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# Exploring Social Dimensions of Personal Information Management with Adults with AD/HD

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**Abstract**

Studies in personal information management (PIM) have primarily examined PIM behavior as an individual activity. In this paper, we discuss social dimensions of PIM, more specifically, socially derived PIM activities. The biggest challenge adults with Attention Deficit / Hyperactivity Disorder (AD/HD) face is managing information and tasks. Accordingly, online forums for sharing PIM strategies is a wide spread practice among many individuals with AD/HD. Those that are not engaged in online forums are also found to often rely on social resources in forming PIM strategies. We discuss social dimensions of PIM emerged from our 16 interviews with adults with AD/HD and coaches of AD/HD. Our findings provide a good starting point towards understanding the social, adaptive and evolutionary nature of PIM practices, which would later inform design implications.

**Keywords**

Personal information management, ADHD, ADD, AD/HD, Social learning, Task management

**ACM Classification Keywords**

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

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## General Terms

Design, Theory

## Introduction

Studies in personal information management (PIM) have examined how people organize and manage information. During this inquiry, PIM strategies have often been described as an individual activity, more so because of the personal nature of PIM. Social dimensions of how people come to form PIM strategies have been under-explored.

For individuals with Attention Deficit / Hyperactivity Disorder (AD/HD), managing information is a central problem that determines the success and failure of their everyday lives. Accordingly, patients with AD/HD consciously make efforts to find good information management strategies to help them get their tasks done, meet deadlines, and reduce clutter at home (or on computers). As a result, a number of online forums are formed in which individuals with AD/HD can share PIM strategies. As our interview data will show, even those individuals with AD/HD that do not use online forums often relied on social resources in coming to their PIM strategies as well.

In PIM literature, the need to explore the adaptive nature of PIM has been noted [1, 2]. We discuss PIM as a socially adapted activity based on our interviews with adults with AD/HD. We discuss how our participants came to form their PIM strategies, specifically on the issues of getting help from friends, parents, and experts and tailoring socially gathered information management strategies through iterative and evolutionary processes. This study of individuals with AD/HD then, we hope, illuminates the social practices

of PIM tools as well as how their life experiences interweave with their PIM strategies.

## What is AD/HD, and why AD/HD?

Symptoms of AD/HD are often known as having problems with procrastination, disorganization, and distraction. In the field of mental health, the currently accepted theory to explain how AD/HD occurs is due to the lack of control over executive functioning (EF) [3]. EF, placed at the frontal lobe of the brain, controls starting, stopping, inhibiting, and switching tasks. Accordingly, this explains the classic AD/HD symptoms: procrastination (starting), hyperactivity (stopping), distraction (inhibiting), and switching between complex tasks (switching). Not all individuals with AD/HD have hyperactivity. However, DSM-IV [4] defined AD/HD as including both hyperactive and non-hyperactive types. Thus in our paper we use AD/HD for indicating both Attention-Deficit Disorder (ADD) and ADHD.

For many patients with AD/HD, medication is not a sufficient solution for the symptoms [5]. Overcoming problems in having AD/HD depends greatly on how AD/HD patients manage information and tasks. Accordingly, finding the right information and task management strategies for them plays a central part in determining the success and failure of their everyday lives [5]. Accordingly, there is a group of professional organizers for which AD/HD patients are major part of their client base<sup>1</sup> and professional coaches whose major goal is to help their clients in structuring information, tasks, and time [6]. Also, a number of online forums

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<sup>1</sup> See [www.napo.net](http://www.napo.net) (National Association of Professional Organizers)

have been formed to allow sharing of PIM strategies among individuals with AD/HD.

AD/HD is diagnosed by counting the number of AD/HD related symptoms that persist for a certain period of time. This means that any individuals can still have some symptoms of AD/HD but are not severe enough to be diagnosed with AD/HD. Accordingly, many adults with AD/HD are diagnosed later in their lives when their working or studying environment changes to require more information intensive tasks. This suggests that individuals with AD/HD have a range of issues that can be very similar in type and extent to the general people: having the inability to deal with information overload and distraction in finishing tasks, rather than being considered as an eccentric group of people that are analytically irrelevant to the general population. Also because finding the right PIM strategies is such a conscious process for adults with AD/HD, individuals with AD/HD were an informative group that could help us uncover deeper understandings about how people might come to their PIM strategies.

### **Related Literature**

For more than a decade, many studies in PIM have identified different ways in which people keep, find, and manage information. For example, we learned about filers and pilers, prioritizers and archivers, frequent filers and spring cleaners, creation-time filers, end-of-session filers, and sporadic filers [7]. We also learned that people often use more than one method depending on the context and the information environment [8-10].

To date, PIM has been studied with an assumption that PIM is an individual problem. In other words, we know little about how social processes are engaged in

forming one's PIM practices. The closest studies are how groups manage information [11], PIM in socially shared spaces [12], and privacy, security, and trust issues of PIM in public spaces [13]. But none of these studies examined social dimensions in individuals' PIM strategies.

While PIM studies have investigated how people organize information, for individuals with AD/HD, there are specific PIM strategies suggested by the experts. Examples include "erasing the evidence" [14] (crossing completed tasks out), "subtract before you add" [15] (finish before adding an item), and "breaking things into smaller pieces" [16]. As well, organization software specifically for AD/HD has been developed [17]. However, how users with AD/HD appropriated these tools and strategies to fulfill their individual needs has been under-explored.

### **Method**

We interviewed a total of 13 adults with AD/HD and 3 coaches of AD/HD. We recruited adults through email who had attended or graduated college-level institutions and had been diagnosed with AD/HD. We also recruited from an online AD/HD forum by sending private messages to those who posted under the adult higher education section. We specifically chose this population within adults with AD/HD because we wanted to interview those who had dealt with some form of information and task overload either from taking classes, research, or from work. We also chose adults over children because adults have more complex issues than children in life in general such as marriage, jobs, and higher education that add severity to the challenge [5].

Our interviews were semi-structured ranging from 40 to 90 minutes. The questions were centered around challenges in having AD/HD and how the interviewees tried to overcome the challenges through finding the right PIM strategies. All of the interviews were transcribed and analyzed using standard qualitative methods with open coding analysis [18]. Because of the nature of our methods as well as the fact that this is an ongoing project, our work should be considered exploratory and generative.

### Findings

The participants varied with great degree in terms of the childhood experiences, the attitude towards medications, the time of the diagnosis, co-morbidity issues, and so on. These differences impacted the ways in which they approached the problems of AD/HD and their strategies in overcoming challenges. We attempted engage on a theoretical understanding of how information management takes into account situational factors – such as educational, family, and job environments, and specifically social dimensions in coming to PIM strategies, and how this informs PIM practices at large and the design of PIM tools. Accordingly, we begin by first explaining the context of our participants' daily lives as a person with AD/HD.

#### *Challenges as an adult with ADHD*

When asked what their greatest challenges were as a person with ADHD, mundane tasks such as planning and remembering things to do, prioritizing tasks, organizing things, managing time, or just starting tasks were challenging for many participants in general. P8, who is a doctoral student in Education talked about his inability to stop procrastinating:

Procrastination is something that a lot of people deal with. But for me particular, even if it's an important task that needs to be completed, it almost takes an act of God to kind of get over the inertia and start work on that... (P8)

These challenges were heightened when the participants were put into more information intensive work or study environments. P6 talked about the recent change in her job, which required too much paperwork and less social interaction that heightened her challenges with ADHD. P1 had not known he had AD/HD until he entered graduate school. The new change in studying environment that lacked structure overwhelmed him, and became diagnosed with AD/HD in his first semester of graduate school.

Accordingly, P1 was constantly looking for ways to put structure into his life by exploring different information tools and organization schemes for school-related documents. His exploration, however, often involved social process: he explicitly asked for opinions about alternative smart phones over group email, observed what his friends did in organizing emails, searched for expert tips online, and received help from a coach.

#### *Social process: Adapting strategies from other people*

One way students with ADHD can formally approach the challenge is through coaches. According to P4, coaches of ADHD, unlike professional organizers, are supposed to help their clients come up with a system that would be easy and natural for their clients instead of teaching supposedly optimal organization schemes. P4 gave an example of a former client that needed help in organizing his day:

...then I mentioned some people use note cards, some people use post-its and made some suggestions and

then he said “yeah I like the idea of the post-it” (P4)

Notice that P4 used the words, “some people use”, when suggesting solutions. P4 gave alternative suggestions derived from “some people” for how he (the client) might organize his day until he found something that he thought might work for him. They met again after a while, and she found that he was no longer using post-its. Rather, he started using a piece of paper in between his clamshell-like cell phone so that he can be reminded every time he opens up the cell phone. As many others did, P4’s client started out his exploration with strategies that were used by other people, and adapted them to his own.

Our participants did not always receive help from experts, but also from people that were around them. P15 received cooperative support from her parents, psychologist, and teachers in her high school that gave her an “extra push” through AD/HD specific classes and tips. While P15 grew up in a supportive environment, often times our participants did not have such a supportive environment in which active social support was available. Rather, many turned to friends, online forums, and books for social support. For example, for P8, most of his strategies were modifications of other people’s strategies:

It’s all kind of modifications of what people have suggested before. For example, I have a colleague who had what she calls a journal ... It was motivating for me. I kind of translated that into something that would work for me. (P8)

P10 had a similar experience. For P10, the important part of discovering what worked was her exposure to what others do, and adapting bits and pieces of what she saw from them:

The ones that work are probably combination of things that other people have said. Like breaking things down to little things and crossing it out is coming from other people. Yeah I guess I’m getting a lot of things from other people. (P10)

In fact, P12 showed a blue dot on his hand to remind about the interview for our study. When asked where he got the idea from, he said people mostly write down things on their hands and has even seen a professor write down on his palm, but for him he just needed a dot to remind himself. Again, P12 developed what he had observed what people did as he went on about his everyday life into one of his PIM strategies.

While these examples portrayed conscious decisions in adapting socially derived PIM practices, we also observed that PIM strategies could be socially inherited from one’s family. P9’s use of a white board on her fridge as a reminder for appointments and to-do lists for the day was adopted from her parents when they used to live together. Now that her parents left the house because one of her parents passed away and the other remarried to someone else, the family’s PIM practice became hers. And for P15, when she went on to college, using a paper planner was a natural thing for her because her mother used it ever since she was little to check schedules and task lists for all of her family members who all have ADHD.

### *Summary*

When asked where they got the idea to try different things, most of our participants could not point out exactly where the ideas came from. They were adapted from bits and pieces of everywhere – what they have heard or observed from others, what they had experienced, or what they read or had been taught by experts. They found their information management

strategies of their own through iteratively trying things out that they learned from the social environment. However, more work will be required to understand this bricolage and adaptation.

### Discussion and Future Work

Although information and task management strategies may seem entirely individual, the information and task management practices of our participants were not solely individual activities. It was a mix and match of socially gathered strategies. Coaches, family members, friends, and work colleagues helped our participants to come up with strategies by suggesting alternatives or sharing their own strategies. At times PIM strategies would unconsciously be adopted from one person to another. Also, our participants were at times consciously looking out for what others had done.

Currently, considering social dimensions in designing PIM tools are limited to social sharing of content. Our findings suggest the need to expand our views towards supporting social sharing of PIM strategies in PIM tools.

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