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This study examines one particular example of an illness career in a sociologically important yet understudied population: university students who have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and certified as eligible for support services by a university clinic. Most adults in America have visited a physician at least once in their lifetime. In our culture this is a regular, taken-for-granted activity for those who feel sick. But how does someone arrive at the decision to seek expert medical help? Sociological researchers have demonstrated that this process is actually quite complex, involving a series of decision-making steps that together can be analyzed as stages in an “illness career.” Using qualitative interviews, I examined the experiences and processes that ADHD students pass through. I use the ideas of the sick role, illness career and gatekeeper to inform my results. Through my analysis, I have created a model for the illness career that contrasts with the traditional linear stages by viewing the different aspects of the career as intertwined. Regarding ADHD, I discovered that this disorder shifts from being other-diagnosed to self-diagnosed as a student progresses through the educational system. I also add insight to structural responses, and to the living experience of the ADHD diagnosed individual.

ADHD AND COLLEGE STUDENTS:
EXPERIENCING AN ILLNESS
CAREER

by

Rebecca L. Conway

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APPROVAL PAGE

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CHAPTER I

INTRODUCTION

Most adults in America have visited a physician at least once in their lifetime. In our culture this is a regular, taken-for-granted activity for those who feel sick. But how does someone arrive at the decision to seek expert medical help? Sociological researchers have demonstrated that this process is actually quite complex, involving a series of decision-making steps that together can be analyzed as stages in an “illness career.” My project examines one particular example of an illness career in a sociologically important yet understudied population: university students who have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and certified as eligible for support services by a university clinic.

ADHD first became established as a diagnosis for children in the 1970s. Because the diagnosis was limited to children, researchers only studied that population. Since the 1970s, the definition of ADHD has changed twice to include new potential victims. Conrad and Potter (2000) showed how the criteria expanded first in the 1990s to include “adult hyperactives,” i.e. those who had been diagnosed with ADHD as children and did not outgrow the symptoms. This led to a second expansion to include “ADHD adults,” those individuals who were not diagnosed as children, but still suffered from the symptoms (see Conrad & Potter [2000] for a more extensive discussion of this history). These changes opened the way for a large new population, adults, to receive an already

common diagnosis.

This new population of adults with ADHD is only now beginning to be studied by sociologists. My research focuses on college students. This group is particularly interesting in that it is composed of young adults in a transitional period of life. They are considered adults (for instance, the definition in the DSM-IV claims that childhood ends at age 18), while simultaneously being denied full adult citizenship as they are unlikely to be self-supporting. Some students have grown up with the diagnosis of ADHD and have their status re-certified by campus experts; others are certified as having ADHD for the first time in the university setting.

The allowance of ADHD to include the adult population creates new ways in which young adults may define their behavior. Children are diagnosed with ADHD after taking a test, often with input from physicians, parents and teachers. They do not have the authority to decide that they are “sick.” In the university setting, the diagnostic process becomes more complex. A physician gives an individual the “diagnosis” of ADHD and provides a treatment for the “illness,” usually by way of medication. To receive special education benefits in the university, however, requires certification as “disabled.” This certification is typically provided by non-medical experts in a university office of disability services.

Since college students are legally adults, a new voice is added to the negotiating process: that of the person with a disorder. Thus, university students potentially hold two statuses, “sick” and “disabled,” with a minimum of two sets of experts to verify their condition. My research focuses on the individuals who are diagnosed with ADHD at the

college level and are also receiving disability services. My goals are to examine the process of legitimating the diagnosis, as well as reasons for seeking and maintaining it, and to add the voice of the diagnosed individual to the current literature. My research asks the following questions: How does a person enter into and proceed through an ADHD illness career? How does this career trajectory differ based on the educational level of entry?

As I will show in the following pages, most of the sociological literature on ADHD focuses on physicians and parents. The voice of the diagnosed person is lacking. If it is heard at all, it is between the lines. My research will help to add this voice to the current scholarship. The voice of the “disordered” is especially important for understanding how individuals interpret themselves and their surroundings. It is very difficult to gain a full understanding of a situation if one constantly remains outside of it. Research of experts and parents is highly valuable, but without also considering the individual, it can be difficult to gain the full picture. Adding the voice of the individual will add a new dimension to the current literature.

On a broader level, adding this voice will contribute to the current literature on illness careers and the sick role concept. It will also provide insight into the role of social networks in a late adolescence transitional population. ADHD proves a useful example for examining these concepts due to the prevalence of the disorder and the recency with which young adults have been included among its potential victims.

Additionally, my research has practical applications. By having a better understanding of patients' lives, physicians and disability workers will be better equipped to help those they have been entrusted with aiding.

What follows are a review of the sociological literature surrounding ADHD and a description of my project and results. In my concluding chapter, I discuss questions raised by my research and suggest directions for future investigation.

CHAPTER II

LITERATURE REVIEW

My research examines illness careers among college students who have been diagnosed with the “illness” and/or “disability” of ADHD. In this chapter I situate my study within the existing literature. There is currently little sociological literature on adult ADHD. In the following pages I begin by examining the literature that does exist. Then I review the concepts of the sick role, illness careers, and gatekeepers, as these notions underlie and guide my research. I also examine how each of these concepts has been applied to ADHD.

Previous Research on ADHD

The concept of a disorder, J.C. Wakefield notes (1992), “... lies on the boundary between the given natural world and the constructed social world (p. 373).” As this quote suggests, there have largely been two perspectives on the nature of ADHD:

- 1.) Biological
- 2.) Social constructionist

What is not included is a third perspective that exists “between” those two: that of the psycho-social or behavioral perspective.

A biological perspective assumes the condition of ADHD is real and that the cause is organic, making medication an appropriate treatment. The social constructionist view questions whether the condition of ADHD is real, thus making the issue of

causation moot. Instead, this view focuses on how interested parties construct the concept and apply it to individuals. The third perspective, psycho-social or behavioral, lies in between these two and assumes that the condition of ADHD is real, but that the cause is in the psycho-social environment, not biology.

This difference of perspectives is not unique to ADHD. It also describes the literature on other similar disorders, such as depression, where debates center on whether the condition should be treated with medication or psychotherapy, as well as on the uncertainty of diagnosis. The media and some scholars tend to treat these perspectives as opposites rather than as complementary (Plomin & Asbury, 2005). In the case of depression, some researchers argue the importance of both environment and biology. Views of ADHD causation, however, are still sharply divided between advocates of biological and environmental causation, when causation is the issue. Many researchers outside of the medical field have taken the psycho-social or behavioral perspective, while the majority of medical experts have adopted the biological perspective.

Both the psycho-social and social constructionist perspectives tend to question the validity of this disorder. Research topics include, but are not limited to, who gets diagnosed, what leads to a diagnosis, the uncertainty of the diagnostic criteria, and how a diagnosis of ADHD affects family members and educators. This literature has mostly ignored college students and adults. Also missing is an account of how a diagnosis of ADHD affects the child or adult. I attempt to address these concerns in my research. What have been studied are the general demographic characteristics, such as gender and race, of people diagnosed with ADHD. In looking at the research conducted on these

different social categories, we see inconsistent findings (Schmitz, Filippone, & Edelman, 2003; Stevenson & Williams, 2000; Schmitz & Velez, 2003).

One explanation for inconsistency may be found in the social constructionist approach, which many sociologists have taken in studying this disorder. This approach examines the ways the media and others guide perceptions of who has ADHD. For example, one study examined the social representations of ADHD in the United States by conducting a content analysis of popular print media. To analyze the data, they drew upon social representations theory (Schmitz, Filippone, & Edelman, 2003). Among the conclusions drawn from this study were that young boys were most commonly identified as having ADHD and in all cases, the boys were white. The authors focus largely on hyperactivity rather than inattention, and they critique the biological and genetic arguments for the etiology of the disorder.

Schmitz, Filippone, and Edelman (2003) argue that the popular media promote the view that more males than females have the disorder. Scholars who have studied formal diagnoses argue that there may instead be different manifestations of ADHD by gender instead of different rates of occurrence (Stevenson & Williams, 2000). A similar inconsistency has been found with respect to distribution by race and ethnicity. One study examined whether acculturation and ethnicity influenced perceptions of ADHD behavior (Schmitz & Velez, M. 2003). Using survey data, Latino mothers ranked whether, and how often, their children engaged in typical ADHD behaviors. The degree of the mother's acculturation to Anglo culture was also assessed. The authors found that acculturation played an important role only in measures of hyperactivity and not the

attention deficit aspects. This work suggests that culture may have an important impact on how we view behavior and whether we associate it with this disorder.

Bussing, Gary, Mills and Garvan (2003) discuss the differential exposure by race to information about ADHD. Through an examination of the differences between African American and Caucasian perceptions of the disorder, the authors find that of these two groups, African Americans report knowing less about ADHD and the supports that are available for helping those with this disorder. They are less likely to receive ADHD information from teachers. Perceptions of ADHD-related behavior as well as opportunities for receiving information about the disorder impact who society “sees” with the formal diagnosis.

Very little research has been conducted on age differences, which is consistent with the diminutive amount of research on ADHD adults. As this disorder has recently been diagnosed in people of all ages, there is more uncertainty as to who the typical ADHD adult is in terms of demographics. This leaves a large space for confusion, leaving researchers and “experts” alike to be uncertain as to what ADHD “looks like.”

When faced with uncertainty of this nature, there are generally three options. Option one is to continue research and find more solid answers, in the interim denying the diagnosis to anyone who does not ‘fit the bill.’ A second option (using the social constructionist approach) is to conduct research that focuses on the definitions of the disorder, and how those definitions come to be justified. Option three is to expand the definition (“bust the boundaries”) to include more cases. The field of mental health has been characterized by repeated boundary shifts. Indeed, some refer to it as

“boundaryless” (Dinitz & Beran, 1971). ADHD “definers” chose to be boundary busters by expanding the age requirement to include all ages, not just those under the age of 18. Peter Conrad (2007) uses the term “diagnostic expansion” when talking about this trend.

A Conceptual Grammar for this Study

In my study, I utilize several key concepts. The first concept is that of the “sick role.” It is used in order to gain an understanding of the privileges and obligations that may lead a person to seek out or avoid a potentially stigmatizing disorder. This concept is encompassed in the second key idea that I use: the “illness career.” As I will show, the illness career provides a basis for understanding the stages or trajectories that lead an individual to a physician’s door and ultimately to a diagnosis. Inherent in this concept is the importance of other people to help legitimate and validate the disorder. The third and final concept, “gatekeeper,” refers to people who have the authority to legitimate a diagnosis. I begin with a general review of each concept, followed by a more specific discussion that applies them to the case at hand, ADHD.

The Sick Role Concept

“Sickness,” “illness” and “disease” are three terms that, in common parlance, may mean the same thing. Sociologists, however, use them to describe different phenomena. The term “disease” encompasses the physiological or biological aspects of ill health. What this term leaves out are the social aspects. A person may have the physiological signs of a disease such as cancer, yet never be diagnosed with it. Conversely, someone else may receive a false positive diagnosis of a disease that he or she does not really have. In both of these cases, the person acts according to what he or she believes. For example,

in the latter case, the individual may radically change his or her behavior by making amends with alienated loved ones and enjoying life as much as possible before the disease progresses. Both of these responses reflect social aspects of disease.

My study relies upon one further distinction, that between people who have a formal medical diagnosis and those who do not. To distinguish between the two situations, I use the terms “sick” and “ill.” Thus, for the purposes of this study, a “sick” person is an individual who has been diagnosed with a disorder by an accepted expert, such as a doctor. Someone who is “ill” experiences symptoms and feels that something is wrong, but lacks the official diagnosis.

Once a person is given a diagnosis he or she is, for my purposes, both ill and sick. Sociologists define a status as a person’s place in society, such as professor or woman. Each social status is equipped with certain behavioral expectations, or a role. For example, one aspect of the role of a professor is to teach. Talcott Parsons (1951) argued that society requires a “sick role.” This requirement helps ensure that only those individuals who are truly sick will be exempted from responsibility, and that those who are healthy will remain productive members of society. His role concept is composed of four components: two privileges and two obligations. The first privilege is that the person is exempt from the responsibilities associated with normal social roles until he or she is “well.” This can be seen in the workplace. Employees are typically allotted a certain number of days off due to sickness, thus exempting them from the responsibility of working when they are sick. The second privilege is that the person is not held responsible for his or her condition, but something else (like a virus or bacteria) is. One

obligation of the sick role is that the person must want to get “well.” The other obligation is that he or she must seek technically competent help (such as a physician) and fully cooperate with the expert in order to get well. For instance, if someone is diagnosed with Post-Traumatic Stress Disorder, he or she is obligated to see an “expert” such as a psychiatrist and follow the doctor’s orders, as opposed to “handling” it alone. Failure to do so can result in sanctions.

Parson’s sick role concept is widely known in the field of medical sociology, and has also been widely critiqued (Fahy & Smith, 1999; Weiss & Lonquist, 2000). One criticism of Parson’s concept is that it does not account for variability in behavior among sick people. Another is that it does not apply to those with chronic illness. One cannot be expected to get better if there is no cure. A third criticism is that it does not allow for social class differences. Researchers argue that it seems only to apply to the middle-class, for lower class people have less ability to leave their jobs (a responsibility from which the sick role claims they would be exempt), as well as a lower ability to afford the required, legitimized help (Weiss & Lonquist, 2006).

Adaptations of the Sick Role Concept

It is out of these criticisms and the idea that the human experience is dynamic, not static, that new ideas have arisen to help us better comprehend the human experience of sickness. Kathleen Fahy and Philip Smith (1999), for example, deploy the idea of agency, pointing out that patients make critical choices, such as deciding to be a “good” and “obedient” patient or a “bad” and “confrontational” one. By drawing upon Judith Butler’s “subject positions” theory, which posits that actors move in and out of positions during

medical negotiations, Fahy and Smith document flexibility in the medical encounter that is not allowed for in the classic sick role conception. Using an ethnographic study of teen mothers, Fahy and Smith are able to show how assuming different positions affected medical decisions. For example, if a nurse chose to be an assistant to the doctor, the outcome was in line with the physician's ideas, but if he or she chose to be a patient's advocate then more power was shifted into the nurse's hands as he or she combated the medical decision. Their analysis shows that the medical encounter does not merely emerge through role prescriptions, but is located in a cultural setting complete with dynamic and mutable differences in the exercise of human agency. Individuals, whether nurse or patient, can choose which role they would like to play.

David Karp (1994) also posits that the sick role is not strictly a static position, but that individuals go through stages or processes. This changes the traditional static version of the sick role into a more dynamic one. In his study on depression, Karp conducted in-depth interviews with individuals who had been diagnosed and treated for clinical depression. These interviews were used to "consider how persons arrive at illness definitions and then reconstruct their identities accordingly (p. 7)." By viewing depression as a career with the patients moving through different phases of a process, he found regularities in the steps taken. He also noted a wide range in the length of time a person spent at each position, which accounts for variability in behavior among sick people. The classic sick role formulation failed to do this. Karp was also able to provide insight into the key factors that are involved in the transitions by illustrating how the involvement with psychiatric experts and medications became a major transition point,

affecting the patient's reformulation of identity, such as reinterpreting the past and developing modes of coping.

The "sick role" concept and the later adaptations have guided some of the current research on ADHD. The existing research focuses mainly on children, but a few studies have begun to include the adult population. A review of this literature follows.

Sick Role and ADHD: Children

Most of the research on the "ADHD sick role" has focused not on the privileges and obligations of the role as they apply to diagnosed children, but rather on the adults with whom they interact: parents and teachers. Furthermore, most of this literature has stressed privileges or benefits accruing to others when a child for whom they are responsible is diagnosed.

Some researchers have argued that parents benefit from being freed of the responsibility to control their children and teach them how to behave. Iilina Singh (2004) explored this issue by interviewing mothers and fathers of boys with ADHD. Through her analysis of the interviews, she discovered that there is a culture of "mother-blame" that comes from the community, society, other mothers, fathers, etc. When a child acts out behaviorally, "others" accuse the mother of bad mothering. By having a child diagnosed, the mother is exempted from the responsibility for her child's behavior. The disorder takes the blame away from the mother (environment) and transfers it to the disorder (disease). Once a diagnosis was given, the mothers in this study reported feeling a sense of relief, as they could no longer be blamed or held responsible for their children's behavior.

This benefit is less available to mothers when they resort to non-medical therapies. Claudia Malacrida (2002) found a culture of mother-blame among advocates of alternative therapies for ADD. In looking at texts discussing alternative therapies, she found that the writers held mothers responsible for their children's behavior. One alternative therapy is providing "better" nutrition, both for a young child during breast-feeding, as well as an older child's diet. Advocates of nutritional therapies hold mothers responsible for providing nutritious food. While alternative healers question drug treatments and medical expertise, they continue to hold mothers responsible for the behavior of their children. Essentially, they expect the mother to raise well-behaved children. If they disagree with the traditional medical model, then the mother is not alleviated from the responsibility for the hyperactive child, but is instead expected to find alternative ways of "correcting" it outside of medication.

Other researchers have focused on the benefits to teachers. James Christian (1997) argued that by controlling student activity, the teacher can focus on teaching the mind. Having students diagnosed with this disorder also helps provide regulation in the classroom and establishes a boundary for distinguishing which behaviors are acceptable and deviant in the school setting. This is consistent with the view of medical ideology as a type of social control, which comes about by "defining a behavior or condition as an illness primarily because of the social ideological benefits accrued by conceptualizing it in medical terms (Conrad & Schneider 1992: 245)."

These studies tend to focus on the benefits to parents and teachers without addressing the possibility that a stigma may exist for the diagnosed child. This may be

especially likely to occur if the child also has access to the benefits without acceptable “proof” of suffering.

Sick Role and ADHD: Adults

Now that ADHD is a diagnosis for adults as well as children, researchers are beginning to examine the situation among the adult population; however, there is still very little research concerning the sick role and ADHD at this stage of life. The literature that does exist discusses two benefits of diagnosis for the adult: comfort and exemption from responsibility.

Emily Mumford (1983) suggests that one benefit of adult diagnosis may be a form of comfort. If a child grows up with a diagnosis, then the life of a patient is all they know. The individual has no reference to a “healthy” childhood, and may therefore want to continue whatever benefits were granted as a patient, including remaining inside a familiar world. Her research, however, pertains to diagnosis in general and was not specific to ADHD.

The other benefit is an exemption from responsibility. While this theme was also found in the case of children, it is experienced differently by adults. The reason for the difference has to do with the way ADHD is perceived in adults. Children are most likely to be diagnosed as a result of their behavior. Being hyperactive or impulsive in the classroom or at home raises concern that something may be wrong. Researchers of adult ADHD argue that in the case of adults the issue is not so much a behavior or hyperactivity, as it is a perception of under-performance (Conrad, 2007; Conrad & Potter, 2000; Diller, 1998). If adults are not succeeding well, explaining their level of

achievement as due to a disorder rather than a lack of effort or ability exempts them from the responsibility of achieving higher levels of success. They may also receive such benefits as special office furniture, special equipment, or other such items that will help the individual in the workplace (Conrad, 2007).

While research is scarce regarding the sick role and adults with ADHD, existing analyses indicate that it is a useful concept with which to understand the benefits and obligations associated with the diagnosis. The benefits and obligations may help to explain why individuals either seek out expert help and thus the diagnosis, or try to avoid it altogether.

These factors may influence a college student's decision to consult disability services. Nonetheless, we know virtually nothing about the paths students take, or the people involved in the process culminating in their appearance at the ODS. In order to examine these trajectories I utilize the concept of the illness career.

Illness as a Career

The entering and exiting of the sick role can be more precisely conceptualized as stages in an illness career (Karp, 1994). A "career" in this sense is not the typical career associated with an individual's occupational experiences, such as the career of a businessman. This conception is of a subjective career that deals with the possibilities and problems involved for someone who continues on a certain path. The process of the illness career involves learning how to negotiate the sick identity and potentially achieve a sick role. It also allows for an ability to resist, "retire," or exit from the role.

“Illness behavior” was defined by Mechanic and Volkart (1961) as “the way in which symptoms are perceived, evaluated and acted upon by a person who recognizes some pain, discomfort, or other signs of organic malfunction (p. 52).” Illness behavior tends to be organized into distinct stages, which together comprise an illness career.

Edward Suchman (1965) describes these stages as 1) Symptom experience; 2) Assumption of the sick role; 3) Medical care contact; 4) Dependent-Patient role; and 5) Recovery or rehabilitation.

According to Suchman, the symptom experience stage involves three aspects. One aspect is the feeling of physical pain. Another represents the cognitive aspects, i.e., the person’s interpretation of the symptoms. The third aspect is the emotional response that results from the first two. The recognition of the symptoms and the interpretation of them tend to be influenced by daily functionality and not medical symptoms. For instance, a person is more likely to interpret a symptom as “too sick to go to work” rather than to utilize a specific medical term.

Stage two involves the assumption of the sick role. It is at this stage that an individual seeks validation of symptoms from significant others, which allows for temporary alleviation of responsibilities and helps the individual to decide what to do next. Visiting a physician for a medical diagnosis follows this stage. The physician may either grant legitimacy to the individual’s symptoms, and thus allow him or her to assume the sick role or deny the severity of the symptoms and thus require the individual to return to “normal.” In other words, stage two provides symptom validation from family

and friends, but the symptoms are not confirmed as legitimate until a physician verifies in stage three.

Upon passing through stage three, the individual moves to stage four where he or she becomes dependent on the physician. The individual transfers control of the situation to the physician and accepts the treatment given. This is consistent with the sick role obligation. Once this occurs, the person becomes a patient. This stage is not necessarily accepted without any reservations. Suchman (1965) notes that many people have trouble with this stage, which, adopting the medical experts' definition of the situation, he argues, interferes with the treatment. For instance, patients may not fully accept the recommendations of the physician, such as bed rest. This shift to perceived helplessness may be seen as a loss of independence that an individual may be reluctant to accept.

The fifth and final stage involves recovery and rehabilitation or death. The patient either relinquishes care or exits the patient role. In either case, the patient no longer receives active medical care. From here the individual has two options. He or she may either re-enter the world of the healthy by reassuming the roles and responsibilities acquired prior to the illness or enter into another type of role, such as a chronic sick role or a dying role.

Suchman interviewed individuals who required three or more physician visits in a two-month period and whose illness had incapacitated them for at least five consecutive days or required at least one day of hospitalization. His sample includes individuals experiencing physical pain, identified by Suchman as the most important indicator leading a person to believe that something is wrong. His assertion raises the question as

to how those who have disorders with no accompanying physical symptoms might reach the same decision. Examples include most mental disorders and, of course, ADHD. My study focuses on individuals who do not necessarily experience physical pain yet come to believe that something is wrong.

One attempt to study people experiencing non-physical ailments is offered by Erving Goffman. Goffman (1961) discusses how mental patients experience a “moral career.” The stages involved in this “career” include being a pre-patient, a patient, and a post-patient. The individual begins this moral career in the pre-patient stage. The pre-patient is the individual who experiences symptoms without necessarily having physical pain or is seen by significant others to be exhibiting questionable symptoms. The person then becomes defined as having an illness and enters into the mental hospital as a patient. Goffman shows how other people push a person through the career trajectory. The pre-patient is formed by the actions of a conglomeration of people, including significant others as well as “mediators.” Mediators are typically agents of an institution, such as physicians, who lead the individual into a mental hospital, where the person becomes a patient.

Goffman’s idea of the “post-patient phase” describes the effects experienced by the individuals if they ever leave such an institution. An example of this can be seen with Schizophrenia. Once released from a mental hospital, a person does not simply re-enter the world of the healthy, as Suchman’s stages suggest, but is instead left with a label of “in remission.” Never again is it possible for the individual to be “healthy.”

These theories of different stages, or career trajectories, provide a basis for examining a variety of disorders. In the case of college students with ADHD, individuals may have progressed through childhood with or without the diagnosis. The stages these individuals go through may widely vary due to the differing ages of entry. The existing literature does not examine such differences, and one of the goals of my research is to examine how illness careers vary depending upon age of entry.

Regardless of how the stages are defined, it is clear that other people have an impact on the process. Charles Kadushin (1966) was a pioneer in studying how others impact an individual's illness path. He discussed how friendship networks are involved in leading a person from feeling symptoms to seeking medical care. By examining a social circle he called, "The Friends and Supporters of Psychotherapy," Kadushin was able to show how members of this group were more likely to know others who had seen a psychiatrist. This knowledge helped to lead the members into their own therapy. The "Friends" also had access to individuals who were able to refer someone to a psychotherapist. This referral process became a crucial step that led an individual to seek therapy. Kadushin's study took place at a time when psychotherapy was rare, and in many sectors of society it was stigmatized, making the networks even more vital.

Having a child diagnosed with ADHD may also result in the parent coming to the decision that something is wrong with him or her. Conrad and Potter (2000) suggest that this difference is due to the way an individual receives a physician's diagnosis. In the case of children, parents and teachers are the individuals involved. Most adults, however, are self-diagnosing. They argue that this is especially true of adults who have children

diagnosed with ADHD, as they focus on similarities between their child's experiences and their own early lives.

Irving Zola (1973) found other factors that are involved in the decision to seek help. By interviewing people waiting to see a doctor on an initial visit, Zola identified five "triggers" that lead a person to seek medical help. They are 1) Occurrence of an interpersonal crisis; 2) The perceived interference of the symptoms with social or personal relations; 3) Sanctioning, which may be seen as significant others strongly encouraging the seeking of treatment; 4) The perceived interference with work or physical activity; and 5) Temporalizing of symptomatology, which involves setting a deadline, such as, "If I'm not better in two days, I'll seek help." Zola's study further clarifies some of the reasons why people seek care. Other social factors, not discussed by Zola, may include the costs, availability of care, and other social stresses such as finding babysitters or substitutes at work.

The processes involved in entering into and proceeding through the sick role were also examined by Fredric and Sally Wolinsky (1981), who focus on legitimation as an essential aspect of the illness career. Through surveys conducted in an ambulatory care setting, they found that individuals go through a legitimation process. They found that people initially seek provisional validation once they decide that something is wrong. Consistent with Suchman's stage two, this allows for a temporary exemption from responsibilities if the family and other significant others validate that feeling; however, people are not bonafide candidates for the sick role until they have a physician's

legitimation. It can be inferred that if the family and significant others do not legitimate the illness the individual may never enter into the sick role.

Claire Glenton (2003) in her study of back pain sufferers illustrates some of the factors that affect the process of legitimation. Through in-depth interviews with sufferers, she found that one important aspect was having a visible, physical disability and visible symptoms. The other important way of gaining legitimation was through diagnostic tests and diagnoses. She found that the sufferers welcomed such tests in order to “prove” that their suffering was real. Without the acceptance of “experts” a person experiencing pain is merely “ill,” not “sick.” The person may even be viewed as a malingerer. A problem may arise if full entrance into the role does not occur. If one has access to the benefits of the role but does not have the necessary supporting evidence, the result can be negative perceptions of the individual, such as that he or she is addicted to the medications (Glenton, 2003).

Larry Nuttbrock (1986) found similar results in his examination of how people enter into a chronic version of the sick role. He interviewed people between the ages of 55 and 85 who had known health problems and were required to visit a physician regularly. Among his findings were that patients conformed to the expectations of others. The “others” were seen as casting the sick role onto the older individual by assuming they were inactive and incapable of doing many activities due to health. This is one more example of how significant others play a key role in the progression through the illness career. Nuttbrock also found that the individual retained some agency in the situation by

embracing the sick role and its advantages. This gives further credence to the dynamic, negotiation process of this role.

The ending of an illness career involves exiting a role, which is in accordance with Suchman's fifth and final stage. Exiting the sick role, however, may simply lead to entering a different one. This issue, however, is beyond the scope of this project and will not be discussed further.

Aside from the literature already reviewed on the sick role and ADHD, no research exists concerning illness careers of people with this disorder. What may be surmised from these studies is that other people are necessary for an individual to enter into a sick role or an illness career. They may be involved in the progressing through stages (Suchman, 1965; Goffman, 1961) or in the legitimation during any phase (Kadushin, 1966; Zola, 1973; Wolinsky & Wolinsky, 1981; and Nuttbrock, 1986). Aside from personal friends and family members, expert validation is still needed (Wolinsky & Wolinsky, 1981 and Glenton, 2003). The following section examines literature on the role of the people who do the validating.

Gatekeepers

A common thread in the literature on the stages of illness careers and the sick role concept is the role of gatekeepers in legitimating an individual's status as sick. A gatekeeper is an individual with the power to control access to goods, services, or information. Physicians, as gatekeepers, have the power to influence the path a patient will take. Their influence involves legitimating symptoms, providing (or not) exemption from work, and giving access to certain drugs.

Historically, physicians had a great amount of power. This was true when Parsons and Suchman wrote in the 1950s and 1960s. Peter Conrad (2005) has since suggested that the role of the physician as gatekeeper is beginning to shift in the postmodern era. By examining changes in the medicalization process in general, he identified “shifting engines” driving medicalization. One engine, Biotechnology, is beginning to shift away from a time when physicians were at the center of medical decisions, such as which drugs to prescribe. While he argues that physicians remain the gatekeepers for many drugs, Conrad insists that they have taken a secondary place to the pharmaceutical companies. This occurred because the pharmaceutical companies are able to promote their drugs directly to the public instead of through the physician.

This shift allows the patient to retain more agency and thus is one limit on the power of the physician as gatekeeper. As noted previously, in Fahy and Smith’s (1999) study on subject positions and Karp’s (1994) study on depression, the reproduction of medical power was not static, but resulted from interaction and negotiations. This implies that some power can be placed back in the hands of the patient. As an illustration, Fahy and Smith (1999) show how women started to have more of a voice in fighting for and legitimating non-traditional childbirth providers, such as midwives and radical nurses.

Other gatekeepers are significant others who validate (or not) an individual’s feelings prior to visiting a physician. Parents are placed in this role in regards to their children. Alan Prout (1988), in a study based on interviews with mothers, provides some evidence for this by examining the processes mothers go through with their children to determine whether or not their symptoms justify keeping them home from school. Prout

concludes that the mother holds the majority of the power in this situation. She makes the final decision as to whether the child is malingering or legitimately ill. The involvement of significant others as gatekeepers was also illustrated in the discussion of illness careers.

Gatekeepers of ADHD

As we have seen, gatekeepers are highly influential when it comes to diagnosis. In the case of children and ADHD, the gatekeepers include parents who may pressure physicians to give a diagnosis, teachers who may pressure parents to seek the diagnosis, and, as in the case of all “medical” disorders, the physicians themselves.

A case of teachers as gatekeepers may be found in a study by Claudia Malacrida. Malacrida (2004) collected narratives of British and Canadian mothers with children who had been diagnosed with ADHD. Her goal was to understand the ways mothers perceive the role of the educator in the medicalization of their child’s behavior. In Canada, teachers were found to be the prime identifiers of children who were eventually diagnosed with ADHD. They also convinced mothers to consider ADHD as a diagnosis and Ritalin as a treatment. In Britain, teachers and doctors were more likely to discourage such labels and drug treatments. Malacrida suggests that the Canadian pattern results from its proximity to the United States. This suggests that within the United States teachers are also gatekeepers.

That all of these groups function as gatekeepers may contribute to the rising incidence of diagnosis. Lawrence Diller (1996) argues that this disorder has become so common that at some universities a physician’s diagnosis is no longer enough evidence to

authorize the benefits at the college level. Instead, school psychologists observe the behavior of students in the classroom to determine if an individual's actions merit a diagnosis.

Little else is known about gatekeepers for adults diagnosed with ADHD. What we do know is that physicians are needed to legitimate a prescription for medication. Disability personnel are needed to legitimate the disorder in order to receive learning disability benefits. Literature on other disorders suggests that spouses and friends may also be involved. Whether parents play a role has not been studied. By examining the transitional population of college students, my study will help add to the understanding of the gatekeepers.

Summary

The concepts of the sick role, illness careers, and gatekeepers provide a strong foundation for examining the unexplored population of college students diagnosed with ADHD. Specifically, the sick role concept helps to provide an answer as to why people may seek to obtain services for ADHD in the university setting or why they may seek or avoid a formal diagnosis as adults. The literature on gatekeepers provides a basis for examining the role of the various people involved throughout an individual's illness career.

College students are an interesting population in which to examine ADHD illness careers. They are considered adults, as they are over the age of 18, yet many students are still dependent on their parents. This transitional period allows students some agency in making a decision of whether or not they have a disorder, and whether or not they need

treatments or provisions, but they may still be under the influence of parents or other gatekeepers. By asking the individuals themselves, I sought to gain insight into the processes involved in these decisions within this population. A discussion of my methods follows.

CHAPTER III

METHODS

As previously noted, the parameters surrounding an ADHD diagnosis now include the adult population. This inclusion created gaps in the sociological literature that need to be filled. One current gap is that the literature tends to ignore the voices of the diagnosed. Even more absent is literature that focuses on adults and college students who are on the border of adulthood. My goal is to begin to fill some of these gaps. My project is an exploratory study that aims to generate hypotheses that will be useful for future research on this topic.

The population of interest is college students (18+) who have been diagnosed with ADHD by the Office of Disability Services (ODS) at a mid-sized public university in the southeast. These students fall into two categories: those who seek university affirmation/recertification of a formal medical diagnosis from childhood, and those who are diagnosed/certified for the first time as young adults. The ODS is the university authority determining the legitimacy of each student's claim to have the disorder. ODS staff have their own diagnostic tests that include assessing each individual's working memory and examining the individual's medical and educational history, as well as examining the scholastic and medical history of each biological parent. Being prescribed a drug for ADHD by a physician is not sufficient for ODS experts to accept that a student is "sick."

Data Collection

I recruited students for my project with the aid of the ODS personnel. My only requirements were that the ODS had certified a student as having ADHD, and that the student was registered with the Department and eligible to receive benefits. The ODS kept a sign-up sheet for this project. If a student with ADHD came into the department, the office personnel either showed the student the consent form or read it to them. The form explained what my project entailed. To indicate their willingness to participate students signed their name on the sheet and provided their email addresses. This list was kept confidential by the ODS staff. As names were added, the office sent me an email with the students' names and email addresses. I then contacted each individual student. My email contained a brief description of my project and a request to send me their hours of availability. Once the student responded we set a day and time for the interview.

The interviews took place in a faculty office at the appointed day and time. Each student was given a consent form to read and sign (A copy is included in Appendix B). With the student's consent, I turned on a digital audio recorder and began the interview. The interviews were semi-structured in nature. I had an outline of topics, questions and prompts to be covered during the interview. I used these as a general guide, while allowing for flexibility in response to the answers. All of the questions were open-ended, and participants were encouraged to discuss everything that came to their minds when answering. A copy of the outline may be found in Appendix A. Additionally, and in keeping with the exploratory nature of this study, I asked follow-up questions to explore any and all tangents that arose during the interview.

My two central research questions were: How does a person enter into and proceed through an ADHD illness career? How does this career trajectory differ based on the educational level of entry? The first two interview questions (“When do you first remember hearing about ADHD?” and “When were you formally diagnosed with ADHD?”) were asked to help the participant establish a starting point and to give me a year of entry into the illness career for later comparisons.

To answer the question of how a person enters into an ADHD career, I asked participants about the steps that led up to their diagnosis and about the diagnostic process. I included questions regarding who first suggested that something was wrong, which professionals were visited, and whether or not there were theories other than ADHD to explain the participant’s situation or behavior (see Appendix A, questions 3-6).

The second aspect of my first research question dealt with proceeding through the illness career. I asked questions about the routines of physician visits, feelings of self and others during this process, and changes in overall experience over time. These were followed by the questions, “Do you know anyone who has been diagnosed with ADHD? How many people?” and “How do you know them?” This allowed me to determine whether or not ADHD students participate in social networks of fellow sufferers.

I then asked questions about the student’s experience with Disability Services. Since each student was registered with the ODS, it was important to find out what led them to register for these services. This aspect of their lives is shared by all my respondents, and is an integral part of their illness career. I concluded with a general inquiry about anything else the participant felt I needed to know.

Once all questions had been asked and answered, I gave each student a piece of paper containing a circle with instructions that they fill in the circle based upon how much their life was organized around ADHD. For example, if their life largely revolved around ADHD in thought and action, they were told to fill in the whole circle. This question was used as a way to help me visually compare interviews with one another. It also gave me a quick understanding of how each individual viewed the impact ADHD has had on his or her life. Once the interviews were completed, I transcribed them for analysis. This process is discussed further in the next section.

Data Analysis Method

I analyzed the interviews using the qualitative program MAX.QDA. This program allowed me to create my own codes and sub-codes based on the interviews. I was also able to use the program to look at all of the interviews at once or one code at a time. This capability allowed me to examine the text with a variety of code combinations. When I encountered a new concept or theme, I created a new code. I continually coded and re-coded my data as new ideas or information emerged from an interview. Again, having flexibility within my coding, especially given the exploratory nature of my project, fostered flexibility during the analysis. My goal was to glean as much information from these interviews as possible and I continually revisited ideas as new ones arose.

The codes themselves came from my overarching research question about the illness career. Using the idea of the illness career as a start, I coded for education, medication, experts, (including family members, doctors and teachers, as well as experiences with the Office of Disability Services). I viewed these codes as referring to

both layers experienced within the illness career (such as a medical layer or an educational layer) and the stages that composed the ADHD illness career.

Additionally, I coded demographic characteristics, such as when the individual was diagnosed and other diagnoses that the individual may have had. The participant's feelings about his or her diagnosis, whether or not the individual knew others with ADHD, and any tips he or she may have had for readers (such as how to deal with the diagnosis), were also coded and examined. The last item I coded and analyzed was the perception of how much each participant's life was affected by ADHD. I used the circle graph from my interview protocol in addition to a participant's explanation of why the circle was shaded as it was to code this item.

As I already noted, these codes were examined both throughout each complete interview to discover the illness career and across all interviews to compare particular aspects of these careers. This helped me to gain a better picture of what each individual illness career looked like, as well as to identify the commonalities among all interviewees. A discussion of my findings follows.

CHAPTER IV

RESULTS

Thirteen people were referred to me by the ODS, seven of whom followed through with their appointment. There were four men and three women, all of whom were Caucasian. The interviews ranged in length from 26 minutes to just over an hour, with an average time of approximately 47 minutes. All but one person was diagnosed with ADHD before the age of 18. Two respondents were diagnosed in the first grade, two in middle school, two in high school, and one as an undergraduate in college. With one exception, participants are currently working on their Bachelor's degree. The other person is a Master's degree student. Significantly, all but one respondent had at least one other diagnosis, indicating a high rate of co-morbidity.

First, I present a picture of the commonalities found among the illness careers. Then, I delineate three aspects that separate and converge throughout the career. These aspects include an "education" a "medical" and a "disability services" aspect. I describe each of these separately, providing comments regarding the interactions among them during my discussion. Next, I describe the gatekeepers (teachers, parents and medical experts), my respondents' thoughts about their diagnosis, and their ADHD social networks. After this brief overview of the results I discuss some of the central themes that emerged from the data.

Commonalities: The Prototypical ADHD Career

Based on my results, a typical illness career of a college student with ADHD is as follows: This individual had a hard time in school and at some point was placed in special classes. She was placed on Ritalin initially and then prescribed at least one other medication. A psychiatrist wrote the prescriptions. Upon entering college, the student registered immediately with that institution's Office of Disability Services upon her parents' insistence, and the accommodation she received was extended time on her exams. The individual has other psychiatric diagnoses in addition to ADHD, typically depression or anxiety.

This prototypical career is comprised of interchanging components that work together and form a rather "messy" lived experience for my respondents. The following takes a look at each one, beginning with education.

Educational Experiences

All respondents had at least one "bad year" or "rough" time-span during school. The only exception was a male who was diagnosed in the first grade. In all other cases, having a difficult time at some point during their formal education led to taking a test to be screened for ADHD, and to their eventual registering for disability benefits upon reaching college. An example can be seen in the following response by a female:

But, my elementary school years were, were, were tough. They were tough because I was the first one, and they didn't know what to do with me, and the school system wasn't willing to work with my family, and it was a good thing I had the parents that I had cause my par- my mom, come high or he- come hell or high water, she is gonna fight for everything for me, you know?

Or in this response by a male:

So, my first, my freshman year of college was really, really hard. I had, I had like a 1.8 and 1.7 respectively. I knew I was smart. I mean, not to be conceited but, but like I said, I knew there was something wrong. And I had a friend in church who was a psychiatrist. So he wanted me to get tested for ADHD. So I did. Ha. And the lady was like, how did you survive this long? I was like, I don't know.

Four respondents were placed in special classes during their school years. In a fifth case, teachers attempted to place the student in special classes, but the parents fought against it and succeeded in keeping her out of them. The other two people were sent to special institutions. One individual was placed in a school specifically for children with ADHD and other learning disabilities. The other was frequently in detention or kicked out of school. While he never went to special classes, he did get sent away to a school with a military regimen for a year. He maintained, however, that this was largely due to behavior that was unrelated to ADHD.

Another common thread throughout my respondents' discussions of school was that many of these students only took medication during the school year or for school related activities. These respondents opted not to take their medication during weekends or summers. This practice was even approved by the respondents' prescribers. A further examination of their medical experiences follows.

Medical Experiences

Taking medication is widespread in American society, and individuals with ADHD are no exception to this. What is noteworthy is not only that all of my respondents have been placed on medication at some point during their ADHD illness careers, but all

except two began their medical experiences with Ritalin. This drug, the original ADD medication, did not work for any of the respondents. All respondents were subsequently prescribed at least two other medications, and most claimed that it took quite some time to get the dosage correct. Even after achieving an appropriate dosage, their bodies adjusted to the medication and the dosages needed to be increased. One male respondent lamented this fact:

I've had to increase it when, since when I started taking it, just cuz I grow, and just cuz I-I grew some and I gained some weight. But since I've quit growing and I've quit gaining that much weight, I've had to increase the dose maybe once. But other than that, since I've started taking it total, I think I've changed it a total of maybe four times in three years. But that's cuz, I was, in those three years, I was growing. I probably grew three or four inches in those three years.

And when I asked him if the increases in medication were strictly because of growth, he responded, "It was a little bit of that, but it's also because my body adjusts really fast to a lot of medication."

Two of the respondents were not currently on any medication. One individual claimed she should be taking medication, but she did not have health insurance or the money to pay for it out of pocket and so has not renewed her prescriptions. The other stopped taking medicine of his own free will right before entering high school and has not taken any since.

The medications are generally prescribed by a psychiatrist. In one case, the medications were initially prescribed by another medical doctor, only to be later re-prescribed by a psychiatrist. In the only other instance of medicine being prescribed by

someone other than a psychiatrist, a gynecologist wrote the prescriptions. This physician was already prescribing medication for other reasons and told my respondent he wanted to be in control over all medications to ensure they would avoid drug interaction problems.

During the conversations about medication, two of the respondents commented that they only take medication when needed for school or “focusing.” This means that they did not take any medications during weekends (unless they needed to study) or during the summertime. One respondent took two years off of school and took those two years off of medication as well. Another individual claimed that she only takes medication for the benefit of others. She reported that she talks “too much,” and thus is not seen by the larger society as “normal.” Being seen as “normal” allows her to feel more normal herself. The medication, she reported, helps to accomplish this:

I never feel like I’m normal when I’m not on my meds. Like, it’s driving me crazy that I don’t have meds right now. Yeah, I don’t ever feel normal. I feel like I’m, I’m different. I feel like I’m the outsider looking in. And that’s just how my life is. It’s how it’s always been. When I’m on meds, I feel a little bit more normal because I feel like I’m more focused, more organized.

I will discuss the implications of this later. Now I turn to the third layer: disability services.

Disability Services Experiences

When asked at what point they registered with the ODS at the university, five respondents replied that they registered immediately. A sixth person waited one semester before registering. He was determined to make it through college without benefits

(against his mother's wishes) and had a goal of achieving a 3.0 GPA in his first semester. He fell a bit shy of this goal. This fact, in addition to having anxiety problems, ultimately led him to register in the second semester. Reasons given by other respondents included that it was better to have the benefits just in case they were needed (a safety net), that they needed immediate use of the benefits, and that it was "just understood" that they would register. This understanding largely came from their parents or teachers, two of the gatekeepers in this study.

Common aspects of the disability services experience include registration and receipt of educational benefits. The most common benefit received from the ODS is extended time on exams. Other benefits include early class registration and the option of taking exams in a room alone. One participant uses the Office for additional resources, such as finding a speech therapist. Two respondents claimed that they use the benefits very infrequently. The reason given by each one was that the "real world" and employers do not offer such benefits to people with ADHD. If they were not going to be able to receive such services in the "real world," then they wanted to learn to live without them now.

Four people transferred from another university, bringing their ADHD diagnosis with them. The ODS accepted transferred paperwork and allowed them to retain their "diagnosed" status. Two people kept their diagnosis from high school and have yet to receive a formal adult diagnosis. One of these two was a transfer student. According to my respondents the ODS accepted their diagnoses without re-testing because they were

so close to the age of 18 when originally diagnosed. The last two respondents were tested and diagnosed by the ODS at the university where my study took place.

For the respondents who were diagnosed with ADHD prior to attending college, experiencing some form of disability services was common. Many of these students, once labeled with ADHD (and in one case prior to the diagnosis), were placed in special education classrooms to meet their needs. The respondents did not go into detail about the processes through which they began these special classes. What can be gleaned from their responses, however, is that they were placed into these classrooms by the school-appointed social worker or counselor. It was also common for these respondents to be in the special classes with other students who had learning difficulties. It did not matter what diagnosed ailment required each student to receive special attention. As one female responded about her junior year in high school,

Here's the thing. He [social worker] had a class, he wanted me to be in, what were they called, but like the Special Ed classes, but he said it's not Special Ed, you know, we don't call it that anymore. But, every time I'd walk by that classroom, the other students, mostly boys, and then they had, I don't know the correct terminology, so excuse me if I say it wrong, but the mentally disabled, you know, or something. Or, and they're like screaming, running around the room, and I was like, I am not going in that room. He wanted me to go there for like an hour, just so that he can focus on, you know, or he wanted me to get pulled out of the classroom, out of my classroom to get put in that classroom... I was like, how am I going to be able to focus in that room?

The Role of Teachers

To understand the extent to which teachers played a gatekeeping role, I asked my respondents about their experiences with their teachers. Experiences with teachers ranged

from “excellent” to “terrible.” When it came to the diagnostic process, however, the respondents did not have much to say. Previous literature indicates that teachers are usually involved in the decision to have a student tested for ADHD (Christian, 1997; Malacrida, 2004), and thus would be a key gatekeeper during the illness career. My respondents were aware that teachers pushed them to be placed in special classrooms, but mentioned little as to whether, and how much, the teachers were involved in the decision to have them diagnosed with ADHD. This could be due largely in part to the fact that teachers are likely to speak with the parents about such matters and not to the child in their classrooms. One respondent had his own theory about why his teachers never suggested ADHD. He suggested that it could have been due to his age, since he progressed through the K-12 years before ADHD became a common diagnosis. Another student theorized that it was her being diagnosed with other learning disabilities and experiencing a lot of anxiety that prevented ADHD being suggested.

The Role of Parents

The respondents also varied in how they spoke of their families. Nonetheless, none of the family members spoken about had opposed ADHD testing, the diagnosis, or the treatments. In fact, in three cases, it was the parents who suggested the testing, and two of these three respondents were pressured by their parents into registering with the ODS. Two respondents had asked their parents if they could be tested. They had been struggling in school and felt that something must be wrong with them. In both cases their parents supported their decision to get tested.

Another common theme was that my respondents portrayed their parents as wanting the “best” for their children. When and where necessary, they fought for their kids. This included fighting for benefits and to keep them out of special classes. Respondents described their parents as supportive, encouraging and wanting to do whatever it took to help their child. This motivation led some parents to pressure their offspring into registering with the ODS and to get ADHD testing, but the children described themselves as willing to obey out of respect and love for their parents. In one instance, after initial disobedience, the respondent ended up ultimately doing what the parents requested. The parents were also described as being very open and honest with their children about their diagnosis and as being concerned with helping them feel “normal” and “capable.”

The respondents declared that they did not know much about how their parents were reacting throughout the process. It can be assumed that the parents have discussed the situation, but this likely occurred behind closed doors. Nonetheless, one mother did begin seeing the same child psychiatrist as her daughter for help in coping with her child’s disorder. The respondent reported that, “My parents were very honest. Cause my mother would cry [laughs] and be like, I don’t know what to do with you!” Her mother brought these issues up to her child’s psychiatrist and began meeting with him separately. He helped her develop coping strategies and ways of dealing with the stress. The mother of another respondent asked her son if she could take some of his Adderall before receiving her own adult ADHD diagnosis. Parents clearly had different ways of dealing with their children and their diagnosis.

Medical Experts

The experts who prescribed the medication were largely psychiatrists. In cases where respondents decided to stop taking medication, or only take it during school weeks, they indicated that their psychiatrists approved. They allowed the individuals to decide for themselves when they needed to take the medication. The only exceptions were medications that required daily doses to remain in one's system for them to work. This type of medication, in order to be effective, had to be taken every day with no exceptions. This took away the ability to stop taking medication during weekends or school breaks for these individuals.

Psychiatric visits generally revolved around receiving medication. This required most respondents to visit their psychiatrists every couple of months or so. In addition, one respondent was seeing another kind of therapist. Another individual was under treatment by a neurologist. Initially he saw the neurologist every three months; this was later decreased to every six months. Now he sees the neurologist only once a year. The only time this changed was during a period of high stress for this individual when panic attacks began occurring. Once the panic attacks ended he went back to only seeing the expert once a year.

Aside from the medication, there was some discussion about “talk” therapy during these sessions. Five of the respondents mentioned therapy. Of these, three were already seeing a therapist for personal reasons in addition to their need to receive ADHD prescriptions. The other two mentioned that they talked a little bit, but did not go into depth about how long or what they talked about. One respondent claimed:

...I mean, there's still a lot of stigma of people that see a psychiatrist. But I just tell them that it's nothing big, I just need medication from the guy. That's all I do. We just chat for a little while, and I'll pick up my medications from him and get, go on my merry way.

Two respondents reported negative experiences with their various medical experts. One claimed that his initial diagnosis of ADHD was incorrect. He had just been diagnosed with Tourette's Syndrome. The Tourette's testing center recommended that he get tested for ADHD. The testing center that gave him the ADHD diagnosis then referred him back to a doctor at the Tourette's testing center. The respondent claimed that his parents thought that the two experts were working together to send one another clients for monetary benefit. This concern caused them to seek a second opinion. The new psychiatrist also diagnosed ADHD.

The other bad experience was reported by a student who was not diagnosed until 11th grade. She had been taken to different social workers (the experts in this case) both in and out of the school system. They gave her many tests and diagnosed her with learning disabilities. They never suggested ADHD, as they attributed all of her problems to anxiety. She asserted that the school social workers made her "feel dumb" and "incompetent," because they never explained to her why they were taking her out of class or what they were doing.

"Good" medical experts were characterized as caring, understanding and encouraging. They also were described as able to offer individualized care to their client. For example, one respondent discussed how "great" her child psychiatrist was to her, as he used creative outlets and did not "write her off" as a behavioral problem.

Interactions with Others with ADHD/Social Networks

I asked my respondents if they knew others like themselves. Four respondents said that they probably did know people with ADHD at their current university, but they just did not realize it. This disorder is not something they discussed freely or asked about. One student noted that there is not an “ADHD culture” like there is a deaf culture. Two respondents knew family members with the diagnosis, but no other members in their social networks. Two others knew a few friends in addition to their family members. This means that over half of my respondents mentioned having a family member who was either diagnosed with ADHD, or whom they believed had ADHD.

Six of the seven respondents have additional diagnoses. The other student claimed that she is drawn to ADHD people. Her evidence for this is that she said she connects with others initially and only later finds out they are diagnosed with ADHD. She feels that these friendship formations are a natural occurrence. While she is friends with others who do not have ADHD, she reported that her closest friends are those diagnosed with the disorder.

Personal Perceptions about Having ADHD

Respondents were asked their personal thoughts about living with an ADHD diagnosis. Two of the four male respondents declared that they did not think that anything was wrong with them. They saw themselves as “normal” individuals. In one instance, the individual was diagnosed at a very young age. At that stage of life, he claimed, boys judge one another based on athletic prowess.

You're judged on, when you're four and five, you know, how athletic you are. That's what, that's what other kinds think of 'oh yeah, he's slow.' You know, that, that means that, that he runs slow, not that he reads slow. But, that's the way that was when you were little, so I was always, you know, I was always normal, I was, yeah. I never knew anything was-was wrong. I was like, 'yeah, I just have this thing.'

He was an athletic child, and since the diagnosis did not affect his performance in sports, he did not feel hindered by the label. The second male also reported that he did not think anything was wrong, but he noted that his grades improved once he began his treatment.

Two of the three females reported that they had very tough, unpleasant experiences throughout life, which made the process of their diagnosis unpleasant as well. One thought that it meant there was something seriously wrong with her. She constantly "felt dumb" and "alone." As she got older, she came to realize that having a learning disability or ADHD did not mean that she was dumb. She does wish that people in authority had explained things to her better, or even at all, during the testing processes. Interestingly, she claimed that she was also able to "put ADHD to the side" when anxiety and depression became overwhelming:

A lot of stuff has affected my anxiety. And, my depression so, um, the one thing I'll let you know is that I've kind of, I kind of left my ADD there when the anxiety and the depression came. Like, I just left it on the side. I-I didn't really like focusing on it. I focused more on, 'I have anxiety and depression.' You know? Um, so right now I'm not doing anything with my ADD. You know?

She is fairly convinced that anxiety and ADHD are related but has compartmentalized these two labels as separate. When she feels anxious, that is the only status she is concerned with. As her anxiety levels decrease, however, she has time to

deal with her ADD diagnosis. The second individual said that she reached the point where she wanted to switch brains. She felt that if she just had a new brain, one that would let her “shut up” and control her speech, then everything would be fine:

...I even told my therapist one time, I was like, you know if I had a spoon, I could scoop out that part of my brain that, that just makes me talk excessively, all the time. Cause it actually drives me crazy. I know that sounds so weird! But I’m just sitting here thinking right now, gosh, shut up already.

Her interpretation was that she does not have a problem talking, she has a problem communicating.

The third female reported that she had resisted the diagnosis. She was already diagnosed with other ailments and did not want anything else to be wrong with her. She said that she was sad about the diagnosis at first but realized that she had to move on. She claimed that the biggest struggle for her personally was deciding between what she “wanted” to do and what she “had” to do. She also insisted that this was exaggerated by her ADHD. In conversations with other people, her biggest issue became making sure she told others that she only visits a psychiatrist for the medication. She still thinks that there is a bad stigma associated with going to a psychiatrist. She does not want to appear “crazy.” She was also very careful to say that she takes drugs for ADHD and not that she “does drugs.” In her words:

I tell people that when I say I, I go to see a psychiatrist, they, I mean, there’s a lot, still a lot of stigma of people that see a psychiatrist. But I just tell them that it’s nothing big, I just need medication from the guy. That’s all I do. We just chat for a little while, and I’ll pick up my medications

from him and get, go on my merry way. I'm not, I'm not a psychopath or anything like that.

This impression management coincides with Charles Cooley's (Allan, 2005) concept of the "looking-glass self" and Goffman's (1959) concept of the "presentation of self."

Cooley's concept is that people learn to see themselves through the eyes of others during social interactions. By "knowing" that there is a stigma attached to people who seek therapy, this respondent is avoiding what she feels would be a negative perception and changing her wording to present a more "normal" self. This is also similar to the respondent who claimed she takes her medication for other people. In doing this, she is convinced others will view her as normal, and thus she will view herself in a better light. Other struggles mentioned by the women included being misunderstood by the rest of society and the battle against "feeling dumb."

The remaining two males did not have much to say about their personal thoughts. One individual said that getting diagnosed was not really a surprise; it just made sense and life went on: "It wasn't like a bomb shell got dropped on me. It was just like, yeah, that makes sense. You know, it's not like you walked in and they're like, you have cancer. It wasn't like that." The other was the individual diagnosed upon entering college. He said that having ADHD was no different than having diabetes. He claimed that people would not make fun of a diabetic for taking insulin shots, so why should it be weird that he takes ADHD medicine?

Men and women expressed their thoughts about their disorder differently. Whether this difference reflects an actual, lived, difference cannot be determined. The

females discussed negative, emotional experiences surrounding their diagnosis while the males were relatively neutral in their descriptions. This communication pattern is quite consistent with the literature that shows how men “‘do what is necessary’ and women ‘do emotions’ (Seymour-Smith, S. & Wetherell, M., 2006).” By men solely discussing the “‘what happened” aspects, they were answering my questions as they were asked. By contrast, the women explained the necessary information and continued to add in the emotions.

Organization of Life around ADHD

To conclude the interviews I presented respondents with a picture of a circle and asked them to color it to indicate how much of their life was organized around ADHD. Responses to this question were quite varied. One respondent opted not to answer, and the other responses ranged from very little of their life being affected by ADHD to ADHD coloring their entire lives. The person who responded that ADHD was her entire life was also the only individual who has no additional diagnoses beyond ADHD. For the ones in the middle, who responded at half or approximately half, their reasoning was largely due to their having to continually take medication or fill out paperwork for the ODS. This bureaucratic red tape comprises the majority of thought about ADHD in these respondents’ lives. The rationale for this is that they do not really talk about it outside of this context. Some evidence of this fact can be seen in that they do not talk to their friends about it.

The results listed above raise many questions and leave many places for further exploration. My perceptions and discussions of what these results imply follows.

CHAPTER V

DISCUSSION

My results provide some interesting new insights about the sick role, illness careers, and the role of gatekeepers. Additionally, they are a good beginning to an understanding of the ADHD illness career, as experienced by the diagnosed individual. I also expanded upon specific aspects of the career: educational, medical, and disability, as well as the gatekeepers involved (teachers, parents, medical experts). In the following pages I consider the implications of my results for our understanding of ADHD illness careers, and I propose a new way of thinking about how illness careers are organized. After an in-depth discussion of the illness career and its components, I discuss gatekeepers as well as how my results may be viewed in light of the sick role concept. I end this chapter with a discussion of some of the limitations of my study.

ADHD Illness Careers

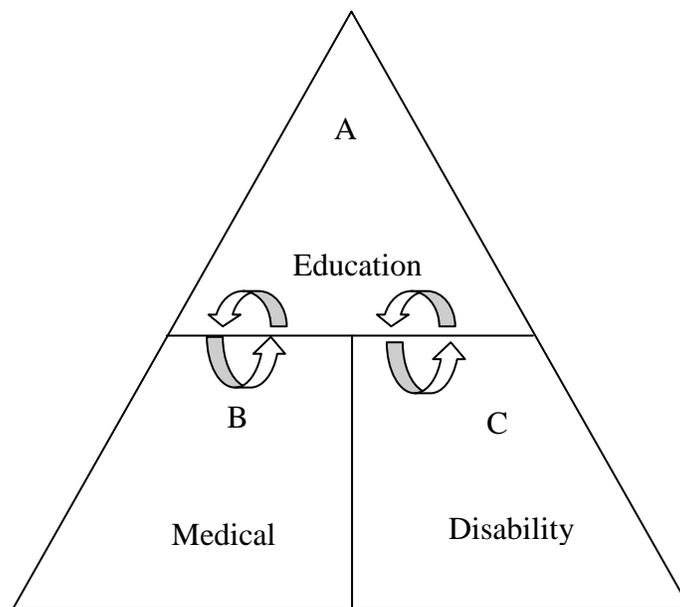
The Case of Separate Aspects

To determine the nature of ADHD illness careers, I sought to find the commonalities among my respondents' experiences. As discussed previously, the career includes educational problems, placement in a special educational classroom, and experiencing a series of medication failures, with Ritalin as the first medication. A psychiatrist was the most likely medical expert and upon entering college, the person typically registered for disability services immediately at the insistence of their parents.

The benefits received were likely to be extended time on exams and a private, quiet examination room. There is also a high likelihood that the person has been diagnosed with at least one other problem, probably depression or anxiety.

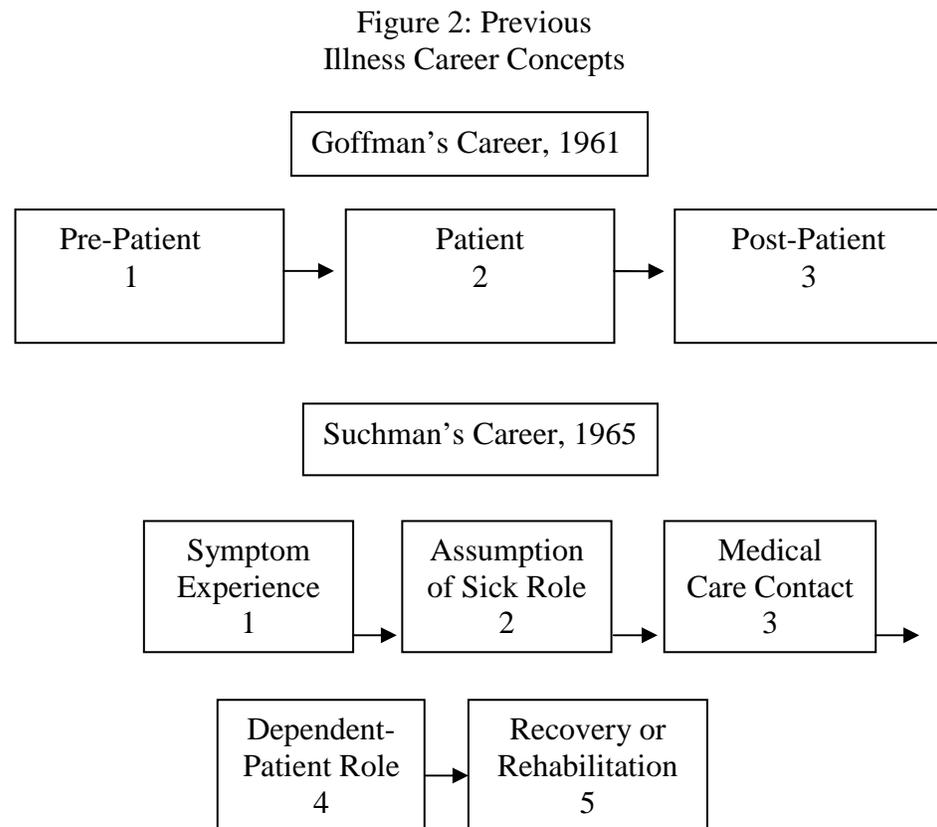
I conceptualized these commonalities into three separate aspects of the general career. Each section (Education, Medical and Disability) has an immediate goal with an over-arching goal of “success,” all of which will be discussed shortly. Figure 1 is a visual depiction of how these three sections work together to form the larger ADHD illness career.

Figure 1:
Illness Career



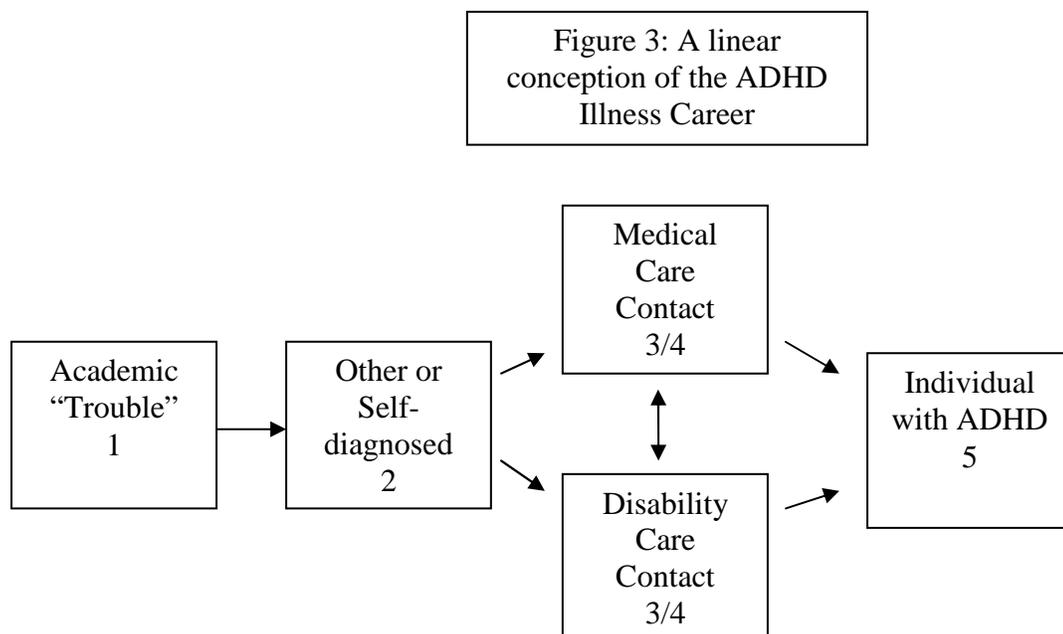
The first thing to note is that this model does not conform to the traditional linear model of illness careers as described by Goffman (1961) and Suchman (1965). These

prior studies have described illness careers as steps or stages in a linear pattern. I created a pictorial review of these stages in Figure 2. In the case of ADHD, I found it very difficult to capture the complexity of the career within a linear model. This idea is not entirely new, as others have suggested the need for greater variability among the stages (Karp, 1994). In my project, however, simply allowing for variability did not completely convey the interdependence that my results seem to suggest.



The linear models imply that one must progress through one step or stage before moving on to the next. It also implies a clear entrance and exit from the career. My respondents' experiences did not have clearly ordered steps or stages, and at some points,

all three aspects of the career occurred simultaneously. Conceptualizing their career as a pyramid allows me to view the components as interrelated, yet not necessarily ordered. There are benefits to the linear model, such as it allows the reader to see the forward movement across time. If I were to create a linear path of the ADHD illness career to better depict the movement, it would look something like the following:



As the reader can note, this conception depicts a general progression that is not found in Figure One. What is lacking in this linear model, however, is that it does not truly explore the inter-workings of the ADHD illness career. This rendition also does not accurately illuminate the prominence of the educational system or show the interrelated connections between the “expert” contact and academic “trouble.” These deeper issues

are the ones I want to explore. I will now return to my discussion of Figure One to further expand on these points.

The second thing to note in Figure One is that Education is located at the top. This indicates that it is the dominating force of the career. The arrows indicate that both the Medical and Disability sections influence the educational section, and education, in turn, influences the other two. It is the educational system that provokes entrance into the other two sections. I will now further assay each section separately.

Education – (Figure One, letter A)

The experiences of my respondents largely revolved around the educational system. This is chiefly due to their being in college and to being interviewed within an academic setting, but even discounting the college years many of their stories revolved around the educational setting prior to attending a university. The goal here appears to be “academic success.” What exactly is meant by “success” can be surmised as academic success in the form of grades or an “acceptable” GPA. Respondents tended to mention their scholastic scores as part of their narrative about what led to an ADHD diagnosis. Whether this goal remains indelible or changes upon graduation cannot be deduced. It is possible that temporary academic success is but a stepping stone for future success in life, socially, or vocationally. Regardless, “success” in education seems to be its own goal.

Experiencing failure or troubles academically was a key component in my respondents’ illness careers. It is this issue that eventually led to an ADHD diagnosis. Being diagnosed provided the legitimization to seek assistance. This assistance came

either by way of medication or by way of disability services in the form of separate classrooms.

Medical – (Figure One, letter B)

The immediate goal of the medical component is an effective medication regimen. Achievement of this goal is seen as an aid to the larger goal: success in education. My respondents described ADHD medication as helping them to focus, and the students themselves claimed that they took it for school settings. A latent consequence, at least according to some of my respondents, is that they feel more “normal” when they are on their medication.

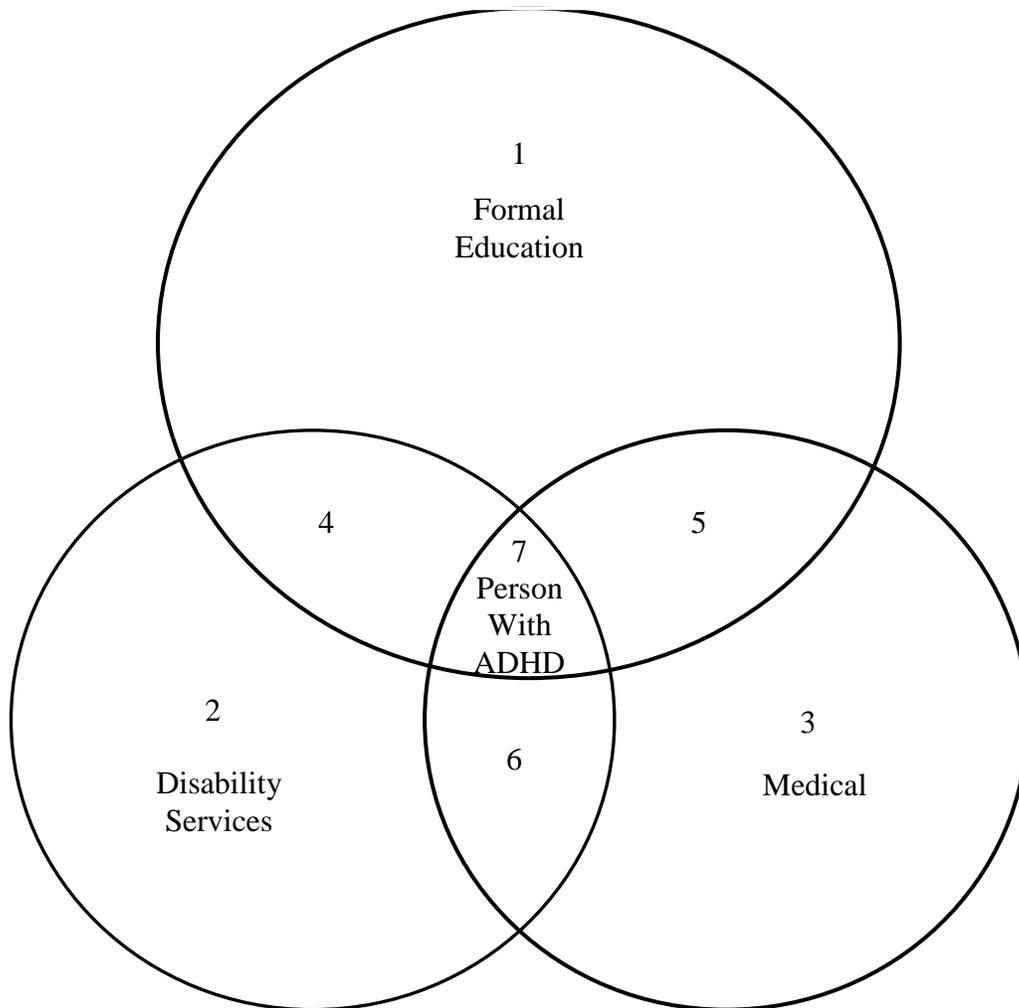
Disability – (Figure One, letter C)

The disability section is also used for educational success. The immediate, manifest goal is to successfully provide benefits, such as extended time on exams, that are needed for each individual. And while not mentioned by the respondents, a latent, hidden goal may be a less disruptive classroom. Again, however, the ultimate purpose appears to be success in academia. Opportunities for receiving disability help were available all throughout the educational career path, from special learning environments in elementary school to all of the benefits provided by collegiate disability offices.

These two sections, Medical and Disability, flow back into the Educational section through their goals of achieving academic success. My respondents have used both medication and disability services to achieve their educational goals, sometimes simultaneously. Additionally, disability services can only be used if the respondent is in

the educational setting. Medication may be used elsewhere, but my findings suggest that few people would be on medication if they were not in the educational system.

Figure 4 – ADHD Illness Career Experiences



The Career Experience

What is missing from my illness career model is the human element; the personal, lived experiences of my respondents as they reside within the illness career. When viewed in light of the lived experiences, the three sections of the pyramid are no longer

sufficient and may be better viewed as separate aspects. These aspects exist independently from one another, yet they may also interact. Together, they converge into a single ADHD illness career experience. I first explore the career experiences as separate entities. I then discuss each area of overlap. Finally, I conclude with a discussion of the experiences as a whole in light of my results and past literature.

As I will show, it is difficult to fully discuss one aspect without referring to another. The notion of stages is still useful, as they show how gatekeepers are involved in making one aspect more salient than another, but it is a bit misleading in that it leaves out the interrelated complexities involved. These aspects are intertwined, and all are involved in the experiences for the ADHD diagnosed individual. (The reader should refer to Figure Four on page 55 for the following discussions).

While it is difficult to discuss each experience separately, there are a few experiences that may be separated out. To begin, I find that in discussing the separate experiences, it is useful to conceptualize each aspect as a component of the post-modern self. The post-modern self may be seen as being comprised of “no fixed, essential or permanent identity” (Hall, 1992, p.277). Identity may thus be contradictory and pull the individual in separate directions. These identities change in relation to cultural or social stimuli as each individual interacts. Each aspect, then, is simply a facet of many identities available to the ADHD individual. Many of the following experiences have already been discussed. I repeat them briefly in this section as a refresher and as a way to further clarify their purpose in the model.

Formal Education (1)

Most respondents had a tough time at some point during their lives as students. A few even described themselves as being “made” to “feel dumb” and others were placed in special classes during their educational years. For the females, self-esteem was low during these years. One of the males had similar experiences until he entered a school that specialized in learning disabilities. The other three male respondents did not report such negative experiences. One was a self-proclaimed “class clown,” one was not even labeled as having ADHD until college and was never placed in special classes, and the third male is the fellow mentioned previously who cited his athletic prowess. He claimed that he was unaffected in school relationships due to his ability to participate in sports and the young age at which he was diagnosed.

Most of my respondents also claimed that they did not know of anyone else at school with ADHD. The lack of conversations about ADHD among friends may be due to early childhood experiences. My respondents who claimed to have negative experiences and low self-esteem may have internalized those ideas and learned to be silent about their disorder. Additionally, over half of my respondents listed a family member as someone they knew with the diagnosis. The family could provide one “safe” space that allowed discussion. Another possibility is that ADHD is not a “visible” disorder like physical handicaps. If people do not mention disorders in conversation, it is highly likely that a friend would not notice whether or not an individual has ADHD. In any case, my respondents generally did not discuss their experiences in education with their friends.

Disability Services (2)

Experiences with disability services were reported as being pleasant at the college level. Everything from gaining benefits to having a place where students felt comfortable to go in and talk when needed were listed as advantages to registering and using the ODS. Conversely, most reports about dealing with the school social workers or other disability staff members at the levels preceding college were largely reported as negative.

This stark contrast merits attention. Keeping in mind that these are how the respondents view and perceive their experiences, I can begin to speculate about causes for the differences. When my respondents discussed how they felt about using disability services and contact with disability staff when younger, those who claimed it was a negative experience also explained to me that it was because they were largely left in the dark. What they were doing in special classes was kept as a mystery and never fully explained. In contrast, the ODS was perceived as being very open and honest about everything, and the respondents had some control over how they would use the office's services. This may be simplified as an issue of knowledge. It may be that if respondents were told what was going on from the beginning, their experiences would have been perceived in a better light.

Medical (3)

As previously noted, most respondents were initially prescribed Ritalin and subsequently at least two additional medications. They also spent some time on each medication in an attempt to obtain the proper dosage. My respondents' experiences involved the medications themselves, as well as their medical doctors.

There was not much emotion expressed regarding thoughts and feelings about taking their medications. They spoke about their experiences rather robotically. It is what they did. What I would like to highlight here, however, is that all except two respondents began their medical regimens on Ritalin, yet this drug did not work for any of them. Ritalin is viewed as being highly effective (Diller, 1998), and has even been “credited with saving marriages, rebuilding faltering careers, and transforming what had been problematic personalities (Conrad, 2007).” If this is the case, then why the stark contrast between what is “known” and the experiences of my respondents? Why do physicians start ADHD medical regimens with Ritalin? Is it just standard medical practice? Does Ritalin really work for most people, and my results are simply skewed due to the small sample size? It could perhaps be due to physicians individualizing each patient’s experience, and thus they may not be looking at the larger picture and changing their prescription patterns accordingly.

Physicians are also beginning to “offer an ADHD diagnosis and a ‘trial on Ritalin’ to adults with certain kinds of life difficulties (Conrad, 2007, p.62).” It appears that general practitioners are trying patients on Ritalin to see if it “works,” without necessarily giving them a formal diagnosis of ADHD. The implications for “trials of medication” outside a diagnosis can be detrimental, especially considering the negative side effects of Ritalin as well as the overwhelming inadequacy of this drug for my respondents. There is also the danger of providing legitimization for a disorder that did not undergo formal diagnostic procedures. This practice may lead to a mentality of accepting the diagnosis simply because the medication proved helpful.

Aside from the medication, most of my respondents were using their medical “expert” for “talk” therapy. Most were already seeing their expert prior to their ADHD diagnosis. This makes sense when considering that almost all of them were diagnosed with either depression or anxiety at a separate point in their life spans. The two respondents who admitted to talking with their psychiatrist appeared to skim over the issue. This was especially seen in the female respondent quoted earlier as saying, “We just chat for a little while, and I’ll pick up my medications from him and get, go on my merry way.” When explaining her situation to me, however, she claimed that she only sees her psychiatrist for medication because she is not crazy. It appears, based on this quote, that she visits him for more than just medications, and that some form of therapy is occurring. This may be underemphasized in order to portray the image she is trying to convey: that she only needs to visit the psychiatrist for medication. If there was not a stigma attached to that behavior, the respondents may have been more willing to discuss the sessions and why they were seeing a psychiatrist as opposed to a general practitioner.

Additionally, this issue of stigma contrasts with some conventional wisdom that suggests there is no longer a stigma attached to visiting a psychiatrist. Perhaps conventional wisdom is correct, and the stigma disappears upon exiting the university setting and entering the workforce. It may be the case, however, that the conventional wisdom is wrong and a stigma still exists for those individuals who are seeing a psychiatrist. My results certainly seem to suggest this.

It is also worth noting that insurance plans and policies discourage psychiatrists from engaging in “talk” therapies. Managed care tends to reimburse diagnoses that may

be treated with drugs (Conrad, 2007; Diller 1998). In order for psychiatrists to maintain clients, they need to be sure they are diagnosing and treating individuals with medication like their fellow general practitioners.

Education and Disability – (4)

Problems in school lead individuals to seek disability benefits. Furthermore, disability benefits are given largely in academic terms. College students claim that they need extra assistance to progress successfully through their academic careers. They achieve this by entering disability services. The majority of benefits received included extra time on exams and in a few instances a quiet, separate room in which to take the exam. These benefits are not just being applied to the academic setting. They are also used for the testing experience itself. Would a different testing experience change the disability needs of these students? Why is it that these students do not receive benefits outside of educational settings? Would they need extra assistance outside the educational sphere? If not, what does that imply about our educational system?

A few of the students in this study were able to retain their previous diagnosis from high school; the rest were retested in order to receive educational disability benefits. This begs the question of whether or not these students would seek out re-testing if they were not in the college system, but instead entered the workforce. If they would not seek re-testing, then the number of adult cases with ADHD would likely decrease. Further research is needed to examine the implications of both the educational system, and the nature and diagnostic process for this disorder.

Education and Medication – (5)

As the results have shown, students largely take medication during the academic calendar, or school week. Additionally, they either take it for school related activities, such as studying, or to be perceived as “normal.” The following quote by a male respondent depicts the idea of taking medication for school:

Yeah, well, really the only, the reason he [his psychiatrist] put me on the medicine to begin with was for school. Like it wasn't, like I wasn't so hyper as the sense of that, like, it wasn't like an acute kind of hyper thing. It was, I just had trouble sitting still like in class, and so the medicine helped me do that. Helped me be able to read and study. But like, like on the weekends I wouldn't take the medicine. Even when I was in school.

Another, when asked if he took his medication on the weekend, said:

I do if I have to study. But like, you know, if I don't have school or I don't have, you know, anything, if I have a job to do, like, I sometimes work construction for my old man, and, you know if I have to do that, you know, swinging a sledge hammer, driving a bobcat, I like to have some focus doing that stuff. But if it's just like a Saturday and I'm just, you know, chilling out, no I don't take it.

As these quotes show, the medication becomes most effective when the need to study or concentrate arises. This once again raises the question as to whether or not our educational system is creating the niche for these students to receive benefits as well as medication. The ADHD college experience, so heavily affected by academics, prevents this population from providing a good clue as to how adults outside the academic spectrum experience their world. Their careers may be vastly different, and may also

follow along the path shown in prior studies (Suchman, 1965; Goffman, 1961), where everything moves along steps or stages much more neatly.

Medication and Disability – (6)

The merging of these two aspects is a bit different from the other two. While the other two convergences were rather interdependent, disability services and medication are much more like two sides of the same coin than interdependent. What is important is that both work together to form this complicated aspect. As mentioned in the literature review, medication is generally viewed with a biological lens, using medical treatments to regulate inattention and hyperactivity. Disability services also help to “cure” the “problem” but do so from a social side, i.e., offering quieter testing environments, extended time on exams, and other educational aid to help the students succeed in the social world. These two converge in that the student receives help through both biological and societal remedies.

This multifaceted approach is beneficial for the student in need of assistance. It also, however, raises questions as to the origins of ADHD. Those from the biological camp insist that it is a biological disorder. Those from the social constructionist camp are much more inclined to say that it is not so much biological but a question of how we define behavior as problematic. They would also examine those who decide when behavior crosses the line into “hyperactive.” If either side were completely correct, then only one remedy would be needed. Since there is still some uncertainty, and both biological as well as social remedies are being implemented, all fronts are covered when it comes to help.

Lawrence Diller (1998) suggests that the use of these medications in the workforce is for achieving optimal performance. It is no longer used for basic, daily functioning, but to achieve what is “best” not just what is acceptable. This issue was seen in the academic sphere in achieving “good” grades. Diller raises the idea that it extends into the workplace, and that individuals are using help to reach this “optimal” performance. It appears that being “good” is no longer good enough.

It also appears that medical experts do not work together with the disability experts. This could suggest an underlying “turf war” between these two groups that leads them to work against instead of with one another. Fortunately, at least from my results, there does not seem to be a detrimental effect on my respondents as a result of any such conflict. It may also be that the respondents neglected to mention any tension between the two experts, or that any detrimental effect on the respondent may be occurring outside of their awareness.

ADHD Career – (7)

In the center of this model all six aspects converge to form the rather “messy” personal experiences of the diagnosed ADHD student and the ADHD “illness career.” What their individual experience looked like, how they thought about their disorder, their emotions and the people they knew are all connected to these three areas.

The fact that few of the respondents knew others with ADHD outside of family relations can be understood through the three combined aspects. In the educational system, most students were placed in a separate classroom with students who had a variety of disabilities other than ADHD. These separate classrooms were only in use for a

small portion of the day, thus discouraging an opportunity to meet other students with an ADHD diagnosis. The respondents spent the rest of their day with their classmates. In the case of the boy who went to a school specifically for ADHD, his educational experience was a large reason why he knew so many others with the disorder. The only other exception here is the woman who was diagnosed solely with ADHD. She seemed to feel that she was drawn to others with ADHD. As no other student mentioned this, it may be the case that, when additional diagnoses are present, the chance of forming connections with others diagnosed with ADHD decreases.

I would also like to add that family appears to be rather pervasive throughout the respondents' experiences. My model (Figure Four) does not portray this pervasiveness, but I would like to emphasize that it permeates into each aspect, including all areas of overlap. Family members are experiencing their child's disorder in potentially varied and separate ways, and are involved in the decisions to visit medical doctors, registering with disability services, as well as discussions with teachers, faculty, or other academic personnel. The parents may be viewed as agents in a "betrayal funnel," where a person is passed from "normal" (or prepatient) to "ADHD" (or patient) through a path of stages with a different agent at each step (Goffman, 1961). My results imply that the parents are the agents at least part of the time.

Medication also discourages ADHD people befriending other diagnosed individuals. Societal norms do not encourage people to discuss what medications they are taking, which makes it difficult for people on ADHD medication to connect with one another through this avenue. Lastly, the Office of Disability Services serves a wide array

of disabled students, and being a recipient of its services in no way brings ADHD people to one another. This is reflected in the following quote by a man who spoke about the lack of an “ADHD culture”:

Well and, I guess in, like I'm taking um a sign language class, and so there's like, this really big like deaf culture. Um, it's really cool, but like, I don't really think there's the ADHD culture. As far as, I mean there might be, I'm just not in the club. You know? But uh, so I don't... I guess I don't talk, it's not like I, I don't, like it doesn't define who I am, and so I don't, it doesn't ever come up I guess.

This could be due to the fact that most students use the services to take tests in a room by themselves. They seek out the services for the express purpose of being alone, not with others. These results are in stark contrast to those of Kadushin (1966) who found that friends lead a person to seek medical care and that they would know others like them who are seeing a psychiatrist. The students in my study were pushed along by gatekeepers other than friends, and most of them had no idea if they knew others like themselves. My respondents were also more likely to mention a family member as having ADHD than a friend. I cannot say whether or not a formal diagnosis occurred for these individuals. It is interesting, however, that family members were mentioned as often as they were. This suggests that while this disorder may not be spoken about in friendship circles, it appears to be spoken about in the family setting. Combine this notion with the pattern of my respondents being tested due to either teachers or parents suggesting something was wrong, or the individual coming to that conclusion themselves, and it begins to suggest that this disorder is experienced by and within the family, and that it may be the family, not the friendship group, that fuels treatment seeking behavior.

Additionally, the responses to the circle question indicate that some respondents only think about ADHD because of the bureaucratic red tape they must pass through to receive educational benefits and for the task of taking their medication. This demonstrates that their personal experiences are affected by the structure of the educational institution itself. The students seem to be able to avoid dealing with their ADHD diagnosis. An extreme example of this can be seen in the woman who was able to put her ADHD completely “to the side,” and not deal with it during times of high anxiety and depression. These feelings seem to challenge Mumford’s (1983) idea that an adult benefit to being “sick” is a feeling of comfort if all a person has known was the life of a patient. The majority of these students have been dealing with a diagnosis for the greater part of their lives, and other than it being something they have to deal with, none of them inferred that there was a sense of comfort in the way that Mumford meant.

This experience was also affected by each student’s gatekeepers in each separate sphere. How and when they moved in and out of each layer was largely dependent on the other people. While the diagram shows separate sections for the merging careers, all of them are intertwined and come together at random points. There is no set order or rule suggested by my results that lead me to conclude that there is anything but flexibility; with the movement among the aspects and with the gatekeepers involved. The only exception is that the student must wait for college prior to using an office of disability services.

Most students did not seek informal validation prior to the diagnosis as was suggested in cases of other studies (Wolinsky & Wolinsky, 1981). This is in part because

the students who were diagnosed early in life were too young to seek validation themselves. They were taken directly into testing, which is the formal validation. Another reason is that many of these students did not think anything was wrong, nor did they want anything to be wrong. Instead of seeking validation for a diagnosis, they sought normalcy. This is consistent with the sick role's obligation to "get well." One female spoke about how she just takes the medication to be seen as normal. She says, "A lot of, you know, for me, I tried to get on medicine, because it helps with people. Really, it's not for me in the long run, it's really for other people."

And another:

You know, it's really, um, people handle you better. Um, and you know, you're more acceptable in society because you're more normal. Um, I never feel like I'm normal when I'm not on my meds. Like, it's driving me crazy that I don't have meds right now. Um, yeah, I don't ever feel normal. I feel like, I'm, I'm different. I feel like I'm the outsider looking in.

There were only slight hints from the students diagnosed at a later point in life that they needed provisional validation. An example can be found in one student who was told by a friend that if taking Ritalin did not work, she must not have ADHD. Validation was thus denied by her friend, although this particular individual insisted that she was unaffected by her friend's opinion. Nonetheless she remembered this experience rather well which suggests some affect has taken place. Additionally, most respondents made a statement at one point or another about how ADHD is over-diagnosed or that ADHD medication is given out too freely, but not in their personal case. Thus they denied validation to others, but not themselves.

It is, however, possible that the parents may have gone to seek provisional validation unbeknownst to the child prior to testing. There may be a lot more that was left unsaid in front of these students than what was explicitly told to them.

Gatekeepers

The gatekeepers were authority figures whom the students encountered along their path. They include teachers, other school personnel, parents, and medical experts. In the cases where the individual was diagnosed prior to high school, this disorder was largely “other-diagnosed.” This means that respondents were told that something was wrong with them, regardless of whether or not they agreed. There were even cases where gatekeepers disagreed and a negotiation took place to decide which authority would win the disagreement. One example is the girl whose teachers tried to place her in behavioral classes while she had a psychiatrist saying she was not a behavioral problem at all, just “hyper.” This battle between these two gatekeepers (teachers vs. medical expert) was mediated by a third gatekeeper, the parents. The parents fought to keep their child in the classroom and avoid her placement into a behavioral problems class. Other students were taken out of their normal classes at some point in time to attend special classes. This occurrence also provides further evidence of the inter-mingling of the components.

There also seems to be a shift with age from ADHD being other-diagnosed to being self-diagnosed. The evidence for this are cases where the individual was diagnosed in high school or later in which they sought out the diagnosis themselves. These later-diagnosed students felt that something was wrong outside of parents, teachers or other gatekeepers suggesting that to them. Other individuals may have helped guide the student

to ADHD, but, as far as they are aware, they made the initial step themselves. Peter Conrad (2007) also finds this self-diagnosing pattern regarding ADHD adults and claims that the diagnosis-seeking behavior is typical for this population. This diagnosis seeking behavior either occurs upon their own child being diagnosed (a pattern seen in my respondents' answers) or through media or a quest to find a biological reason for academic struggles.

Regardless of when the student was diagnosed, a main commonality was that the central gatekeeper involved in the decision to register for disability services was the parents. The students reported disagreement with this attempt, though they registered out of respect for their parents. When it came to the disorder itself, the main gatekeepers were those who interpreted the results from the ADHD test. Most people have the diagnosis as a result of a test, and in almost all cases the medical expert was a psychiatrist. The psychiatrist still had power, but as suggested by Conrad (2005), the power is shifting further away from medical experts, which does indeed allow for more agency. This is evidenced in the negotiation process found in the medication process.

Sick-Role

The traditional sick role concept included the notion that there were two benefits and two obligations felt by those who were sick. Briefly, the benefits were lack of responsibility for the sickness and exemption from life responsibilities while sick. The obligations were to get "well" and to seek out and comply with competent help. ADHD is a bit unique in that, as a childhood disorder, the people receiving benefits and complying with the obligations include not only the "sick" individual, but also their parents. It is

when the individuals become adults that they may experience the benefits largely for themselves, and this is also when they are held responsible for the seeking of treatment.

In my study, the feelings of the parents were not usually mentioned. They were largely kept out of the respondent's consciousness and most likely discussed behind closed doors. When benefits to parents were mentioned, it was in reference to the relief felt by providing aid to a struggling child. This idea is much more altruistic than the concept of mother-blame found in other ADHD studies (Singh, 2004; Malacrida, 2002), which is to be expected as I only interviewed the children. I provide another vantage point from which to view the parental role in such situations.

There were a few cases where a teacher was portrayed as not wanting the student in the classroom. Most of the students have also spent at least a portion of their career in a special education classroom. As Christian (1997) claims, teachers may benefit from a child being diagnosed if they feel the diagnosed individual is hampering classroom order. My results complement this literature by providing the perspective of the student within the classroom. I would also like to add that there were a few cases of teachers who were portrayed in a positive light, and rather than benefiting from the diagnosis, they seemed to focus on the child and providing him or her with the time and attention they needed. This again may provide a richer understanding of classroom dynamics by taking the student into consideration.

When the children reached adulthood, I assumed that the sick role would help explain why individuals may seek to obtain services for ADHD or why they may seek or avoid an adult diagnosis. What I found did not really answer either of these questions.

The concept of the sick role still aids in understanding the process, but most students said that they registered with the ODS for their parents' sakes, not necessarily for their own. They may also be trying to avoid taking personal responsibility. They did receive academic benefits, however, which suggests that their motivations for personal gain may have been present, but not overt. I also did not find them avoiding the adult diagnosis like their earlier-diagnosed peers. The adult diagnosis was merely a step in receiving disability benefits.

Educational Level of Entry

The educational system is central to the ADHD experience. Thus, I examined career differences based upon the educational level of entry as opposed to age. The two main differences I found based upon this analysis were the lack of personal provisional validation and other versus self-diagnosis of ADHD.

Wolinsky and Wolinsky (1981) found in their study that respondents tended to seek provisional validation from significant others prior to receiving a formal one. As mentioned earlier, with ADHD, seeking provisional validation is dependent on the grade in which an individual entered into the illness career. Those diagnosed early were not given the option to seek provisional validation. They simply obeyed those in positions of authority, normally their parents, took the test, and received formal validation. Those diagnosed later in life, however, were more likely to have at least hinted at provisional validation from others. What is interesting here is that when the students needed to validate themselves in front of friends who think that ADHD is over-diagnosed, the diagnosed individuals agreed with the statement but claimed that they were one of the

few genuine cases. This allowed them to still receive some validation from their peers, while denying validation to others diagnosed with the disorder.

The other difference deals with how the person was diagnosed. The educational level of entry seemed to affect whether or not the individual sought out the diagnosis (self-diagnosed) or was diagnosed by someone (other-diagnosed). When respondents were diagnosed before they reached high school, the disorder was other-diagnosed. Someone else told them that there was something wrong. The students who were diagnosed in high school or college, however, were self-diagnosed in that they felt that something was wrong with them and asked to be tested of their own volition. This suggests that being diagnosed later in life provides one with more agency and puts greater control in the hands of the diagnosed individual. This finding is also consistent with the current literature (Conrad, 2007).

Limitations

The results of this project raise quite a few research questions. These results, however, are affected by a few limitations that need to be noted. The first and most obvious limitation is the sample size. Seven individuals do not comprise a large enough group to make definitive claims. Furthermore, while I found some trends, this study only included those cases in which a university office had legitimated the diagnosis. Another issue is that all respondents were Caucasian and were recruited from a single university. These factors limit the generalizability of my findings.

The other intriguing and possibly limiting item is that all but one of these individuals had additional diagnoses to their ADHD diagnosis. It may be the case that

people with only ADHD are far different from those experiencing multiple disorders, or it may be that having multiple disorders is typical of the ADHD college student. More research is needed. This study is too limited to do more than speculate and guide future studies in this under-studied group.

CHAPTER VI

SUMMARY AND CONCLUSIONS

The purpose of this project was to analyze ADHD illness careers, examining the process of legitimizing this diagnosis and reasons for seeking and maintaining it. I also sought to add the voice of the diagnosed to the literature. In addition, I wanted to examine how a new variable, educational level of entry, would affect the progression of the illness career. Due to the small sample size, this research is exploratory, with the goal of generating hypotheses for future research. The central findings of my research include my reformulation of the illness career concept, structural versus individual responses to social problems and ADHD as an “illness identity.”

Previous conceptions of the illness career were largely linear (Goffman, 1961, Suchman, 1965) with some later research adding flexibility to these earlier conceptions (Karp, 1994). As I have highlighted in my discussion, I have reconstructed these linear ideas and created two additional conceptions to add to the original. My findings seemed to demand a flexibility that the linear model could not accommodate on its own. In the case of ADHD, the career was viewed with two aspects: the career and the lived experiences within the career. The first depiction of the ADHD illness career (see Figure One) was a triangle that portrayed the saliency of formal education within this career, and the other two key components: Medical and Disability. Since this model lacks the personal, lived experiences of the individual diagnosed with ADHD I created a second model (see Figure Four) to provide a visual portrayal of these “messy” experiences to compensate for the limitations of the first figure.

These two additional models provide a richer picture of the ADHD illness career. I was able to use my results to offer depth at the micro level to the linear patterns of the past. The linear patterns are still useful in that they provide a depiction at a broader level that is especially valuable for showing movement through the career over time. My additional models may prove useful for adding depth to other illness career research.

The second central finding is the importance of structural versus individual responses to social problems. The current climate in American education appears to lean towards individual solutions to the issue of “hyperactive” children in the classroom. The goal here is to encourage the child to conform to the current educational structure. For example, one response is to medicate the children to “help” their behavior to become less “hyperactive” and to help them to focus on their schoolwork. By contrast, my results, especially regarding the ODS, imply that structural changes may prove just as effective in “helping” children in academic settings. Taking medication did appear to work for my respondents once the proper medication and dosage was achieved. What also worked, however, were the benefits they received through the ODS in the form of separate, quiet exam rooms and more time to take their exams. The effectiveness of structural changes provides a call to change the educational system to conform to the needs of the student as opposed to the other way around. My results imply that if all students were given the option to have more time on exams and the ability to have a quiet, distraction free setting in which to take examinations, there might be fewer students seeking the ADHD diagnosis in the university setting. The educational system is so rigid that it seems to

create a disability instead of making structural changes to accommodate different students' needs.

My results also suggest the necessity of other structural changes such as implementing exercise into the school day and striving to keep physical education as part of the curriculum rather than removing it. When asked for further information not covered in the interview, five of the respondents claimed that exercising helped them tremendously. I only mentioned exercise to one of these individuals. These five all agree that exercise helps them to focus and control their hyperactivity. One individual even raised the issue of physical education in the classroom. He asked questions such as:

What are the implications of removing it? If exercise truly does help ADHD individuals, wouldn't the educational system fare better with leaving physical education in the curriculum as opposed to eliminating it altogether?

The respondents themselves are validating the benefits of exercising on their ability to focus. A structural change to add more exercise into the school day instead of less would likely help students remain focused without medication. What are the implications of removing physical education from the school system? Will that cause an even greater increase in the number of cases of ADHD among students? Would leaving exercise in the schools decrease the frequency of diagnosis? The answers to these questions may have serious implications for the American educational system.

In the case of medication, there are two interesting matters. One is that my respondents only took ADHD medication to get through the school year and the other is the claimed willingness of psychiatrists to let them do this. The current medical structure,

as highlighted by Conrad (2007) and Diller (1998), suggests that it encourages psychiatrists to prescribe medication and give diagnoses in order for insurance companies to provide financial assistance. This may be part of the reason for psychiatrists' apparent willingness to let their clients pick and choose when they take their ADHD medication.

What is also interesting to note, is that taking medication for school is in stark contrast with how society views other performance enhancement drugs. One needs only to turn on the television and watch the news or sports channels to see that the practice of athletes taking steroids (another performance enhancement drug) is prohibited. Why is this practice encouraged for students enhancing attention yet discouraged for athletes enhancing muscle? What is it about the educational system that creates a space of acceptance for this behavior?

Lastly is the emergence of ADHD as an "illness identity." My respondents discussed at different points during the interview how they "felt." Within the academic setting prior to college, my respondents "felt dumb." Many of them currently do not "feel normal." Within these emotions are internalizations of each respondent's illness identity. The way they viewed themselves in light of their surroundings generally led them to interpret their behavior through an ADHD lens. What a non-diagnosed individual may view as a normal behavior (such as having a lot of energy) would be viewed by a diagnosed individual as evidence for the disorder.

The greatest degree of internalization was from the only respondent diagnosed solely with ADHD. Compared to the other respondents, she knew more individuals with ADHD, befriended such individuals, and internalized the diagnosis as part of her identity

to a greater extent than all the others. Other aspects of the career remained the same, such as seeing a psychiatrist, registering with the ODS immediately, and having a difficult time in school growing up.

The goal of my respondents was to appear “normal.” This included “feeling normal” and being “understood.” They wished that society had greater understanding for them when they forgot an appointment or that people would show greater patience toward them and their talkative natures. They claimed that if society knew them better, their lives would be better. Using the “us versus them” language implies that they have internalized an identity within themselves that is not found in others.

In light of my research questions, I found that educational level of entry was not a key factor impacting an individual’s illness career. Gatekeepers, educational experiences, the process of registering for disability services and medical experiences remained quite similar. Two areas of difference, however, are that individuals diagnosed at later points in life were more likely to seek help on their own as opposed to doing so at someone else’s suggestion, and that students diagnosed later tended to seek provisional validation prior to seeking a formal diagnosis.

Beyond the scope of my study is how ADHD adults fare in the work world. One of the concerns raised by these students was that there will be no Office of Disability Services in the work world. This was used as a reason for not using too many services and for attempting to do things on their own. Will the need for medication still exist in the work world? Or is it as Conrad and Potter (2000) claimed, that people with ADHD will begin using their diagnosis as a rationale for not succeeding? Will places of

employment continue to provide special furniture, separate work spaces and other benefits as Diller (1998) has found? All of these questions merit further investigation.

My results suggest the following:

- 1.) Being diagnosed with ADHD later in life increases the amount of personal agency.
- 2.) People diagnosed earlier in life are more likely to have been diagnosed by others rather than seeking out testing for themselves.
- 3.) People who have struggled with learning in the educational system are more likely to have ADHD suggested to them as a potential reason for their struggling than those who do not struggle.
- 4.) Parents are more likely than any other gatekeeper to encourage registering for disability benefits.
- 5.) If exercise is required of students daily, the number of ADHD cases will decrease.

These are just a few of the hypotheses generated from my results. More research is needed to test these hypotheses as well as the many provocative questions brought up elsewhere in my discussion. This study lays the groundwork for this future work and will help bring about a greater understanding of ADHD as well as a new way to think about illness careers in general.

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Appendix A

Interview Protocol

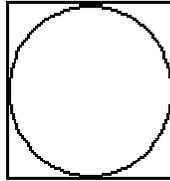
1. When do you first remember hearing about ADHD?
[Age, Grade, Level, Season]
2. When were you formally diagnosed with ADHD?
[Age, Grade, Level, Season]
3. Please walk me through the personal experiences that occurred prior to your formal diagnosis.
4. Once the decision was made that you might have ADHD, what happened next?
5. I would like to hear you talk a little about your experience with professionals, starting with your first visit that dealt with this issue.
[Type visited, Conclusions reached]
6. Please tell me more about the actual routine of visits.
[How often visit, Changes over time]
7. Now I want you to tell me a little bit about your ability to speak for yourself during the diagnosing process.
8. Do you know anyone who has been diagnosed with ADHD? How many people? How do you know them?

Switching gears a little bit, I want to hear about your experiences that led to your decision to register with ODS.

9. What factors were involved in this decision? People? Were some people supportive of or opposed to your registering?
10. Is this your first year at UNCG? If no, why are you registering now as opposed to your first year here? What is different about this year that resulted in your decision to register?
11. At UNCG, the documentation validating the diagnosis is only accepted if it is less than 3 years old. How do you maintain the diagnosis and keep it current and up-to-date? Who is involved in this process?

12. Is there anything else that you feel I should know about your experience that we have not covered?

13. Imagine your life as this circle. Take my pen and shade in that part of the circle that represents how much of your life is organized around ADHD?



Appendix B

Consent Form

CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: ADHD and College Students: Experiencing an Illness Career

Project Director: Rebecca Conway

Participant's Name: _____

DESCRIPTION AND EXPLANATION OF PROCEDURES:

The purpose of this project is to gain a better understanding of the past and present experiences a person with ADHD in college goes through. If you are at least 18 years old and agree to participate, a time will be set up for you to be interviewed. The interview process will last approximately one hour. The interviews will be audio taped and then transcribed for analysis. You will have the opportunity to ask questions during the interview. You may also terminate the interview at any point without penalty. Your participation is entirely voluntary.

The only record of your name will be this consent form. Once the interview is complete, it will be given a number. There will not be a list that links your name to your interview number. This ensures that your name cannot be associated to your interview. The only information that will be used is the interview questions and answers. Once analyzed, the data will be reported in a master's thesis. The information will be stored in a password-protected file on a computer. The consent forms will be stored in a locked cabinet in the Sociology Dept. After four years, all data will be deleted from the computer and all consent forms will be shredded. The audiotapes will also be smashed and thrown away.

RISKS AND DISCOMFORTS:

Due to the sensitive nature of the topic, you may feel uncomfortable talking about some of your experiences. Should you begin to feel uncomfortable, you may refuse to answer the question, or end the interview all together. You will also be made aware of the nature of the questions prior to starting the interview. You may refuse to even begin the interview, without penalty or prejudice, should you feel uncomfortable.

POTENTIAL BENEFITS:

Most of the literature on ADHD focuses on physicians and parents. If you participate in this study, you will help to add the voice of those who are diagnosed. This will benefit the larger society by helping people such as physicians understand the experiences of the people they treat. It will also benefit organizations such as the Office of Disability Services to gain a better understanding of the students they help.

You may also feel the benefit of having your voice heard. This may be a form of release for you as well as a freeing experience.

By signing this consent form, you agree that you understand the procedures and any risks and benefits involved in this research. You are free to refuse to participate or to withdraw your consent to participate in this research at any time without penalty or prejudice; your participation is entirely voluntary. Your privacy will be protected because you will not be identified by name as a participant in this project.

The University Institutional Review Board, which insures that research involving people follows federal regulations, has approved the research and this consent form. Questions regarding your rights as a

participant in this project can be answered by calling John Doe (XXX) XXX-XXXX. Questions regarding the research itself will be answered by Rebecca Conway by calling XXX-XXX-XXXX or email rlconway@uncg.edu. Any new information that develops during the project will be provided to you if the information might affect your willingness to continue participation in the project.

By signing this form, you are verifying that you are at least 18 years old, and are willing to participate in the project described to you by Rebecca Conway.

Signature

Date