

**ONLINE NARRATIVES BY ADULTS WITH AD(H)D  
WHO WERE DIAGNOSED IN ADULTHOOD**

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**Abstract**

This study systematically analyzed life stories of adults with AD(H)D who were diagnosed in adulthood, using an adapted version of Labov's textual-analysis method. These life stories provided an opportunity to examine the processes experienced by these individuals before and after the diagnosis of AD(H)D, from their perspective. The results indicate that the narrators experienced repeated failures in many aspects of life. Many of them internalized negative views to which they have been subjected in their social environment. Consequently, they developed self-blame which subsequently further hampered their functioning. Once diagnosed with AD(H)D, these adults were able to construct a more coherent view of their life and of their difficulties, move beyond guilt and understand that they could overcome their challenges. Consequently, many of them began to take a more positive view of themselves and of the course of their lives, and to admit to some positive aspects of having AD(H)D.

**Keywords:** Adults; AD(H)D; Online narratives; Narrative analysis; Qualitative research; Coping; Internet-based research

### **Introduction**

Attention-deficit (hyperactivity) disorder (AD(H)D) is the most common childhood neurobehavioral disorder, presented in 6%–9% of all children (Faraone et al., 2006). For several decades, AD(H)D was mostly considered a childhood disorder. Symptoms of AD(H)D in children, however, continue into adulthood in approximately half of all cases and current estimates of adults with AD(H)D indicate an incidence rate of 4%–5% among adults (Kessler et al., 2006).

The consequences of AD(H)D for the lives of adults have received increasing attention in recent years (Barkley et al., 2007). Still, there is a need to examine how these adults view the processes that they have been enduring since childhood as individuals with AD(H)D.

The internet has been growing in importance as a focal point of research in social science in recent years. Still, the study of web sites about AD(H)D is still in its infancy. This study attempts to address this situation by investigating forty adults with AD(H)D diagnosed in adulthood, who decided to share their life experiences as online narratives. Our interest in AD(H)D management processes of adults and their modes of empowerment, as reflected in these individuals' life stories, led us to explore the internet as an environment that may promote empowerment and management of AD(H)D among adults.

While some authors have suggested that AD(H)D is a social construct that sets learning, attention, and learning difficulties in a social context of human functioning (Stolzer, 2009; Timimi & Taylor, 2004), our research focused on the self-perceptions of life experiences and the management processes of individuals who reported themselves as having been diagnosed with AD(H)D by medical professionals.

### **Characteristics of Adults with AD(H)D—Implications for Functioning and Adjustment in Various Domains**

A recent survey of the impact of AD(H)D on adult life indicates that the disorder has a severe and pervasive effect in several areas of the lives of adults (Barkley et al., 2007). AD(H)D is found to correlate with difficulties in cognition, education, occupational functioning, marital life, parenting, financial management and healthy lifestyle throughout adulthood (Barkley et al., 2007; Ernst et al., 2003).

In general, adults with AD(H)D attain lower levels of schooling, have more concomitant psychopathological conditions and are more likely to engage in substance abuse than adults without AD(H)D (Barkley et al., 2007; Kessler et al., 2006).

Despite the substantial challenges that adults with AD(H)D experience, however, living with AD(H)D does seem to be manageable. Thus, for example, some people with AD(H)D seem to outperform others in educational achievements, especially those who struggle to attend postsecondary studies. Frazier, Youngstrom, Glutting, and Watkins (2007) suggested that these individuals may be better able to compensate for their difficulties.

To understand the way persons with AD(H)D marshal compensating forces, one may consult studies that examine how such people perceive their life with AD(H)D. Very few studies examine how adults with AD(H)D manage their AD(H)D from their own perspective (e.g., Rucklidge, Brown, Crawford, & Kaplan, 2007; Waite & Ivey, 2009). Even fewer studies have used the life-story investigation method in their inquiry (Shattell, Bartlett & Rowe, 2008; Waite & Ivey, 2009). Such studies are useful in identifying the meaning that the narrator gives to his or her life and the strategies that he or she uses (Koro-Ljungberg, Bussing, Williamson, Wilder & Mills, 2008). Studies investigating the personal narrative are needed in order to know how people with AD(H)D assemble a world of new meaning which they can better manage. Shattell, Bartlett, and Row (2008) used narrative research to investigate how adults with AD(H)D view their childhood in retrospect. Meaux, Hester, Smith, and Shoptaw (2006) limited their inquiry to the meaning of pharmacological treatment as perceived by college students. Some narrative research on adults with learning disabilities exists (e.g. Valle, Solis, Volpitta & Connor, 2004; Connor, 2009). However, a thorough search of the literature about adults with AD(H)D revealed a paucity of narrative research on the meaning that these adults impart to their living with AD(H)D in adulthood. Similarly, it remains necessary to determine how adults with AD(H)D that was not diagnosed in childhood judge the importance of the diagnosis in their lives and the contribution of their awareness of their AD(H)D to the management of their lives.

### **The Importance of a Diagnosis for Adults Living with AD(H)D**

Diagnosing AD(H)D in adulthood is not a simple process. In this process, careful attention should be paid to differential diagnosis and the possibility of comorbid conditions - other psychiatric disorders or addiction (Donnelly, 2006; Biederman et al., 2006). Due to the concurrence of AD(H)D and other disorders, physicians sometimes misidentify this disorder in their adult patients, thereby delaying or thwarting the correct diagnosis (Able, Johnston, Adler, & Swindle, 2007). Few studies describe how adults with AD(H)D who were not diagnosed in childhood cope with their difficulties (e.g., Rucklidge, Brown, Crawford & Kaplan, 2007). It has been postulated that the

hardships of children and adults with undiagnosed AD(H)D are especially acute (Able, Johnston, Adler, & Swindle, 2007; Okie, 2006; Rucklidge, Brown, Crawford & Kaplan, 2007; Waite & Ivey, 2009).

Those who favor diagnosing AD(H)D hold this view because, in their estimation, diagnosis and comprehensive evaluation are prerequisites for focused intervention with adults (Gibbins & Weiss, 2007). Furthermore, adults with AD(H)D experience a continuum of failures in different domains. People with undiagnosed AD(H)D and those around them do not know the reason for the behavioral and functional difficulties that they experience or observe and thus may blame their behavioral difficulties on flawed character (Okie, 2006; Waite & Ivey, 2008). It has also been proposed that a diagnosis of AD(H)D may induce adults with AD(H)D to stop blaming themselves for their difficulties (Wadsworth & Harper, 2007). By the same token, an AD(H)D diagnosis may stigmatize persons with special needs and label them as flawed and weak. Accordingly, the labeling of a person with AD(H)D may diminish his or her self-confidence (Waite & Ivey, 2009).

Since the effect of the AD(H)D diagnosis on the perceptions and management processes of adults with AD(H)D has received little attention (e.g., Waite & Ivey, 2009), it is important to examine this issue further.

### **The Internet and AD(H)D**

An adult who is diagnosed will likely seek further information about the condition and about social support. Both psychological support and information about management of AD(H)D are important for the success of medical treatment for AD(H)D (Koro-Ljungberg, Bussing, Williamson, Wilder & Mills, 2008; Young, 2007).

The internet can provide persons with disabilities with information about organizations, medical and psychological support, etc. Therefore, it is useful in understanding treatment processes and management of various health conditions (Fleischmann & Miller, 2007; Noruzi, 2007). It may also be used to explore educational, therapeutic, counseling and even medical interventions (Noruzi, 2007). Finally, individuals may obtain professional advice or information from online narratives published by others (Fleischmann, 2004, 2005).

Recently, the internet has been shown to be useful in gathering information about AD(H)D and the inner lives of children with learning disabilities (Foroushani, 2008; Raskind, Margalit & Higgins, 2006; Young, 2007). Raskind et al. (2006) examined online messages of children with learning disabilities who used a website designed to provide a safe and anonymous environment. They found that these children identified themselves as belonging to a group of children with learning disabilities or attention problems. They seemed to perceive the site as a safe

environment that allowed them to explore and discuss their identity at large, including their learning and social problems. In addition, some of these children found relief in belonging to a community or group of children with learning and attention problems and in being able to receive support from experts.

Recently, adults with AD(H)D have been publishing online narratives that document ways in which they cope with their condition from their perspective. Therefore, these sites provide an opportunity to explore in depth the inner world of adults with AD(H)D, as they view it. Some of these life stories describe how individuals with AD(H)D, diagnosed after their childhood and adolescence, cope with the challenges that AD(H)D poses. In this study, we explore how the narrators of these stories view themselves.

Despite the intensive research regarding AD(H)D in adults, it is still necessary to explore how they personally understand the ways by which they have come to manage their condition. It is also important to explore the meaning that they give to the recognition that they are characterized with AD(H)D. In this article we reveal the processes that characterize how adults with AD(H)D cope in their daily lives and how their diagnosis in adulthood was an influential turning point for them.

## **Methodology**

### **An Overview of Labov's Methodology**

The online life stories that we examine in this study resemble monologues. In these narratives, adults with AD(H)D recount their lives for readers. One of the most important and influential methods of narrative analysis of monologues is that proposed by Labov and Waletzky (Elliott, 2005). In this method, not only does the content serve as a vehicle for the communication of messages, the order of appearance in the monologue does the same (Labov & Waletzky, 1967). The instrument that Labov and Waletzky (1967) developed allows one to understand not only the essence of the monologist's narrative but also how the narrators assess it. In a previous study, we found Labov's method effective in decoding the messages conveyed in online life stories (Fleischmann & Miller, 2007).

Therefore, this study will use Labov's method to reveal the underlying meaning of the personal narratives that we have gathered. The resulting content analysis will allow us to classify the attitudes, perspectives and feelings that the narrators express and, on the basis of the outcomes, to construct a typography of the processes and experiences that the narrators (adults with AD(H)D) have undergone.

Labov's method was designed to analyze personal narratives that appear in verbal monologues (Labov, 1972, 1982; Labov & Waletzky, 1967). However, the methodology had to be somewhat adapted in order to accommodate the length, the unique structure and the special characteristics of the online narratives, as well as the websites at issue here and the context of the medium in which they are presented (Fleischmann, 2004, 2005; Fleischmann & Miller, 2007).

The result is a unique methodology that allows the researcher to characterize textual units within narratives, identify commonalities among narratives, locate significant parts of a narrative and uncover the meanings and underlying messages of the narrative by using different parts of the monologue. Thus, the methodology may be useful in viewing the narrative as a series of answers to questions. All the following terms were derived from Labov's original model:

1. The "Abstract" (a Labovian expression) appears at the beginning of the monologue and serves as an introduction, is somewhat distinct from the narrative that follows and explains what the essence of the story is.
2. The "Orientation" describes the setting of the events, identifies the protagonists and presents the theme of the narrative.
3. The "Complicating Action" explains the sequence of the events and pinpoints the critical activity that changes the course of the story.
4. The "Evaluation" addresses the meaning that the narrator assigns to the event.
5. The "Resolution" specifies the outcome of the story.
6. The "Coda" returns the reader to the present and indicates what comes next.

### **Adapting Labov's Methodology**

Several modifications were required to implement Labov's methodology for the analysis of personal stories in websites. Stories on websites are often split over separate pages in the site. In addition, the stories are often longer than the narratives selected by Labov. Consequently, in our examination of online content, the "end product" (the analysis) will not adhere strictly to Labov's preliminary objectives, although it will follow it in spirit.

We made the following accommodations to Labov's method: the information on the home page of the websites and the opening to the life-story pages (see below) was defined as the "abstract." The "orientation" was based on the site's "table of contents" (subtitles in the narrative or hyperlinks on the main page that direct readers to other pages)

or the content following the “abstract” on the life-story page. The “complicating action” was found at the beginning or, at times, in the middle of the life story. The “evaluation” was based on passages in the narrative that followed the “complicating action.” The “resolution” appears toward the end of the main narrative. We derived the “coda” from a separate passage following the “resolution.”

Our earlier research suggested that adapting Labov's model for analyzing internet-based narratives did not reduce the model's ability to identify the fundamental nature of life stories and for deciphering the meanings the narrators attributed to their life story (Fleischmann & Miller, 2007).

To validate and complement Labov's method of analysis, we also performed a thematic analysis based on grounded theory as set forth in the methodology of Glaser and Strauss (1967) and Strauss and Corbin (1990) (Miller & Fleischmann, 2010). The results of the thematic analysis indicate that the narrators' messages and the processes that they have undergone were very similar to the message found in the analysis based on Labov's method (see “Results”). Still, the analysis based on grounded theory better emphasized the processes experienced by the narrators. Therefore, grounded-theory methodology was more efficient in uncovering different management styles among the narrators (Miller & Fleischmann, 2010). In comparison, Labov's method was more efficient in deciphering the fundamental nature of the life stories and the meaning attributed to them by the narrators (Miller & Fleischmann, 2005).

### **Websites: Authenticity and Criteria for Use**

The search for Internet personal life stories of adults with AD(H)D was conducted at the end of the year 2004. An additional search was conducted from August 2006 to February 2007. Both searches used Google as a search engine.

Our study used forty personal life stories of adults who were diagnosed with either ADD or ADHD and who accepted their diagnosis. We used either the personal websites of people with AD(H)D who recounted their life stories or sites focusing on living with AD(H)D (with the exception of one site, which focused on brain dysfunctions) and included referrals to life stories of people with AD(H)D. In all, fifteen sites were included (see Table 1), containing a wide range of referrals to personal life stories (from one to dozens), usually on separate pages.

In some cases, certain life stories were referred to several times. It suggests that the internet as a medium was used to create a structure in which certain life stories may be interwoven across several sites. The length of the life

stories ranged widely, from one internet page to dozens. Each story recounted the narrator's management of AD(H)D.

[INSERT TABLE 1 HERE]

### Sample

The stories selected for the sample were chosen using conventional data-mining methods. At the outset, search engines were used to cross-reference two keywords: "ADD or ADHD" and "stories". Suitable websites that this method unearthed were subsequently used to find links to other promising sites. All the sites included in the present study were either personal web sites constructed by the narrators, or sites dedicated to some aspects of AD(H)D and included personal life stories.

Only life stories that met the following criteria were included:

1. Stories in which AD(H)D was formally diagnosed after adolescence, as reported by the narrators. Life stories in which it was clear that AD(H)D was self-identified were excluded.
2. Stories in which the adult's primary diagnosis, as reported by the narrators themselves, was AD(H)D.
3. Stories in which the content included a personal narrative.
4. Stories in which the main problem, in the narrator's judgment, was AD(H)D.
5. Stories written from a personal perspective and in the first person.

The contents of the personal life stories were shown to three external judges, who are adults with AD(H)D, in order to evaluate their authenticity. The readers reported that the stories—some running into dozens of printed pages—indeed constituted authentic and highly descriptive portrayals of reality. The stories were written in the form of personal narratives, told from a personal perspective and constructed as monologues. From the standpoint of scientific research, these stories were addressed to a general "anonymous audience." The narratives may, however, also provide unique insights for explaining the processes that individuals with AD(H)D undergo as they grow up and reach adulthood.

### Procedure

The research was divided into two stages:

***The individual-narrative stage.*** first, the components of each separate narrative were identified using Labov's method, which was adapted in the manner described above.

*The overall-narrative stage.* after the individual narratives were analyzed in accordance with Labov's method, common threads in all of them were pinpointed, in order to reveal a typology that characterizes adults' retrospective memories of their experiences with their attention disorder. Similarly, common themes that recurred in many stories were used to aggregate the data and reveal common patterns and concepts.

### **Ethical Aspects of Using Web Sites**

The ethical and legal aspects of using internet content are still in their formative stages (e.g., Santos & LeBaron, 2006). In general, the use of online content for research purposes is permitted if the Web site is considered to be in the public domain (Eysenbach & Till, 2001). When sites are presented in such a manner, their status is similar to that of published material. However, we believed that we must address the ethical dimension of the further publication of such material. Consequently, we applied the following guidelines:

1. We did not include websites that set limitations on use or access (e.g., registration requirements for entering the site).
2. We included only sites that were written for the public at large and offered links and "services" to the public.
3. All the sites chosen addressed the reader in the third person in the general sense, expecting readers to understand the messages being presented. Sites in which the author sought to remain anonymous were not used. It seems that the "code" of website authors is to publish their experiences in order to help others to cope. Thus, we reasoned that further publication in this study would serve to advance the narrators' original objectives or, at least, would not clash with them.
4. We respected the privacy of the adults with AD(H)D as individuals and participants in a virtual community.
5. Lastly, although this study strives to uphold conventional scientific standards of inquiry, we aimed to present the narratives as the authors perceived and sought to present them.

## **Results**

### **Abstract**

Two opposing but interrelated messages were found in the abstract. The first was confusion: AD(H)D poses multiple challenges for which the person with AD(H)D should not be blamed. Therefore, the individual who does

not know the cause of his or her difficulties is confused. The second is clarity: when a person with AD(H)D understands the reason for his or her peculiar behavior, he or she can manage his or her special traits more efficiently and use them more advantageously in life.

The sites expressed these messages in the following ways:

1. Confusion: fourteen of the fifteen sites described several challenges: difficulty in concentrating, inattentiveness, organizational and task-completing challenges, difficulty in understanding social situations and social challenges and emotional problems. These sites explain that when persons with AD(H)D do not know the reason for their difficulties, they find it difficult to make their way in the world. The author of one site described a sense of detachment—“The real world is just beyond my grasp”—or confusion and inattentiveness and, as a consequence, anxiety:  

I lived my life in a constant state of panic: what was I forgetting?” The narrators described cognitive challenges such as forgetfulness, confusion, inattention and emotional and social problems. Since they did not understand the origin of their difficulties, they blamed themselves for having flawed personalities or, as one of the authors termed it, “a terrible and shameful failing in my personality.
2. Clarification: The site authors explained that people with AD(H)D, while having typical AD(H)D traits, are not necessarily rendered incompetent for this reason. By recognizing his or her value and unique traits, a person with AD(H)D may do well. Indeed, all sites demonstrate that adults with AD(H)D may lead successful lives. Most of the sites state that they aim to help “AD(H)Ders” to “achieve success in their lives.” Some sites describe the help that is needed for successfully living with AD(H)D. Others emphasize the positive aspects of AD(H)D. The “Living with ADD” site, for example, mentions one such advantage: the ability “to do five things at once.” Thus, the reader can understand that one may not only cope with AD(H)D but also sometimes even gain advantages from it.

#### **The abstract according to the life stories.**

The message that people with AD(H)D who recognize their special traits may succeed is included in the abstract of most of the personal stories (29 of 38 stories that have an abstract). This message is conveyed by describing a positive characteristic of the story (e.g., “It is a story of hope”), by describing positive aspects that often accompany AD(H)D, such as creativity; or by sharing accounts of personal achievements, such as having a wonderful family despite the disorder.

Twelve abstracts state that the goal of the personal story that follows is to share with the reader some strategies that may lead to success.

People say that the internet is a great place to get information; indeed, it has had a profound effect on my life. But the information I sought wasn't found in a file or a program...it was found in the people...the people on alt.support.attn-deficit, the people on Dan Diaz's ADDult list...these are the people who shared their stories and let me know that I wasn't alone anymore...and so I now share my story with you.

## **Orientation**

### **Orientation by sites.**

People with AD(H)D are the “stars” of the sites (see subsection 1 below). Their characteristics are detailed in the referrals to their stories and, briefly, in the titles of the referrals.

The characteristics of the person with AD(H)D are portrayed as unique, rather than negative.

The titles inform readers that the protagonists experience some challenges, but may obtain help and lead successful lives in spite of this. Therefore, most of the sites center on management of AD(H)D and offer suggestions for more effective self-management in functional domains that may challenge people with AD(H)D (see subsection 2 below).

The following referrals were encountered:

1. Description of challenges and advantages for adults with AD(H)D. The sites included referrals to other sites and sources of information about AD(H)D (including books or online bookstores that focus on AD(H)D). One site, for example, refers to a link that lists advantages of having AD(H)D, which include the following:
  - a. We learn to cope with difficulties so that any hardship we encounter later on seems ‘a piece of cake.’
  - b. Hyper-arousal in childhood becomes, in adulthood, lots of hours of life that are utilized. While everyone else has already tumbled into bed, we are still going full-speed.
  - c. The ability to empathize with differences makes us ‘more human’.
  - d. We have the capacity to be sensitive to the surroundings [...].
  - e. We’re very intelligent—as a rule.

2. The location of the personal narrative at the site: most sites (13 out of 15) include referrals to personal stories
3. Suggestions for people with AD(H)D who face challenges: Thirteen of the fifteen sites refer readers to sites or information sheets designed to help them with challenges that they may face in various aspects of their lives. The readers are offered three types of management methods:

3.1. Referrals to sites including suggestions. Some titles of referrals offer general help without specifying any particular type of help (e.g., “Tips”). Several titles are clearly aimed at adults with AD(H)D: “Live an Optimal Life with Your ADHD,” “Couples” and “Relationships.” The message conveyed by these referrals is that when a person with AD(H)D is liberated from his or her confusion and understands where his or her problems originate, he or she also knows how to cope with them.

Even when success comes, however, it may bring difficulties in train. In one referral, “I Feel the Successes Aren’t Mine,” the writer offers assistance to an AD(H)D patient who overcame his confusion: “What happens when an adult starts to treat himself and rings up successes? It’s not always easy to get used to the idea that he’s really successful now.” The author of the site offers a suggestion:

Think about the queen in the Snow White story. One morning she gets up and her mirror tells her something new: “You’re not the prettiest girl in town...” She’s awfully surprised and gets totally disoriented [and later does horrible things].

What happened to you was the other way around: one morning you got up and the world handed back reflections other than the ones you’ve been used to. Suddenly, as you said, it tells you, “You’re successful!” How do you get used to that???

You must surely be perplexed and surprised, and you need time to get over the surprise and “connect” with the new reflection that’s staring back at you [...].

- 3.2. Connecting with others on the internet. Most sites (12 out of 15) included referrals to Internet forums (including chats) and support organizations for individuals with AD(H)D. All sites offered the option of contacting their author(s).
- 3.3. Referrals to treatments and evaluations. Most sites (12 out of 15) included referrals to various types of therapies, consultations and assessments. Some referrals had general titles (e.g.,

“Treatment”). Others had more specific titles, such as “Various Paramedical Treatments for Emotional and Behavioral Support” or “Complementary and Alternative Medicine Treatments.”

### **Orientation according to personal life stories.**

Most of the personal stories (35 out of 40) include some type of orientation. All stories contain some information about the narrator and many include some reference to his or her challenges. Most of the stories that include orientation (23 out of 35) recount how the narrator copes with AD(H)D. Half of the orientations mention additional characters, such as family members and friends. In orientations where AD(H)D is implied, there are allusions to the difficulty that AD(H)D has caused the narrator and his or her family and friends. One of the narrators emphasizes the troubles that her husband has to deal with. Between the lines, however, a narrative of success and a happy relationship protrudes:

First—a little information about my life now. I teach special education in a San Antonio middle school. I have been married for 20 years (still happy I’m married) and I am a mom of two wonderful girls. One is in high school, one is about to move out to the dorms at UTSA. All three of us have some form of ADD. My Girls have ADD, and I have ADHD. My poor husband doesn’t stand a chance.

### **Complicating Action**

Difficulties are described as early as the school years (see Section 1 below), in relationships with friends during childhood and adolescence (Section 2) and with parents (Section 3). The difficulties continued after adolescence and presented challenges in college and at work (Section 4) as well as in intimate relationships (Section 5). All these difficulties took a toll on the narrators’ self-confidence and self-esteem (Section 6).

The ongoing challenges also induce a sense of stress and eventually helplessness, as continuing failures defy solution.

Unsurprisingly, some narrators experienced serious emotional problems (Section 7). In most stories, there were testimonies that the narrators and significant people around them could not understand the reason for the numerous challenges these individuals faced. Since the origin of these challenges could not be detected, they did not receive the proper social support or develop the necessary skills or tools for efficient management of these challenges. Furthermore, these challenges were interpreted as negative characteristics.

When the narrators finally discovered that they had AD(H)D, they sought formal evaluation, which helped them to understand the reason for the challenges that they had been experiencing throughout their lives. Only then were they prepared to cope with their disorder (Section 8).

1. **Problems at school:** In all stories that mention school years (38), the narrator describes having experienced difficulties at school. One narrator expresses it this way: “School was like a huge punishment for me [. . .]. I attended approximately 10 schools before going to high school.” Most narrators say that their teachers suspected that the academic failure was due to laziness or maladjusted personality. One narrator, who did well on her tests but did not perform certain tasks, reveals that one of her teachers said to her, “Your test scores show you are very bright, so you must just be being lazy.” In other words, the unexplained contradictions that typify the narrator’s behavior gives him or her the appearance of having a flawed personality. Importantly, several narrators mention teachers who had a positive effect on their lives. One narrator received support from a teacher at a facility for juvenile delinquents. This teacher accepted him as he was, thereby helping him read and advance in his own way.
2. Most narrators mention social challenges explicitly. Here is one example: “I was very attractive and so I was always so confused about why no one seemed to ‘like’ me.” As a result of the ridicule and alienation that many narrators experienced, they felt rejected. This author’s social hardship seems to have been aggravated by her ignorance of the reason for it. In her confusion, she was unable to find an appropriate way to cope.
3. **Problems with parents:** Some narrators (in 14 out of 40 stories) reported having had interpersonal problems with parents that exacerbated their social maladjustment.
4. **Difficulties at work or in college:** Most narrators (32 out of 40) reported that their hyperactivity, inattention and disobedience made it hard for them to retain jobs or attend college. Here is one example: “In the 12 years since finishing college I’ve probably had 15 different jobs. Fired from some, left others before I was fired.”
5. **Interpersonal challenges in intimate relationships.** About half of the life stories (21 out of 40) described such difficulties.

6. Diminished self-confidence: Most of the narrators did not understand the reason for their difficulties and, therefore, adopted the attitude of those around them, believing that they had difficult personality traits.

One such narrator is Bruce:

I was real smart! Why, then, would it take 30 to 45 minutes for me to put on my “snow clothes” to go home at the day’s end? Why did I “space out” in the middle of art projects?

The constancy of failure in many aspects of life diminished many narrators’ self-confidence, an issue clearly described in 36 out of 40 stories. One of the narrators felt that after failing in all aspects of life without understanding why “... my confidence was so completely shattered. I hadn’t been successful in anything”.

7. Psychological problems: About one-third of the narrators (14 out of 40) described having experienced depression or anxiety that required psychiatric care. These problems originated in their constant failures and sense of helplessness.

8. “Seeing the light” - the importance of understanding: This was a turning point for most narrators. Almost all of the narrators (36 out of 40) attained the insight that helped them trace their problems to a disorder. They arrived at this evaluation either by chance, after their child was diagnosed with AD(H)D, or by a conscious effort to seek the truth and the origin of their challenges.

One of the narrators ruined her marriage and had difficulties at work. Given the friction that typified her relations with the world, she had accepted the derogatory opinions of others about her. After her son was diagnosed with ADHD, however, she asked for an evaluation as well. When she found out that she, too, had ADHD, she understood why she had found life so hard, was absolved of her guilt feelings and had a sense of relief: “I was relieved to find out what was wrong with me.”

Once the narrators learned about their AD(H)D, their self-perceptions changed. One narrator reported having acquired computer and internet skills at some point. While surfing the web, she found a support forum for individuals with AD(H)D: “I stumbled onto Usenet’s alt.support.attn-deficit in early 1994 and for the first time in my life I felt like I’d found people who understood me.” After reading information at various sites and discovering that she had AD(H)D, she transformed her life story from a series of failures to a comprehensible narrative.

## Evaluation

The evaluation included two interrelated messages. The first is the insight that people with AD(H)D should not be faulted for their troubles. The second message, related to the first one, is that individuals with AD(H)D can experience success in their lives.

1. Individuals with AD(H)D are not at fault. Most narrators (26 of 40) initially blamed themselves, or were blamed by others, for the “problematic personality” that lay at the root of their difficulties. After their diagnosis of AD(H)D, they realized that many of their challenges traced back to their AD(H)D and that they should not be blamed for them. A typical example of such an evaluation was: “[. . .] My entire life everyone thought that the something-wrong-with-me was due to my lack of self-control and willpower [. . .]. We now know that [it] is not true.”
2. One can cope with AD(H)D and lead a successful life: Most narrators (33 out of 40) assumed after their diagnosis that it was possible to cope with their AD(H)D and hence succeed in life.

One narrator stated, “I decided that my life was starting over. I wanted to make sure that I was giving myself the opportunity to improve so I cut loose the things that held me back.”

## Resolution

After accepting their AD(H)D, the narrators were often able to see themselves more positively (Paragraph 1 below). In addition, the treatment of their AD(H)D improved their functioning, enhancing their success in life (Paragraph 2) and self-confidence (Paragraph 3).

1. Change in perception of the cause of one’s troubles: The life stories demonstrate that the narrator’s self-image improves once he stops perceiving his or her personality as the cause of the maladjusted behavior and this, in turn, helps him free himself of his or her feelings of guilt and shame.

One narrator wrote:

The most wonderful thing for me was to find out that it’s the way the cards were dealt [sic] to me, not a flaw in my character. I finally had an explanation for the things I do, and don’t do, or forget to do.

Thus, one of the female narrators was able to forgive herself and never again perceived herself as flawed: “My entire life everyone thought that the something-wrong-with-me was due to my lack of self-control and willpower....we now know that is not true. I am a survivor...”.

Evidently, then, one's ability to recognize oneself as having AD(H)D makes one's world comprehensible and, therefore, manageable and able to be dealt with. In the foregoing quotation, like others, the perception of AD(H)D not as a serious illness but as a human condition emerges from between the lines.

2. Improved functioning: Since many narrators forgave themselves following their diagnosis, they were willing to explore ways that could help them better cope with their lives. For example, the narrator mentioned in the preceding section said that "[...]the puzzle piece that made the most sense in my life, was my diagnosis of ADHD. Since then, I have been working on getting and staying comfortable in my skin". Thus, beginning to cope and the determination for taking an active role in changing one's life, generated by the new self-perception, resulted in improved functioning.

The narrators describe an overall improvement in their abilities, such as defeating unhealthy habits, improving their organizational skills through coaching and other professional intervention and acquiring learning techniques in order to improve memory or develop relaxation techniques. Another improvement occurs at work or in college, due to career changes that better fit their characteristics, or proper pharmaceutical treatment that enhances their functioning. Many narrators also describe an improvement in family or social life as the result of better understanding by family members of the reasons for their behavior, better selection of friends who can appreciate them for who they are and better interpersonal skills.

3. Improved self-confidence: Most narrators report an improvement in self-confidence after treatment (37 out of 39 stories in which the issue is mentioned). One narrator relates that she had once found it difficult to understand why her relationships failed. After her diagnosis, she states confidently: "For the first time in my life I am OK. AND, guess what? I am still a beautiful woman and know that I will find true love some day with someone who appreciates my loving spirit."

### **Coda**

Two topics were found in the coda. The first states that the awareness of the presence of AD(H)D, together with a willingness to use strategies that are appropriate for a person who has AD(H)D, make it possible to cope with the disorder appropriately. This message appeared in almost all stories (38 out of 40). The second topic was pleasantries and farewells.

1. Confidence and future expectations: Most narrators claim that have already coped with AD(H)D successfully or will do so. They deliver this message in three main ways:

1.1 A summary (in 36 out of 40 stories) that describes an improvement in the self-perception and self-image of the individual with AD(H)D. One narrator, for example, stated, “For the first time in my life, I feel confident that I have a very bright future with my family and business, and it feels good.”

1.2 An emphatic statement inviting the reader to use information from the website and the personal story for his or her successful management of AD(H)D. In 12 (out of 40) codas, a phrase such as the following appears: “There is a lot here. Hopefully there is something you can use.”

The narrators clarified that they were inspired by life stories published on the Internet by other individuals with AD(H)D. They hoped that their own online stories would help other readers in the same manner. For example, one of them wrote: “I hope someone found some comfort in similarities in my life as I did in the other ADD stories here.”

1.3 A statement that having AD(H)D is not a punishment but may actually carry advantages and that living with AD(H)D has made the individual’s life more meaningful. Such descriptions suggest to the reader with AD(H)D that his or her path may take a similar turn. One narrator wrote, for instance, “I thank God for this journey. It has made me unique. Another related the following:

I see that I am gaining the respect of family and co-workers by being a worker among workers and achieving the related success. In seeing the upside to an ADD diagnosis (high energy, ability to handle multiple tasks, strong communication skills), I no longer say, “Why me?” but rather, “Why not me!”

Thus, she evidently perceives AD(H)D not as a disorder but as a trait typified by characteristics that, in some cases, give those who have them an advantage.

Only two narrators could be considered as '**exceptions**' compared to most of their counterparts. They wrote their life stories shortly after being diagnosed and, in their codas, express some doubts about their future: “Will this treatment work? Only time will tell, I suppose.” These narrators have not yet had time to learn about the possible advantages of having AD(H)D and do not yet know how to use the various strategies to improve their functioning.

2. Pleasantries and farewells: Half of the narratives (20 of 40) end in this manner, making them more intimate and personal and, in a sense, more reminiscent of conversations or personal letters than of conventional stories. One narrator chose to end the story in this manner: “If you have any questions or thoughts, feel free to send them to me.”

### **Discussion**

The results indicate that adults with AD(H)D who were not diagnosed as children undergo a dramatic change after diagnosis. Before discovering their AD(H)D they had difficulties in most domains of life. The terms often used in these stories often reflected the medical model, which might suggest that over the years the narrators have internalized a pathological perspective of their challenges. The narrators described failures at school, in college, in family life and at work. These adults, their teachers, parents and friends did not understand the source of their unacceptable conduct and attributed it to lack of motivation or to pathology. Many adopted the attitude of their social environment and assumed that their personality was the cause of their problems, thus feeling guilty about it. Many of them described confusion and helplessness. They suffered from diminished self-esteem and had difficulty using their talents. One of the adults with AD(H)D explained his condition: “The marvelous creativity hindered by the absolute inability to get organized and STAY organized.” After discovering that they had AD(H)D, most of the narrators change their perceptions about their past. They now believe that they understand what they have gone through in life; therefore, they stop blaming themselves for their difficulties and feel capable of surmounting their current challenges, using their talents and achieving success. Thus, the diagnosis is a turning point for many of them—from depression and dissatisfaction to a path leading to success and fulfillment.

### **Guilt and Narrative Reconstruction**

Most of the websites and narratives included in this study indicate that AD(H)D poses substantial challenges to daily functioning. These primary difficulties create secondary ones—emotional, interpersonal, social, academic and occupational. The primary impairments reported in the personal narratives and their implications for various aspects of daily functioning reflect findings reported in the literature on adults with AD(H)D (Biederman et al., 2006; Ernst et al., 2006; Kessler et al., 2006). Difficulties in interpersonal skills were associated with conflicts with teachers,

clashes with parents and/or marital problems. Consequently, most narrators blamed themselves or were blamed by others for their difficulties, which were ostensibly brought on by their flawed personalities.

The narrators' guilt feelings were accompanied by stress and, in some cases, by emotional disorders. Feelings of guilt and shame accompanied by psychopathology are described in studies on children (Ostrander, Crystal & August, 2006) and on adults (Erk, 2000; Nadeau, 1996; Wadsworth, & Harper, 2007) with AD(H)D. Self-guilt is especially typical of adults with undiagnosed AD(H)D (Okie, 2006). Fundamentally, guilt and shame may serve to correct behavior, but when the guilt is unjustified and exaggerated it impairs functioning (Bybee & Quiles, 1998; Ferguson et al., 2000) and cooperation between adults with AD(H)D and caregivers (Wadsworth & Harper, 2007). When a person offends others he or she may experience guilt feelings. He or she may be absolved of this guilt by devising an alternative narrative in which his or her behavior is construed as sound (Dimaggio, Salvatore, Azzara & Catania, 2003). The realization that the narrators have AD(H)D allowed them to find a "culprit" for their behavior and thus to build a new life-story in which they are not depicted as having poor character but rather as having unique traits that were not responded to properly in their past. The strategies of management of AD(H)D, described abundantly at the sites, demonstrated to the authors of the sites that life with AD(H)D may be fruitful. Accordingly, the release from self-guilt was a turning point in the attribution of most narrators and gave them the ability to mobilize for the construction of a new path in their lives.

Most narrators report an overall experience of constant failure, leading to stress and impaired self-esteem and amplifying their sense of helplessness. Antonovsky's salutogenic model (Antonovsky, 1979, 1987) may further elucidate the need of the narrators to create new narratives after their diagnosis of AD(H)D, as it offers an alternative to the classical medical (pathogenic) model. According to this model, people have a sense of coherence, a general tendency to view the world and their experiences as comprehensible, manageable and meaningful. By developing this sense of coherence, they can better cope with stressful situations. Therefore, according to this model, writing the narratives may have helped their authors to understand the reasons for their difficulties (comprehensibility). After the diagnosis, the narrators understood, as one may discern in the life stories and the many AD(H)D management strategies that the sites offer, that their world is manageable (manageability). Therefore, they believe in what they have done and their chances of success and, in turn, in the meaningfulness of their lives (meaning). Many narrators viewed AD(H)D not as a disorder or a shortcoming but as a state of difference

that also has advantages. It appears that, by developing a stronger sense of coherence, the narrators also developed a more positive self-perception.

### **The Virtual Community as a Resource for Information and Support for People with AD(H)D**

The internet served the narrators as an important medium for accessing information about AD(H)D (Noruzi, 2007). It also created a pool of personal narratives by adults with AD(H)D that have “happy endings.” As some of the narrators indicated, this type of information was helpful for comprehending and possibly even reframing their personal narratives. In addition, the internet was helpful for these adults as they could find tips for successful management of AD(H)D and referrals to support. Furthermore, the internet was a useful means of communication that enabled them to express their feelings and connect with others, thereby mitigating their sense of loneliness. Thus, many of them become members of virtual communities (cf. Fleischmann, 2004, 2005). In addition, since most sites allowed visitors to correspond with their authors, receiving correspondence may also enable the author to connect more actively with other people; this, in turn, may further reduce his or her loneliness. The internet seems to have become a path of empowerment for narrators and others. The narratives analyzed in this study reveal that some adults with AD(H)D took a further step in the process of managing their condition, by documenting and sharing their life experiences in order to educate, inspire and assist others who live with AD(H)D. Thus, the personal narratives provide a potent instrument for the empowerment of others.

Furthermore, the narrators have reported that the information that they acquired for web sites and online stories not only equipped them with management strategies, but also elucidated the real nature of their difficulties, thus enabling them to attain an absolution of sorts for their difficulties and failures. This absolution and the ability to overcome at least some of their emotional challenges were facilitated by the retelling, reconstructing and reframing of their life stories (Pennebaker & Seagal, 1999). They also gave the narrators a chance to view themselves as people with potential that they could fulfill—given proper support, environmental accommodations and treatment.

### **Conclusion and Implications for Practice**

The above examination of the life stories suggests a four-stage model for the development of the adults with AD(H)D who were not diagnosed in childhood. In the first stage, the undiagnosed children with AD(H)D need to cope with difficulties which their basis is obscure. This stage might last into their adulthood. The continuous

failures, which are the result of an inefficient self-management harm the self-confidence and self-esteem of these individuals with AD(H)D. Consequently, they might adopt a narrative in which they blame their "maladjusted" character for hindering their success. In the second stage, their inevitable guilt intensifies their inability to cope with the outcome of their AD(H)D. In the third stage the diagnosis of AD(H)D allows them to embrace a new narrative in which they are not portrayed as having a problematic character, but rather as having special needs and qualities that were previously ignored or misunderstood. These special needs require a new and adjusted attitude for managing their challenges. In the fourth stage the adults with AD(H)D who adopt this novel view and are released from their guilt might use their special talents and experience successes. Some of these individuals help others who are in the first, second or third stage, by posting their life stories in the Web sites.

This model, which is the outcome of the foregoing analysis of the discussed life stories, has several practical implications for living more successfully with AD(H)D in adulthood, as supported by the literature (e.g., Weiss et al., 2008). First and foremost, while learning about and accepting one's difference could be a challenging process for anyone, it is a prerequisite for taking responsibility for one's life and for developing a more positive self-image. Receiving professional confirmation of one's AD(H)D is also helpful for stopping the process of self-blaming or being blamed by others.

The positive changes in one's life may enhance self-esteem and may even create the perception of one's unique AD(H)D qualities as a gift.

Since the formulation and development of personal narratives appear to be a powerful tool for adults living with AD(H)D, professionals who counsel these individuals should guide and assist them in developing such narratives and positive perceptions about themselves. In the process of writing such personal narratives, adults who live with AD(H)D could be referred to personal stories of other adults with AD(H)D who managed to cope with their challenges (e.g., Rodis, Garrod & Boscardin, 2000). An exposure to people who successfully manage their AD(H)D or their writings could reaffirm individuals who struggle with AD(H)D that they should not be blamed for the challenges they face, or that AD(H)D is an all-encompassing aspect of their personality. In addition, such an exposure could illustrate additional ways in which the struggling individual could better manage his or her personal challenges.

Professionals in the fields of education, medicine and helping professions would benefit from adopting the perception of many narrators who do not perceive themselves as deviant or impaired. By adopting this approach,

the identification of AD(H)D among children and adults would be more efficient, as in the process of identification these professionals would seek not deviance from the norm but a characteristic which has some disadvantages as well as advantages. Earlier identification of individuals with AD(H)D would enable them to receive necessary support and guidance. Furthermore, interactions of individuals with AD(H)D with other individuals who successfully manage similar challenges, based on the salutogenic model, might help those who are still struggling to develop the perception that the challenges they face are manageable. These interactions may help them learn that with the proper support and self management they could lead a meaningful life, and that having AD(H)D might even give them a competitive edge in some situations.

### **Limitations of the Present Study**

The sites and personal stories surveyed for this study represent only a small, self-selected and non-representative sample of all adults who are living with AD(H)D and managing their life more efficaciously. In addition, it is important to note that the information about the formal evaluation and diagnosis of AD(H)D was reported by the narrators themselves and it was not possible to cross-refer it with medical documents. Moreover, to reduce the potential bias of life stories of adults who have self-identified themselves with AD(H)D, all the stories were examined by external judges, who are adults with AD(H)D, to verify their authenticity.

These stories point the way for other individuals to explore this approach for the acquisition of new understanding and meaning of themselves and the lengthy process of managing AD(H)D. These new insights may help these adults become more successful in gaining control over their lives and, in turn, may strengthen their sense of coherence and continue to lead them down the road to success and fulfillment.

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Table 1

*Names, URLs, and Number of Referrals to Online Personal Stories*

Name of site	Referrals (N) <sup>a</sup>	URL
Living with ADD	18	<a href="http://www.livingwithadd.com/index.shtml">http://www.livingwithadd.com/index.shtml</a>
AdultSeekingKnowledge <sup>b</sup>	10	<a href="http://www.healthyplace.com/Communities/Add/ask/">http://www.healthyplace.com/Communities/Add/ask/</a>
ADD/ DHD Resources <sup>b</sup>	10	<a href="http://user.cybrzn.com/~kenyonck/add/bc_home.html">http://user.cybrzn.com/~kenyonck/add/bc_home.html</a>
ADHD Among Adults <sup>b</sup>	3	<a href="http://www.tapuz.co.il/tapuzforum/main/links.asp?id=201&amp;catId=6061">http://www.tapuz.co.il/tapuzforum/main/links.asp?id=201&amp;catId=6061</a>
Attention Deficit Disorders resources <sup>b</sup>	2	<a href="http://www.addresources.org/article_adhd_addvice_rob.php">http://www.addresources.org/article_adhd_addvice_rob.php</a>
adders.org <sup>b</sup>	1	<a href="http://www.adders.org/">http://www.adders.org/</a>
Jeff's Story Getting Started	1	<a href="http://www.addcoach4u.com/gettingstartedjeff.html">http://www.addcoach4u.com/gettingstartedjeff.html</a>
Addconsults ADDvice from a certified NON-Expert <sup>b</sup>	1	<a href="http://www.addconsults.com/articles/full.php3?id=1299">http://www.addconsults.com/articles/full.php3?id=1299</a>
Welcome to my ADDventure	1	<a href="http://www.geocities.com/Wellesley/2495/ab8.html">http://www.geocities.com/Wellesley/2495/ab8.html</a>
GNIF Brain Blogger 2006	1	<a href="http://brainblogger.com/2006/12/15/brian-thompsons-struggle-with-adhd/">http://brainblogger.com/2006/12/15/brian-thompsons-struggle-with-adhd/</a>
Beth Dodge's Little Corner of Cyberspace	1	<a href="http://www.pcnet.com/~dodge/whoami.html">http://www.pcnet.com/~dodge/whoami.html</a>
Coaching Key to ADD	1	<a href="http://www.coachingkeytoadd.com/sjk.html">http://www.coachingkeytoadd.com/sjk.html</a>
My take on ADHD <sup>b</sup>	1	<a href="http://members.tripod.com/LadyBats/story.html">http://members.tripod.com/LadyBats/story.html</a>
The road upwards—for personal empowerment <sup>b</sup>	1	<a href="http://www.haderech.co.il/hbh14.html">http://www.haderech.co.il/hbh14.html</a>
ADHD around the clock <sup>b</sup>	1	<a href="http://www.tapuz.co.il/blog/viewEntry.asp?EntryId=9917">http://www.tapuz.co.il/blog/viewEntry.asp?EntryId=9917</a>

<sup>a</sup> Number of referrals means the number of referrals to personal stories included in the present study.

<sup>b</sup> This site included several life stories.