express shock at how young I was for my medical condition. In fact, my original surgeon refused to operate on me although I was almost 19, and I was passed on to a pediatric surgeon. I wondered if I was one of the only chronically ill youth in America.

## **II. BACKGROUND AND SIGNIFICANCE**

While I felt isolated, the research literature suggests I am not a unique case. As LaPlante underscored, almost 50 percent of the working-age population has one or more chronic health conditions (LaPlante 1991: 61). The Center for Disease Control claims that 90 million people in the US have a chronic illness, or approximately one in three people. Sixty percent of the chronically ill are between the ages of 18 and 64. The number of people who are chronically ill has been growing over the past few decades. This increase in the prevalence of chronic illness in the United States is partially the consequence of the aging American population (Manton and

Liu 1984). The growth rate of the older population in the Americas has been higher than that of the total population for many decades (National Institute on Aging). For example, the U.S. ratio of the number of persons aged 60 and over to the number of youths under age 15 was 76 in 1997. This ratio is expected to be 122 by the year 2025. According to the CDC, 90% of senior citizens die from a chronic illness. In other words, the demographic change has also been accompanied by an epidemiological transition. According to the National Institute on Aging, the term "demographic transition" refers to a gradual process whereby a society moves from a situation of high rates of fertility and mortality to one of low rates. This means that the population age structure goes from a triangle shape (with more children at the base of the triangle and less elderly at the apex) to a rectangular shape (with the number of children at the base being equal to or slightly less than the elderly at the top). The "epidemiologic transition" refers to a long-term change in leading causes of death from infectious and acute to chronic and degenerative.

Moving toward an older and more chronically ill American population over the past several generations has led to major changes in medical education. Since infectious and parasitic diseases have mostly been eradicated, the focus of medical education shifts to a study of chronic illness and the populations prone to becoming chronically ill (National Institute on Aging). We are also currently training our medical students to think about health and illness in terms of risk groups. Kaufman stressed that risk awareness as both function and expression of medicine is now firmly embedded in understandings of the role of medical care in late 20<sup>th</sup> century society (Kaufman 1994: 434). Using risk groups based on demographic characteristics can be considered statistical profiling. Age is the base for categorizing disease. Although age

might be used to maximize the chances of correctly diagnosing a patient, the age of the patient can determine everything from how aggressively they are treated to what disease they are diagnosed with (Keeler et al. 1982; Teather 1974). Cultural assumptions tend to have an effect on who is considered “at risk” for chronic illness. Risk groups are also a result of the increasing HMO-ization of medical care. Medical professionals are expected to make a diagnosis in as little time as possible, leading to the utilization of age as a predominating basis to categorize diseases and the people who suffer from them (Wilson 1985; Aitchison 1977).

These macrosocial changes led to a generational conflict over resources, specifically medical resources. Societal resources are allocated differentially to different age groups (Turner 1998). The large aging population, represented most recently by the baby boomers’ generation (people who were born during the demographic 1950s Post-World War II baby boom), has provided additional incentive to focus resources toward older Americans. More money is being allocated to advertisement toward the elderly, because they are currently the largest consumer group (Pampel 1994). Large consumer groups hold the majority of political and spending power.

In addition, norms and expectations about aging change between generations (Settersten & Mayer 1997). The aging baby boomers have higher expectations than previous generations for extended high quality of life. Older people are increasingly retaining their ideal of personal agency and demand high quality of life (Kaufman 1994). Our society associates youth with health and beauty. The elderly are associated with slow degradation and increasing dependency (Waitzkin et al. 1994). Therefore, the baby boomers have demanded products to

retain their youth for as long as possible. The baby boomers' expectations of remaining younger longer have led to more appearance enhancing techniques, such as plastic surgery.

These phenomena have changed our identity as a country and also led to a theoretical problem. Talcott Parsons was an American medical sociologist who developed the theory of the sick role in order to explain the social aspects of one type of deviant behavior - being sick - and how it functioned in society. His theory consisted of four parts; two rights and two obligations of people occupying the sick role. The rights consisted of: 1. Exemption from normal social roles and 2. Not being held responsible for the illness or condition. The obligations included: 1. Try to get well and 2. Seek professional medical care. Parson's theory of the sick role is becoming less applicable to the majority of the population's experience. Since Parsons only considered acute illness when formulating the theory of the sick role, the theory has been criticized for the limited applicability to chronic illness (Williams 2005). In cases of chronic illness, the "sick" patient will never recover and return to full social functioning (Parsons 1975), violating the obligations of Parsons' sick role. This also has implications for people who occupy the sick role for the majority of their lives, like chronically ill youth. Specifically, chronically ill youth violate their obligation to become well and therefore do not "function properly" in society for their entire lifecourse after illness onset.

America is now focused on the elderly, but what about the youth? All of the previous literature and my past experiences naturally lead me to ask, "Is there medical ageism against the youth?" "Ageism against the youth" is defined as a set of beliefs, attitudes, norms, and values used to justify age based prejudice and discrimination against young people. The statistical reality of disease prevalence reinforces our opinions about young people. This can



lead to incorrect profiling, like misdiagnosing a chronically ill youth. Incorrect profiling can further propagate institutional discrimination against young ill people by solidifying our opinions about young people as correct.

Since chronic health problems among young people are not currently in the forefront of medical thinking, I would like to see how our notions of age and risk have affected youth who are actually chronically ill. Research that focuses on the health of youth, often classified as people aged 18-35, pertain mostly to their sexual practices, but rarely discuss other illnesses. In this study of whether or not medical ageism against youth exists, I explore if ageism against youth is evident in the way medical students are taught to diagnose and the experiences of chronically ill youth. This question will tell me something about current medical education. Additionally, I will explore another way in which our cultural ideas about age may be reinforced: in advertising. If society associates youth with health and portrays this in the media, and medical studies also espouse this belief, then it is being cyclically reinforced since both venues are in agreement. These conditions in the medical field influence the understanding and experiences of chronically ill young people by affecting the length of their diagnosis time, their perceptions of being believed by medical professionals, the paradox of being a “healthy sick” person, and the available treatments offered to them. My research is sociologically significant, because no one has ever asked this question before. This topic is interesting in general, because it takes an accepted idea – that ageism exists against the elderly – and expands upon that idea to describe the potential biases directed toward different age groups through their experiences in society, specifically in the medical field.

### **III. METHODOLOGY**

I used mixed methods to explore my thesis. Since there is no literature that is directly focused on medical ageism against the youth, I felt it necessary to study my topic from many angles: content analysis, in-depth interviews with two populations, and an online vignette survey. This type of research is considered triangulation; it combines different qualitative methods to explore various dimensions of a theme with some of the objectivity that quantitative research has (Herzog 1993). Content analysis allowed me to explore what medical students and doctors are exposed to in the images of illness utilized in their medical training. I used in-depth interviews to further explore themes of how age affects medical experiences and diagnosis. I interviewed chronically ill youth and medical students. Chronically ill youth were interviewed because of their continuous exposure to the medical system and their experience being young and diagnosed with conditions typically more prevalent in elderly populations. I interviewed medical students to explore what they are being taught about diagnosing patients, how age of the patient affects diagnosis of that individual, and what they have learned about chronic illnesses. I also decided to do an online survey with several vignettes in order to provide a controlled analysis of the influence of the patient's age on their medical diagnosis. I would not have been able to make a strong case for my thesis without exploring different aspects of this topic. Each aspect of my topic was accessible through different types of data collection.

#### **a. Content Analysis:**

I chose to use content analysis for a few reasons. My literature review mentioned the fact that as the overall population ages, more advertisements and resources are being allocated

toward or for older people. The ads reflect the greater array of services that are being targeted toward the aging population. I wanted to explore how the idea of medical ageism against the youth is enforced through advertising by neglecting to portray younger age groups and directing more attention toward images of older groups. To do this, I used a source that was targeted at medical personnel. I looked for advertisements that were relevant to my topic. My criteria were that the advertisements were recently published, advertised in a medical journal, and for a disease that both the young and the old can contract. It was challenging to locate advertisements at all, because most medical libraries do not index their journals by whether they include advertisements. I chose the journals from prior knowledge of famous medical journals that covered applicable medical topics. I chose each advertisement for its best fit to my criteria.

A relevant sample of contemporary American medical journals was chosen for review. The journals were printed between 2002 and 2009 to capture the recent demographic situation. The advertisements chosen from these journals had to be advertising a product for a disease or illness that people under 65 could contract, regardless of how rare it is. All advertisements came from four journals: The New England Journal of Medicine (one), the Journal of the American Medical Association (JAMA) (ten), The Journal of Cardiovascular Electrophysiology (three), and the American Journal of Cardiology (four). The audience for these journals is medical personnel. Not all advertisements in these journals were chosen, because some did not fit the criteria for what was being advertised. From all of them, 18 advertisements were chosen: seven advertising pacemakers, three for depression medications, two with medicines for pulmonary problems, two explaining heart disease medications, one for

stroke medication, one of medicine for acute pain, one of medication for diabetes, and one for blood pressure medication.

## **b. Interviews:**

### ***1. Chronically Ill Youth***

I conducted semi-structured in-depth interviews with chronically ill youth to see if they would discuss common themes regarding their medical experiences. I chose to use semi-structured in-depth interviews in order to allow respondents to expand on ideas important to them. I constructed the 26 question questionnaire (see Appendix A) based on my literature review and content analysis, addressing such issues as age stereotypes, medical resources, and interactions with medical personnel. I interviewed 25 chronically ill people who were diagnosed with an illness in their youth. Respondents had a wide range of illness like Crohn's disease, lupus, fibromyalgia, diabetes, hepatitis, etc. and were diagnosed between the ages of ten and 20 years old. Participants were recruited via flyers (see Appendix B), support group meetings, and three email listservs targeting chronically ill populations with a recruitment script (see Appendix C). In particular, I attended two support groups from previous knowledge of their existence and passed out flyers (see Appendix B): one targeted toward Crohn's and Colitis, and the other a general Chronic Illness support group. I reached my interview goal in eight weeks of the initial recruitment. The sample demographics are as follows (Figure 1):

<b>Chronically Ill Youth:</b>	
White:	19
Non-White:	6
Male:	6
Female:	19
Under 25 years old:	19
25 years old and Above:	6
<b>Total:</b>	<b>25 interviews</b>

Each interviewee was given a \$5 gift card to Starbucks at the beginning of each interview. They were asked to read and sign the Informed Consent form, including permission to tape record the interview. Interviewees were encouraged to ask questions about the study and the interviewer before beginning. All interviewees complied. Interviews were held in coffee shops and conference rooms, as requested by each respondent. The interview length ranged from 20 minutes to one hour.

Because of my own status as a chronically ill youth, my identity could have influenced the interviews. However, I consider it beneficial that I could sincerely empathize with my respondents. I felt that it made them more at ease to discuss intimate details about their medical history and what living with a chronic illness entails. Sharing my own stories may have encouraged interviewees to relate their experience to mine. For example, if an interviewee asked why I was researching chronically ill youth, I would explain that I myself am a chronically ill youth. I would also mention my health status if it seemed as though the respondent would appreciate my empathy. I only alluded to my disease when it seemed relevant to the interview, so not all respondents were aware of my condition. In order not to bias any answers, I tried to keep my explanation focused only on what illness I have. Other experiences were shared with respondents who seemed interested after they completed the interview.

## **2. Medical Students**

I also conducted semi-structured in-depth interviews with medical students to determine if they would report common themes about their medical education that reflected medical ageism. I constructed the 21 question questionnaire (see Appendix D) based on my literature review and a preliminary interview with a medical and doctoral student (MD/PhD student), addressing such issues as age assumptions (what we unconsciously think about people of different ages), differential diagnosis (how medical students learn to diagnose a patient by combining symptom presentation and patient characteristics to list and rank possible diseases), and interactions with patients. I interviewed a total of 23 medical students. Participants were recruited via flyers (see Appendix E) and an email listserv for the medical school at a large research university. I initially intended to interview only second year medical students (M2) and above, because the differential is first taught during the second year. I accepted interviews with a few first year medical students (M1) to compare what has been taught about age before the differential. The sample demographics are as follows (Figure 2):

<b>Medical Students:</b>	
White:	13
Non-White:	10
Male:	13
Female:	10
M1 – First year medical student:	4
M2 – Second year medical student:	8
M3 – Third year medical student:	5
M4 – Fourth year medical student:	6
<b>Total:</b>	<b>23 interviews</b>

Each respondent interviewed was given a \$5 gift card to Starbucks at the beginning of the interview. They were asked to read and sign the Informed Consent form, including permission to tape record the interview. Interviewees were encouraged to ask questions about the study and the interviewer before beginning the interview. The actual interviews were held in coffee shops and conference rooms, as requested by each respondent. The interview length ranged from 20 minutes to one hour and a half. Because I only had one connection through the medical school, sending recruitment through her email could have influenced the students who chose to respond. I provided the recruitment script (see Appendix F) for my study, and the medical student forwarded it from her email address to all medical students, urging them to help out a researcher friend. Knowing her could encourage or discourage certain students to reply.

**c. Online Vignette Survey:**

In order to better explore the effect that patient age has on a medical student's differential diagnosis decision-making process, I decided to distribute an online survey to medical students attending a large research university. To reiterate, differential diagnosis refers to how medical students learn to diagnose a patient by combining symptom presentation and patient characteristics to list possible diseases in order from most to least likely and most dangerous to the patient to least dangerous. I constructed the survey using the Qualtrics software. Aside from eight questions about basic demographic characteristics, each student was randomly asked only one of four possible vignette questions (see Appendix G). The vignette describes the symptoms reported by a fictitious patient and asks about either: (1) a 20 year old

patient or a 50 year old patient, and (2) the “classic” presentation from a medical textbook of either diabetes or cardiac arrhythmia. Participants were recruited through the same listserv used to recruit medical students for the in-depth interviews described above. My medical student contact used the same technique of forwarding my recruitment script from her email. I have received completed surveys from 60 medical students to date. The sample demographics are as follows (Figure 3):

<b>Online Survey:</b>	
White:	43
Non-White:	17
Male:	29
Female:	31
M1 – First year medical student:	11
M2 – Second year medical student:	21
M3 – Third year medical student:	13
M4 – Fourth year medical student:	15
<b>Total:</b>	<b>60 surveys</b>

Because I only had one way to contact medical students, it is possible that people who took the online survey were already interviewed by me. While this may have influenced their interpretation of the question, they might not have been aware from one question that the focus of the survey was age.

#### **IV. RESULTS**

##### **a. Medical Students:**

Medical students are influenced by media depictions of disease and by the curriculum of medical education. These different venues in combination could reproduce ageist tendencies. Advertisers concerned with profits and prevalence markets are focusing on the largest potential



consumer base. As a result, medical personnel are exposed to advertisements that associate the elderly with medical conditions and certain medical treatments. Medical personnel may then have a biased opinion of what diseases are possible when they meet young ill patients.

These medical advertisements are somewhat representative on many characteristics, but not on the age of the portrayed patient. The representation of gender is fairly equal: eight advertisements portray women as being sick, two are ambiguous, and eight show men. Race is not as representative: three advertisements portray African Americans, while the other 15 show Caucasians. While the 16% representation of African Americans is higher than the current population of African Americans in the United States (12%), there are no other non-white or non-black groups represented even though Hispanics are now the largest minority group in the United States and Asians are very much a part of America, too. Of most interest to me is the lack of young people portrayed in the advertisements: 12 advertisements clearly portray people over the age of 65, and the remaining six represent people over the age of 45. For example, even though 25% of all new pacemakers implanted are in people under 65 years of age, 100% (all seven) of the pacemaker advertisements depict people who have gray or no hair, occasionally showing them with small assumed grandchildren. The activities shown in all advertisements analyzed are no more active than gardening (five) or fishing (two), activities that are considered active living for the elderly because they require dexterity and mobility that are less likely as people age. These activities are also leisure activities implying that people using these products may be retired, implicitly speaking to an older population. The majority of the advertisements blatantly portray clearly older adults, while none of the advertisements showed young adults (ages 18-35).

Several themes emerged. One is the unintended effect that these articles can have on medical personnel. If you only see images of elderly people with certain conditions or needing certain care, it is hard to look past those images and correctly identify the same condition or needed care in younger people. Another implication is the differing lifestyles between the elderly and the youth. Once medical personnel diagnose a young person with a certain illness, they may be limited in knowledge regarding how to treat a disease. If the treatment only allows for the patient to engage in mostly passive activities, such as gardening or soft sports like golfing and fishing, then this treatment might have implications for a younger person's lifestyle expectations. The language used in these advertisements also offers the illusion of improving life, but not bringing it back to a highly productive and active level. For example, a pacemaker can make "everyday better" or put you "On 'course' for a better life (golfing)." A pacemaker can help you "keep up with the (grand)kids" or "spend more time with the best catch of [your] life (your significant other)."

Even if the ads do not explicitly create the statistical profile that younger people are healthy, the absence of younger people from medical advertisement encourages that generalization of reality. Since these advertisements are meant for medical personnel to see, the absence of young people associated with illness may color diagnosis decisions. If old age becomes a defining characteristic of people who have certain diseases, then the chances of a doctor misdiagnosing younger chronically ill people increase. Advertisers are not conspiring against the youth, but their advertisements are engaged in a crime of omission that is transferred throughout the medical field.

Medical students receive messages regarding age and disease from advertising, because they are required to use these journals as resources. This emphasis on age is also reinforced through their education. Age is at the crux of their medical education – the differential diagnosis. A differential diagnosis involves first making a list of possible diagnoses, then attempting to remove diagnoses from the list until at most one diagnosis remains. Removing diagnoses from the list is done by making observations and using tests that should have different results, depending on which diagnosis is correct. Differential diagnosis is also ordered or ranked from the most likely to least likely; sometimes, from the most life-threatening to the least. The method of differential diagnosis is based on the idea that one begins by first considering the most common diagnosis first. As a reminder, medical students are taught the adage: "When you hear hoof beats, look for horses not zebras," which means look for the simplest, most common explanation first. In order to see how age plays a role in the differential diagnosis, one third year medical student exemplified the opinion of many respondents saying, "Age is very very important because a 55 year old with chest pain is completely different from a 21 year old with chest pain in terms of what you think and how you order the differential."

However, many medical students expressed some concern about the focus on age. One fourth year student with a pediatrics focus explained,

"So, the age piece, I think it's really important to think about age when diagnosing a patient just based on the prevalence of certain diseases in certain ages, but I also think we need to make sure that if a certain disease presents at age four to six weeks old for example, if that's like the text book definition, we need to be thinking about that, but if they're three weeks old, that needs to be on our differential still, and I think a lot of

people like put it way down on the differential just based on the fact that it's not within the exact age range that we think about things. It's important to use age, but it's important to think outside of the age box."

This sentiment was reiterated by many medical students. While everything they know about diagnosing is based on age, they want to make sure that "textbook cases" are not overlooked merely because they do not fit the age criteria. This is often the case for chronically ill youth. Their symptoms may imply a certain disease, but their age puts it further down the differential, increasing testing and diagnosis time. One second year medical student summarized the experience as, "Maybe their presentation was that, but you just don't think that that rare thing could be happening."

Age is also built into medical education through the patient summary that students are required to give their superiors. One fourth year medical student pointed out how the differential and summary were related,

"Age and sex are automatically two things that help generate your differential. Age matters a lot because it's a risk factor for things, like cancer. A 20 year old, I'm much less likely to think of cancer for them than a 65 year old. But it also matters in other areas. Actually, when we're presenting cases to our superiors, we always start with a one liner kind of summary. So, age is essential to know in order to give that mandated summary."

Many medical students may take for granted that they are required to know the age of their patient. This learning exercise dictates how they report and proceed.

The information from the online vignette surveys I conducted with medical students also validates the idea that age is influential. When provided the textbook symptom

presentation of Type II diabetes, 100% of students correctly identified the disease in their first diagnosis, regardless of the purported patient age (that I varied: either 20 or 50). This could be due to the prevalence of diabetes in our society. However, of the 12 medical students who were asked about a 20 year old patient, 25% mentioned some sort of possible mental/emotional problem or drug use problem as their second or third diagnosis. Of the 20 medical students who were asked about a 50 year old patient, none mentioned mental/emotional problems or drug use as a possible diagnosis. When asked about the textbook presentation of cardiac arrhythmia, this difference is even more evident. For the 12 medical students asked about a 20 year old patient, over 41% mentioned a mental/emotional problem as the first diagnosis. When including the second and third diagnosis in addition to the first, 75% overall mentioned a mental/emotional problem as a possible diagnosis. For the 16 medical students asked about a 50 year old patient, only 19% mentioned a possible mental/emotional problem, and never was it the first diagnosis. Only 33% gave the correct diagnosis for the 20 year old scenario and 88% gave the correct diagnosis for the 50 year old scenario.

While the symptom presentation for cardiac arrhythmia might overlap with other illnesses, this particular cluster of symptoms was typical of cardiac arrhythmia in patients of any age. For example, fatigue and rapid heartbeat could be symptoms of drug use, but in combination with chest pain, shortness of breath, and fainting, cardiac problems are typically considered first.

## **b. Chronically Ill Youth**

The experiences of medical students have the potential to affect the medical experiences of chronically ill youth in their future medical practice. Many chronically ill youth reported long diagnosis times, often with many misdiagnoses. One man with a cerebrospinal fluid leak illustrated this point. When I asked him when he was first diagnosed with a chronic illness, he responded “Correctly? Well, it’s a long story.” Long diagnosis times were reported even for illnesses common in youth, like Crohn’s disease. Many youth also reported feeling as though they were not taken seriously by their medical providers. One woman with diabetes recalled, “I’m like I think there’s something wrong with me. And she’s [the health care provider] like no you’re crazy, you’re young and healthy and she’s like, you know, she started giving me all of these excuses.” Another woman with lupus had a similar experience: “They [the health care providers] didn’t believe me. They’re like no nothing is wrong with you, you’re a teenager.” Often this disbelief of medical practitioners takes the form of looking toward mental/emotional issues to explain young people’s symptoms. One woman with fibromyalgia stressed, “I did feel like he [the practitioner] was sort of implying to me that I was having a psychosomatic problem.”

Even after diagnosis, the assumptions practitioners made about young people were evident. One woman with Crohn’s underscored, “I think they really underestimate my pain.” Many youth spoke of paradoxical expectations that they would be a relatively “healthy sick person.” One woman with rheumatoid arthritis believed, “I feel as though I am bothering them too much if I have a few problems in a row. They would express disbelief at the number of complications I was experiencing.” Some youth also complained about the level of functioning

that their providers assumed was acceptable. One man with heart disease underlined: “I felt as though my doctor didn’t expect me to be able to do the activities I did before. For example, I wanted to do sports that involved running. He suggested that I take up new hobbies, like fishing.” These expectations could be due to the messages that medical providers receive from the medical advertisements in popular journals, like JAMA. Not only are the depictions of elderly people, they are depictions of lower function than an average young person would desire.

These chronically ill youth also reflected on how their age specifically made a difference in their life experiences. In general, they experienced a lot of discomfort in dealing with their new role as a sick person, but still a young person who was often assumed to be healthy. A few people expressed this sentiment by using phrases such as “Look at me, you know I look really healthy,” and “What I dislike the absolute most is just you have an invisible illness.” One woman with many autoimmune disorders added, “I don’t like how the normal people, the not sick people, treat me. They just completely ignore the fact that I’m sick and I get dirty looks when I ride the elevator up one or two floors because of my arthritis, or when I have to order special from the waitress.”

This experience of age conflicting with illness was often expressed through talking about coping with future-oriented thinking that their peers did not have to engage in, even on a daily basis. When speaking about the effects of chronic illness on future health, one woman with a nervous system disorder proposed: “When you’re young you don’t really think okay, ‘What is my health going to be like when I’m 50?’ You don’t care about things like that.” This shows that chronically ill youth perceive that how they treat their illness now affects how healthy they will

be when older. Another woman with cancer spoke of how being sick has changed her ability to be spontaneous. She summed it up as, “I can’t just up and leave, I have to plan everything out.” One man with hepatitis spoke more generally about limitations. He noted: “College students hate to hear it, but if you have a limitation, you should stick by it or be prepared to face the consequences. If you don’t mind feeling like crap for the next week because you want to party hard, then, don’t complain. But if you actually want to get stuff accomplished, work within the disease, not against it. You can’t escape your health.” While these experiences are not directly related to the medical field, I use them to illustrate how our society views youth and health. Medical professionals are influenced by the society they live in.

There was very little difference between the reported experiences of medical students. Since their education strives to be standardized, this finding makes logical sense. More variation was expected and found between the reports of chronically ill youth. While there were many common themes, some people self-identified as chronically ill, but seemed unfazed by their illness. These chronically ill youth often reported a great social support network and typically had a least one parent who was a doctor.

## **V. DISCUSSION AND IMPLICATIONS**

I set out to explore if medical ageism against youth exists. After reviewing the literature, analyzing advertisements in medical journals, and interviewing both medical students and chronically ill youth, the answer is yes. Although unintentional, many factors have led to overlooking this medical population. The youth in my study had a wide range of illness from those common in older people to rarer diseases. Regardless of prevalence, many of them



experienced the same disbelief from medical professionals. To reiterate, this is not active discrimination. Practitioners have been trained to act on the basis of population averages or typical patient populations. Advertising often uses a target age group or consumer population and are not directly discriminating against people from other groups. However, I believe that my research has shown that many factors contribute to create an environment that is not conducive to the best treatment we could provide for chronically ill youth. Small changes are possible to rectify the institutional ageism.

My study was limited since I only interviewed people in at a large research university. While the medical students are probably similar to medical students at other institutions, the chronically ill youth potentially have a higher socioeconomic status than average. This study is also cross-sectional, so I am not able to follow these students throughout their medical experiences. Time and funding also influenced what I could explore in this field.

As Kaufman stressed, when illness is associated with old age, “opportunities to prevent, evaluate, and treat specific problems [in young people] are ignored (Kaufman 94: 431).” The standardization of health care has many unintended consequences. For example, computer programs and lists are being developed that take a patient’s characteristics such as age and symptoms and generates an automatic differential and treatment plan. If someone presents symptoms in alignment with the textbook definition of an illness, they should not have to go through a long process of diagnosis merely because they do not fall into the “right” age category of people who statistically have that disease. The HMO-ization of medicine has also led to a huge time crunch for medical professionals. This lack of time necessitates the use of

risk groups and diagnostic check-lists that may consistently overlook a particular age group, like chronically ill youth.

This “statistical medical profiling” is reminiscent of racial profiling in law enforcement. While there is a statistical reason to implement these stereotypes, they can be damaging to the very people they judge and miss salient populations. For example, it is often the case that statistical profiling is correct. However, for the people who fall outside of these defined categories, like chronically ill youth, the results can delay proper health care. Perhaps there needs to be more sensitivity training to diversity within medical populations. One chronically ill youth who was also a medical student suggested,

“I think it’s nice to train residents and med students to see rare diseases or disease in rare populations, like if patients are amenable to talking about their diseases, that’s something that I think the medical community should take advantage of and I really wouldn’t mind talking about it, just to expose people further to a rarer illness or rarer age group.”

This training could be strategically programmed in the same way that the medical field has become more sensitive to socioeconomic status in order to reduce “non-compliance.” In medical education, students are taught to evaluate SES to tailor treatment plans in the hopes of increasing compliance and success. Diversity training has also been conducted for race and ethnicity. This method could work for age as well. Awareness that age is not always the best indicator of specific disease could decrease time to diagnosis in some patients. If symptoms are reviewed without the lens of age, typical presentations can be recognized and addressed. If medical education reduces its overriding emphasis on age, other factors such as symptom

presentation could be equally valued in diagnosis. If patients are seen as individuals and not as part of a risk group, diagnosis accuracy may improve. While chronically ill youth are still considered “rare,” policy and treatment regimes should include their experiences as well. For example, if the standard of care is to maintain everyday functioning in chronically ill patients, this may have to be adjusted for youth who need to function at a higher level. This higher level of functioning may be addressed through additional or different medication or treatment regimes to still allow for high physical or mental activity.

Another policy implication stems from institutions that assume all young people are healthy. For example, academic environments rarely provide the flexibility and increased support that chronically ill youth may need to succeed, like extended time to completion of degree. The theoretical implications of this research imply that Parsons’ concept of the sick role may need to be revamped in order to encompass prolonged occupation of the sick role due to age or chronic illness in general. Since an acute process is one that has a finite timeline on it and a chronic one is one that will persist for essentially an indefinite amount of time, there needs to be consideration of this difference. We need to continue to develop sociological theory, medical training, and medical treatment to accommodate the lifecourse needs of people who develop chronic conditions early in life. This development is necessary to make sure we are accurately evaluating society and provide alternative explanations that could lead to better cultural or societal acceptance of and accommodations for chronically ill youth.

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## APPENDIX A: Chronically Ill Youth Questionnaire

### Semi-Structured Interview Questions for Chronically Ill People

#### Basic Background:

- When were you first diagnosed with a chronic illness?
- Did your family have any history of this same illness?
- How much time elapsed between your first sign of sickness and your diagnosis?
- How did you decide to seek medical attention?
  - Did you make the decision or did someone else? Did you have a choice?
  - Where did you seek medical care? What factors went into deciding where you went to try to get care?
  - What did you know about this illness when you were first diagnosed with it?
  - How seriously did you take your illness when you first went to seek medical attention? How was it affecting your day to day life?
- Were you ever misdiagnosed?
  - What do you think it means to be misdiagnosed?
  - Can you tell me the story of your diagnosis, and any misdiagnoses you had along the way?
  - Do you think that you now have the “right” diagnosis?
  - Are you going to keep looking for new opinions?
- Did you ever feel as though you were not taken seriously by your medical providers?
- Are there any personal characteristics you have that you think affected the way you were diagnosed or have been treated by medical care providers?

- What are these characteristics?
- Why do you think they have affected your diagnosis or treatment? How did you notice this?
- What would you say you disliked the most of your diagnosis, treatment or care, and learning to live with your condition?
- What were/are the best aspects of your diagnosis, treatment or care?
- How much does your illness affect your day to day life today?
- There are many factors that shape the plans we make about our future – plans about school, work, family, and other things. Do you think your chronic illness have affected the plans you are making?
  - If so, how?
  - What other things affect your planning?
  - Does having your illness affect your planning about the same amount as, more than, or less than the other things that affect your planning?
- What advice would you give to a person like you about having your illness?
- What advice would you give medical care providers who treat people who have your illness?

# Chronically Ill People Needed

For Research on Your Medical Experiences

**Are you a chronically ill person?**

**Would you like to be a part of research about your  
medical experiences?**

**Involves:**

- **30-45 minute interview (phone or in person)**
- **\$5 Starbucks gift-card**

**Sara Achauer**

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## **APPENDIX C: Chronically Ill Youth Recruitment Script**

Hello,

My name is Sara Achauer. I am a Sociology student at the University of Michigan. For my Honors thesis, I am studying chronically ill youth, medical students, and their medical experiences. I was wondering if you would participate in my study. To be eligible to participate, you must be over the age of 18 and have a chronic illness. If you are interested, I would like to interview you at your earliest convenience. The interview takes no longer than 45 minutes, and we can do it wherever you are most comfortable. A \$5 gift card to Starbucks is my gift to you for participating. Let me know if this sounds interesting to you and when a good time to meet would be.

Thank you,

Sara Achauer

[sachauer@umich.edu](mailto:sachauer@umich.edu)

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The IRB approval number is HUM00029402.

## APPENDIX D: Medical Student Questionnaire

### Semi-Structured Interview Questions for Medical Students

#### Basic Background:

- How long have you been a medical student?
- Could you please define chronic illness?

#### Medical Training:

- My understanding is that a part of medical training involves learning how to diagnose a patient in a medical visit. Is that true?
  - If so, what have you been taught about diagnosing patients the first time you see them?
- Have you been taught to formulate a differential diagnosis?
  - If so, how would you define “differential diagnosis?”
  - What do you think about using differential diagnosis as an approach to diagnose patients?
  - What are your sources of information when developing a differential diagnosis?
- What characteristics of your patients are important to you for diagnosis?
  - Do you use population risks or demographic information in your diagnosis?
    - If so, in what way?
- What characteristics are important for making treatment plans for a patient?
- Has a diagnosis ever surprised you?
  - If yes, what was it and why did it surprise you?

- What do you think are the most important chronic diseases from a public health perspective- which matter the most for population health overall?
- Which diseases should we be spending the most research dollars on?
- What are the most important causes of major chronic conditions that affect the health of Americans today?
  - Is there anything we can do to intervene and protect people from developing chronic conditions?
  - Should we?
  - Who should we target?
- What do you think are the implications of the current demographic trends in America for your own future practice of medicine: specifically, the aging of the population, but also any other demographic trends you think are important?

# Medical Students Needed

*For Research on Medical Education*

Are you a 2<sup>nd</sup> year or above medical student?

Would you like to be a part of research about medical education?

Involves:

- 30 minute interview (phone or in person)
- \$5 Starbucks gift-card

*Sara Achauer*

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**If you are interested, please contact SARA ACHAUER for more information.**

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## **APPENDIX F: Medical Student Recruitment Script**

Hello,

My name is Sara Achauer. I am a Sociology student at the University of Michigan. For my Honors thesis, I am studying chronically ill youth, medical students, and their medical experiences. I was wondering if you would participate in my study. To be eligible to participate, you must \*be over the age of 18 and be a medical student\*. If you are interested, I would like to interview you at your earliest convenience. The interview takes no longer than 45 minutes, and we can do it wherever you are most comfortable. A \$5 gift card to Starbucks is my gift to you for participating. Let me know if this sounds interesting to you and when a good time to meet would be.

Thank you,

Sara Achauer

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The IRB approval number is HUM00029402.

## APPENDIX G: Online Vignette Questionnaire

### *Demographics:*

Sex: Male

Female

Other/Prefer not to disclose

Age:

Race: White/Caucasian

Black/African American

Native American

Asian/Pacific Islander

Hispanic/Latino

Other/Prefer not to disclose

Year in Medical school:

*Question (\* Each person taking the survey will be randomly assigned only one of the following four questions.):*

1. Below is a vignette about a hypothetical patient. After reading, please give me your first impression of what the patient might have. You may list up to three diagnoses, but please rank them with number one being the most likely.

An otherwise healthy 20 year old patient complains of:

- Frequent urination
- Excessive thirst
- Unusual weight loss

- Increased fatigue
- Irritability

What do you think they have?

1.      2.      3.

- 2.** Below is a vignette about a hypothetical patient. After reading, please give me your first impression of what the patient might have. You may list up to three diagnoses, but please rank them with number one being the most likely.

An otherwise healthy 20 year old patient complains of:

- Fatigue
- Fainting or near-fainting spells
- Rapid heartbeat or pounding
- Shortness of breath
- Chest pain

What do you think they have?

1.      2.      3.

- 3.** Below is a vignette about a hypothetical patient. After reading, please give me your first impression of what the patient might have. You may list up to three diagnoses, but please rank them with number one being the most likely.

An otherwise healthy 50 year old patient complains of:

- Frequent urination
- Excessive thirst
- Unusual weight loss

- Increased fatigue
- Irritability

What do you think they have?

1.      2.      3.

- 4.** Below is a vignette about a hypothetical patient. After reading, please give me your first impression of what the patient might have. You may list up to three diagnoses, but please rank them with number one being the most likely.

An otherwise healthy 50 year old patient complains of:

- Fatigue
- Fainting or near-fainting spells
- Rapid heartbeat or pounding
- Shortness of breath
- Chest pain

What do you think they have?

1.      2.      3.