**NSCI 483: Interview Plan**

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March 4, 2024

**Disorder:** Attention Deficit Hyperactivity Disorder (ADHD)

**Interviewee:** GL is a 22-year-old graduate student at a university in Ontario. She suspected that she had ADHD after experiencing difficulties in her undergraduate coursework and was diagnosed in 2022. GL manages her ADHD independently.

**Contact and Consent:** I will reach out to GL via email to schedule a 30-min Zoom call. Included in the email will be the letter of information and consent form. I will let GL know about confidentiality and give GL opportunities to ask questions over email and over Zoom.

**Confidentiality:** I will inform GL of what personal data will be included on the assignment (ex. age, occupation). I will collect data on a document only identifying GL by a pseudonym of her choice (GG). The final assignment will be written with this pseudonym.

**Proposed Questions:**

1. Welcome! Please introduce yourself with your name, occupation, and brief history with ADHD.
   1. *Diagnosed around 2 years ago. Had it all my life, but prior to then, I was high functioning until I went to university. First year is when symptoms started to influence my academic life. Second year, when more content being introduced (especially with COVID-10), symptoms became unmanageable. Halfway through 3rd year, got diagnosed*.
2. Could you describe the process from which you suspected you had ADHD, consulted with a physician, and received a diagnosis?
   1. *Never suspected I had ADHD in school age, because high functioning, had good grades, no problems in friendships/relationships.*
   2. *In second year, one of my closer friends was diagnosed. As I heard him talk, I related to symptoms. Of course one anecdote isn’t enough, but I heard others’ experiences and related more. Started suspecting I might have it. That’s why I started seeking a diagnosis + a physician who could answer questions I had. Unfruitful during the pandemic, when all physicians were heavily burdened. Led me to 3rd year, when I was told by a few friends that university doctors can see you a lot faster. Psychiatrist waitlist shortened from ½ a year to 2 months. Got started on the process (1 month long) to get a diagnosis from family physician.*
   3. You were diagnosed with ADHD in adulthood. How do you think that has affected the process, compared to if you could be diagnosed in childhood?
      1. *Had a very big impact. One reason I wasn’t diagnosed as a kid is because I was high-functioning, it made it harder for people to believe I had ADHD. A lot of symptoms were masked because I did well in school and seemed fine. That lengthened the process. The type of ADHD I have affected the process: I’m more ‘attention-deficit’ than ‘hyperactive’ (which I think more females have), and I don’t fit the stereotype of the kid bouncing off the walls.*
   4. Follow-up questions: what tools were used for diagnosis?
      1. *Had to be screened for other conditions (ex. depression, anxiety). When I was seeing the doctor, he gave me a questionnaire. Very extensive talk with me to ask about symptoms, my background. My doctor was very well-versed in kids with ADHD, so he was comfortable prescribing me medication (but this is not usual). After, when I saw the psychiatrist, it was a more extensive look in my background (asked for report cards, teacher’s comments, grades, statement from a close friend/parents + fill out checklist). 1-2 h long appointment where we talked at length about symptoms. Wanted to rule out psychiatric challenges.*
      2. What specific symptoms did you report? *Lack of attention, lack of focus, lack of motivation. Always really hard to study for exams – if the deadline is not a couple hours/days away, it’s not real, and only stress is able to motivate me to get things done. Very hard to find motivation to do things unless stressed, or random niche interest. All of a sudden you feel super motivated, you feel hyperfixated. All or nothing response [looks like she is having a flashback at this]. Something I prominently remember is that when people are talking to me, it’s usually easy to focus on the other person is saying, esp when they are directly addressing you. For me, I get distracted by a million other things (ex. hopping onto thought to thought to thought). Led to embarrassing things (ex. getting caught not paying attention to someone when they are directly addressing you).*
   5. Did you experience any significant challenges? How do you believe that ADHD diagnosis can be improved?
      1. *Challenges: 1. high-functioning, me being more attention-deficit instead of hyperactive. Stereotypes of ADHD are large barriers to getting a diagnosis. 2. COVID-19 healthcare system was backlogged by more urgent cases. Mental health is not prioritized as high as someone who has a heart attack… which is fair enough, but at the same time, you get pushed back and back and back… Even seeing a doctor was very hard.*
      2. *I think improvements in diagnosis come from getting rid of stereotypes associated with ADHD + understanding the fact that just because you’re high-functioning for a big period of your life doesn’t mean you don’t have that disorder. Taking people more seriously. Lots of the barriers I faced were COVID-related, so it’s hard to suggest an improvement for ADHD specifically.*
3. How do you treat your ADHD?

*Cocaine equivalent. I’m kidding. But not really. I’m currently on medication to manage symptoms such as lack of motivation. At a point in time when I was still seeing a doctor, I saw an academic counsellor, and I did not find it super helpful because she was suggesting study strategies + trial/error to find one that sticks. I already tried a lot of those things, so it wasn’t super helpful.*

* 1. What treatments are available, and how did you decide that your treatment was best for you? Did you experience barriers to accessing treatment?

*Treatments available: medication, academic counsellor … apart from that, I’m not sure what else you can have. Barriers: the moment I was able to book an appointment with the doctor, everything was smooth. The main barrier was lack of access to physicians who specialize in ADHD. In terms of treatments, my side effects are mostly manageable, but some people experience severe side effects that they cannot take it. Certain meds cannot be combined with others, which excludes some. I’m lucky that my university insurance covers my meds, but a monthly prescription (esp for a med you take every day), racks up quickly. There’s a lot of stigma. Another concern I’ve had with stimulants is effects on cardiovascular health… but ehhh… we’ll deal with the consequences later.*

* 1. Is your treatment effective? What side effects do you experience?

*For me, the treatment has been very effective. I’ve seen a big improvement in academic and social life. I’m a lot better at studying – I’m finally able to focus on actually learning. Getting everyday things done is manageable, even booking an appointment or following through with plans. Side effects: hard to sleep (have to be careful when you take it), appetite suppressing- if you’re not eating at all it’s not good for health, and you feel nauseous about food even if you do feel hunger. But I think I have adapted to this side effect. My medication is actively prescribed as an appetite suppressant. Increased heart rate + blood pressure.*

* 1. Beyond medical treatments, what else has helped you cope with your ADHD? (i.e., the use of therapy, the use of specific cognitive strategies).

*I don’t know if I have a strategy or specific therapies. I was lucky enough that being on medication was good enough. One interesting thing I had to learn was to not burn myself out. Once I got on the meds, it felt like I could control my studying, and I went ham with it. I threw off my work-life balance, leading to ridiculous burn out. Learning from that, I need to find a better work-life balance.*

Follow up: do you think you want to? *Not for now, things are manageable.*

1. Having gone through undergraduate studies and now completing a Master’s degree, you must manage a demanding academic workload.
   1. How would you compare your experience in school pre- vs. post-diagnosis? What aspects have become easier, and are there any aspects that have been challenging?

*Pre-diagnosis: struggled a lot with schoolwork, getting 70s on midterms, got 37% on one quiz. Couldn’t bring myself to study anymore – if a midterm was in a couple hours, still couldn’t study. Post-diagnosis, with help of meds: was able to pick and choose whether or not I wanted to study. Could do things even when I didn’t feel motivated. Another big change is that I have a better understanding of how I personally function. I know that I can’t sit in a lecture room for 1-3 h just focusing on the lecturer, so what I do instead is take a recording or review notes before I go in, go back to lecture and consolidating. I cannot understand people and listen to things for a short period of time, even with meds.*

* 1. Some people with ADHD may require accommodations: for example, receiving extra time to complete an exam. Have you used accommodations before? Do you find them helpful? If not, what types of accommodations (if any) do you believe would be beneficial to help students with ADHD in the future?

*Accommodations received for extra time + writing in a room separate from most students in the class. In my classes with 600+ people, writing an exam is extremely distracting. Extra time helps a lot too + extensions on assignments. Meds help manage symptoms, but they don’t cure. My marks have increased compared to previous years. Current accommodations are pretty good, but as we move to complete more tasks online, personally I find the use of computers to write an exam to be WAY more distracting than a physical exam. So having paper exams as an option might help students.*

* 1. MCAT accommodations? *F\*\*\* the MCAT! Despite having two diagnoses from two physicians, my diagnosis was not valid in their eyes. They require you to take a $5000 psychiatric evaluation that is so ridiculously niche and specialized. But why do I have to pay for a diagnosis? That is such a huge barrier to anyone with a psychological disorder. I don’t have $5000 to be diagnosed again, and I think it’s so unfair. There are cases where kids ‘cheat’ their way into accommodations, but I think there are many kids who don’t have the money for it. There are kids who have done the test, but their application to get accommodations was still rejected, and AAMC will not tell you why they reject your request for accommodations. It becomes ‘pay-to-win’. Even when I wrote the MCAT, I didn’t have accommodations, I was writing in a room with many students, hearing clicking of many students was very frustrating. For the first section, I could not read any of the passages. I don’t think getting a separate room should be such a huge barrier.*
  2. Kids ‘cheat’ to get accommodations? *The AAMC said that they’re worried that kids might be ‘faking’ diagnoses to get extra time, special advantages. I think it’s something that people will do, people will always find loopholes, but I also feel like there’s a huge population of people who are in genuine need of accommodations. Big barrier to people who need accommodations the most.*

1. Learning and memory disorders can be accompanied by a sense of stigma. Have you experienced stigma due to your ADHD?

*Yes. Oh my god. I would say that people don’t understand what ADHD is – they think it’s just hyperactivity. But attention deficit is part of the name. Some people like to casually throw in ‘oh my god, I’m so ADHD’ as a fun side comment to describe someone more energetic than normal, which enforces the stigma. I remember doing an assignment with two people, and the third person kept interjecting with comments, and I asked them to let me think, my ADHD is going crazy. Then they said ‘oh my gosh, why does everyone keep saying they have ADHD these days?’ That irked me – I was just asking them to respect the study space, and requesting them to respect my needs. Then he went ‘ah, that was a joke’. When I first started taking my meds, I got a lot of heat from my parents. When I was moody or being irritable, my parents would give a negative comment: ‘oh it’s the meds again’. But if anything, my meds should make me happier? It’s a lack of understanding of the disorder/meds that lead to offhand comments that bother me.*

* 1. Have you experienced any difficulties with family or friends? Alternatively, have you felt supported by your family or friends?

*At first, my parents were against the idea that I have ADHD since high-functioning. At the end of the day, my mom said ‘I don’t think you have ADHD, but if you need to, go get checked out by a doctor’. When I started taking my meds, I got a bit of heat, but now I feel supported. My friends don’t care if I have it, which is nice. Generally, I feel very supported.*

* 1. Some people argue that we live in an ‘ADHD’ society, and that we are attaching a medical diagnosis to a condition that is ‘artificially’ produced (ex. with social media; with overstimulating work/school environment; with sedentary lifestyles, in which we are no longer using energy as much as we used to). What do you think about this?

*Something that was always in the back of my mind is ‘did I make my diagnosis up?’ Especially during COVID year, I wondered whether it was just burn out. But at the end of the day, I think environment is important in the development of any disease… epigenetics… you can say it’s artificially produced, but if this is the environment, then this is the environment. I don’t think it makes the diagnosis any less valid. It’s like calling a patient with cancer invalid because they lived near a nuclear reactor.*

Follow-up: the question becomes whether to move the patient away from the nuclear reactor or to medicate. *Why not treat both things?*

1. At a societal level, what changes do you hope to see to make people with ADHD feel more welcomed and included? What resources, research, or interventions would be valuable to support this goal?

*I think there needs to be a much better understanding of ADHD. There are so many stereotypes, not enough understanding of all aspects of ADHD. This would make quality of life much better. Small things like understanding when I request people to slow down and let me follow. In terms of resources, more physicians with an understanding of ADHD, but I know that’s a hard ask, but it would make things faster. Research – please give me better meds that won’t make my cardiovascular system die. Interventions – not sure.*

* 1. Follow-up: what do you think about eye saccade research? *VALID! Tell me why counting is so hard! The other day, I was working with organoids in the cell culture room. These are 3d gels – it is IMPOSSIBLE to count! I had to shift the microscope around to get to all parts of the gel! I lost track so many times. Took me a horrifically long time.*

1. Is there any other insight or information you would like to provide?

*I think ADHD sucks in that it’s not really great for our society, but at the same time I think ADHD has perks. There’s a ‘golden spot’ of stress that I hit, where everything becomes so clear, and I can do things really really fast when I’m off the meds. It’s really cool. Off the meds my head is loud (like trains railing one after another), but on the meds it’s an echo chamber. The cool thing about many trains is that I can jump from them really quickly, I can solve a puzzle and immediately know which path to follow, but I can’t explain it to another person. On the meds, I’m a little slow.*

Follow-up: people say that ADHD might have been an evolutionary adaptation in the right environment (ex. monitoring the environment for salient stimuli). *I agree with that. For example, my mom said I had great memory because I pick up on the smallest details. But I actually have poor memory. With ADHD it’s hard to prioritize things - everything is a priority, so you notice even insignificant details.*