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Working with uniqueness: optimizing vocational strengths for people with tourette syndrome and co-morbidities

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Abstract

This paper shares discoveries from a grounded theory inspired study of "optimizing vocational strengths" and the unique attributes of Tourette Syndrome and co-morbidities, including Obsessive-Compulsive Disorder and Attention Deficit Hyperactivity Disorder (or TS/TS+), in the workplace. This one year study featured 16 participants with various levels of workplace functioning and health status and was set in an art college. Data gathering methods included individual/group interviews alongside observations of, and products from, studio art workshops in drawing, sculpture, performance, and creative writing. Data collected in this way elicited a breadth and depth of representation and harnessed the uniqueness and imagination of participants pivotal to recovery and supporting vocational optimization. The process of "optimizing vocational strengths" is revealed both visually and textually in this paper and is instructive for educational and vocational supports for people with TS/TS+.

1. Introduction

An innovative investigation into the process of optimizing vocational strengths people with TS/TS+ was established between nursing/medical researchers and art educators in Western Canada. Our research used a qualitative research design based in the grounded theory (GT) tradition (Glaser, 1992, 2003). Art workshops were a means of data generation and products from the artistic workshops were pivotal to the group interviews and ultimately illustrative of findings of a process of working with the uniqueness of TS/TS+ to optimize vocational strengths.

2. Background

Tourette Syndrome (TS) is a neurological condition characterized by motor and phonic tics. Robertson (2006) notes an incidence of TS as high as 1 in 100. Freeman's (2000) study of 3,500 individuals with TS in 22 countries found that 88% had co-morbidities, a condition known as TS+. The most frequently observed co-morbid conditions are Obsessive-Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), depression, anxiety, and Sensory Integration Dysfunction (SID) (Freeman, 2000), collectively known as TS+. Challenges of self-concept, relationships, mood, anxiety and behaviors are common in the condition (Stefl, 1984) and, given the range

of co-morbid conditions and social symptoms, difficulties navigating career are not surprising for those experiencing TS/TS+.

There is little research about what happens along the employment continuum for adults with learning disabilities (Gerber, Price, Mulligan & Shessel, 2004), and a dearth of research specifically navigating careers with TS/TS+. Shady (1995) found that, for most participants, TS/TS+ greatly influenced job choice, with a lesser number reporting having been dismissed or denied employment because of TS/TS+. While there are studies of adult ADHD and employment that address impairments in performance from a quantitative perspective (Biederman, Mick, Fried, Aleardi, Potter & Herzig, 2005) much less is known about the *process* of career navigation for individuals with TS/TS+ in adulthood. The dearth of career theorizing for this demographic is visible more practically in the field. To address this overlooked aspect of research and practice, we posed the initial question: *How do people with TS/TS+ navigate careers?* Expanding from Shady's (1995) empirical findings, our research focused on qualitative data gathering with the deployment of art workshops to address the questions at hand.

3. Research Method: Grounded Theory and the Arts

Our research question focused on the process of career navigation for those experiencing TS/TS+, an emerging field of study in the area of disabilities accommodations (Gerber, Price, Mulligan & Shessel, 2004) and mental health intervention (Krupa, 2007). Grounded Theory (Glaser & Strauss, 1967, Glaser, 2003) was appropriate to assessing the social process of career navigation at this early phase of knowledge development in the field. The method has been utilized across disciplines as wide as nursing (Schreiber & Stern, 2001), business (Goulding, 2002) and the arts (Marshall, 1997).

Ethical approval for the study was obtained and a team of researchers and advisors with expertise in substantive areas served as formal advisors to the study. The criteria for participant inclusion in this study were indicators of having TS/TS+, living in the community, concerned with vocational struggles and willing to engage with the group interview activities of drawing, sculpture, performance and creative writing. Informed consent was received prior to commencing data collection.

Participants were recruited through posters in libraries, health centres, specialist clinics, and academic institutions, as well as via networking, newsletters, word-of-mouth and email canvassing from a national support group. 30 people responded to our call for participants, of which 16 (ranging in age from 19 to 78 years) met the study criteria. One participant had a formal TS diagnosis, eleven had formal diagnoses of TS+, three had suspected diagnoses of TS+, and one had a formal diagnosis of conditions often co-morbid with TS, i.e. chronic ADHD, depression, anxiety. 7 participants were females and 9 were males.

3.1 Data Gathering and Analytic techniques: Four phases of Activity

In both GT and artistic projects there are a number of things happening simultaneously. The 8 months of data gathering did not occur in a linear fashion or from a specific hypothesis. Rather, like an artistic project, pieces of the whole picture were put together, moved around, compared and reshaped to find their final relationship in terms of a composition. Rather than beginning by researching the literature & developing a hypothesis, data collection formed our first steps in the study.

An incremental approach to interviewing participants occurred in four phases, including: 1) Pre-screening, screening interview and questionnaires; 2) Art workshop/interviews 3) In-depth validation interviews, and: 4) Feedback questionnaire. In the first phase, 30 potential participants were pre-screened by phone interviews. Lead investigators then conducted 20 screening interviews, held in an office setting. Following screening, 16 people were included in study. Initial screening interview data was coded for inclusion into later data collected. The codes were

grouped into symptoms, psychological factors, vocational considerations and environments. These codes and concepts were brought forward to aid in the structure and terms of the second phase of mentored art workshops.

In phase 2 of the study, investigators offered group art workshop interviews exclusively established for this study and held at an art college in a mid-sized Canadian city. Art workshop interviews included discussion of work in mediums such as: drawing, sculpture, performance and creative writing. Fourteen of the 16 individuals identified in phase 1 consented to participation in the workshops. Topics of career navigation were explored from a wide range of possibilities. For instance, a drawing project asked participants: 'if your symptoms could draw, what would they look like?' seen in Figure 1.

Figure 1: Participant Artwork "Tornado Management"

During the 10 weeks of weekly art workshops, investigators gathered data by way of direct observations, field notes, and group interviews and review of art products with participants at the workshops. The research team was also involved in the analysis of the findings throughout this phase, which shaped the terms used and structure of ongoing workshops. Art workshops in phase 2 included sculpture and performance art. A clay self-portrait project made in a small group setting enabled participants to share feelings, build trust and make connections between their experiences. Diana's sculpture of a dragon-like figure opened the group conversation to all of their symptoms, relating to both art and career. Diana reflected on her sculpture:

> *It's that whole snoring dragon thing. The dragon is me. The dragon is who I am; it is the craziness; it is the fact that I have been nuts my whole life; it's all the art; it's all the anger; it is everything that makes me awesome…and horrible. Because I had to fit in, I had to squish it down and so he sleeps, you know?*

Another participant used poetry to represent the way in which medications shaped her work life. Drawing workshops encouraged participants to complete a graphed matrix, in which they compiled text entries to select preferred media and topics. One participant, while making decisions about the use of colour or black and while another participant, Allison, surmised that *"to me a job is black and white: it's just about money to live. Careers should be more colourful."*

3.2 Analysis: Uncovering the Process of Optimizing Vocational Strengths

Data was analyzed using the GT method of memo writing to develop relationships between the categories that we found in phase 1 interviews and workshop artworks. As concepts were uncovered from the workshop data, new categories were formed which became the basis for in-depth interviews, phase 3 of the study. These interviews were audio recorded and transcribed, all those involved in the workshops, fourteen of the original sixteen participants, consented to this phase of the study.

Through the emergent themes discovered in the 3 phases of data collection, researchers synthesized the processes of career navigation through the GT method of memo writing, arriving at seven categories: *Alienation, Trial and*

Error, Conflict surrounding Autonomy and Authority, Managing Symptoms, Wishing, Managing People and *Finding an Audience*.

Categories and patterns derived from the three phases of data were "checked" in this way; fit and relevance were confirmed. The process determined there were no patterns in occupational choice, and, like Shady's (1995) study, participants reported a wide range of vocations. Similarly, training and qualifications did not feature as important aspects in the process of optimal navigation of career. Rather, the seven trends presented themselves as an interwoven whole in a process of "Optimizing Vocational Strengths".

4. Findings: A Process of Optimizing Vocational Strengths

As stated previously, the theory of "Optimizing Vocational Strengths" for people with TS/TS+, involves seven categories. These are described here, including visual and textual explanations of the emergent theory.

4.1 Alienation and Feeling an Outsider

Vocational success was determined not just by occupation or career, but how comfortable participants felt within a job or vocation. Even when participants were successful in getting the job they wanted, or the career they trained for, they were not necessarily satisfied, often feeling an "outsider" because of their diagnoses, which they often kept secret.

All the participants in the study felt "different" from other people in their workplaces. This self-assessment was often due to tics, intrusive thoughts, obsessions, compulsions, or being prone to impulsive actions. These traits produced feelings of difference or alienation, particularly if they considered themselves socially awkward. For some participants this sense of alienation was intrinsic, such as Joyce who told us: "*When I am in the workplace I feel intrinsically – like within – different from the others because I am not as composed.*" For other participants, like Cheryl, alienation was an experience of how others treated them and was illustrated in her statement: "*It seems like most people aren't willing to accept those of us who appear different, but do they really understand?*" Overall, a sense of being wound up by oneself or another, was a graphic image of this process of alienation and being inside or outside of the workplace norms (Figure 2).

Figure 2: Participant Artwork "Wind Up"

4.2 Trial and Error in Jobs and Career Choice

In contemporary employment patterns it is common for many people to experiment with change in employment. Individuals with mental health conditions, however, may experience more job turnover than they would like. A 1995

survey of Canadians with TS/TS+ indicated that 20% had been dismissed from a job because of their condition and 17% said they had been denied a job due to their TS/TS+ (Shady, 1995). Our findings affirm the relevancy of the turnover and "trial and error" within the process of career optimization. This aspect was found to apply to a variety of contexts. One participant with ADHD, OCD and suspected TS experienced external barriers and considerable personal drive towards trial and error, choosing to shift jobs regularly: all impacting career stability. This participant reported she was refused job assignments after she told her temp agency she had ADHD. Mona's career navigation took her across a wide career canvas; she explained of her trial and error process:

> *I am changing constantly; I am always picking up a new career, trying it for two years,and walking away. And I am not afraid to do the big thing; it's not like, "Should I work at the donut store or should I work at the she store?". It's not that: it is huge leaps. Art to construction; construction to farmer's market; to post office . I don't necessarily need a segue.*

Participants tried out jobs or environments in order to find preferences and strengths. Some preferred working with people, while others liked to work with children or animals, and some preferred indoor and others outdoor work environments. Scratching one's head in vexation, asking "*why am I here*?", as in the sculpture produced by one participant illustrated the "trial and error" process our participants experienced (Figure 3).
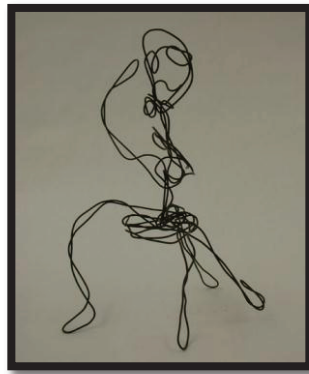

Figure 3: Participant Artwork "Why Am I Here?"

4.3 *Existing in Conflict: Autonomy and Authority*

A key to optimizing workplace and career achievement, in our study, was recognizing internal causes and triggers of conflict in one's self, and being able to predict external triggers brought on by contact with others and the environment. Conflict was commonplace for people with TS and its related conditions, often as a result of dealing with authority figures. Reasons for conflict related to both symptoms and environment.

Symptoms leading to conflict were experienced by individuals with TS/TS+ and included anger or difficulty maintaining an even temper, anxiety, depression, distractibility, frustration, or adverse effects of tics or addictions. There was also a connection between alienation (described previously) and workplace conflict. Furthermore, autonomy and attitudes towards authority were a link between symptom-related and sensory-related conflict. All participants preferred a high degree of autonomy or self-determination in their work routines. Participants recorded a high incidence of thinking and/or feeling that they knew the best way to do a particular task.

> *I don't like people to tell me how to get it done. I have my own process and I need my own process. And it is damn good because the end product is worth it, so they should not have any issues.*

Findings indicated that authority challenged all participants, requiring them to develop skills to interact with others productively; without generating conflict or alienating one's self, colleagues or clients, instead learning when to

disagree and when (and how) to keep silent. This process was met with many difficulties as Mona's story illustrated

It has been terrible sometimes for me, oh my God. I have spoke up where I have felt "Okay, this feels
right." And it felt like people were open [to my authority] but it just goes bad politically for you.

Acquiring skills for greater self-awareness was necessary but not easy for people with TS/TS+, OCD and/or ADD/ADHD. Participants frequently reported that they felt urges, or acted upon impulses, to express uninvited opinions, and urge to spontaneously react to the opinions of others. Conversely, when thoughts or feelings were internalized, and not expressed, this also led to conflict. One participant described her process of balancing autonomy and authority as follows: *"I used to think I knew better ('cos I'm different) but now see that others have lots of experience and advice."*

4.4 Managing Symptoms and Self Control

Maintaining composure at work was important for achieving career success and managing individual symptoms and sensory triggers, such as those discussed previously. Stan described the importance of composure and considerable energy he spends managing his symptoms for the sake of fitting in to his workplace:

The worst thing in a work situation is to blow-up, blow-up or lose it in any way because then it looks
like, "What a loser, you are out of control".

The process of self control was an individual one for our participants, what worked for one person was not necessarily optimal for others. One common thread in this process, however, was stress, which consistently worsened symptoms. Successfully navigating self control and symptom management was central to career success for Joyce who explained the magnitude of adjusting to a shift change in her schedule:

They changed this shift on me, which really upset me greatly. I know me and I know what happens
because I won't get enough sleep on the third weekend of any month now and I will get really
miserable. What really worries me when that happens – I get less sleep – I have more symptoms.

Self awareness and management of symptoms, managing stress and exercising self-control, were all attended to by all participants who described strategies that ranged from regular breaks in a quiet place, to avoiding addictive substances, using positive thinking, regulating obsessions and compulsions, managing sleep patterns, physical exercise, healthy eating, and establishing communication strategies that didn't "push buttons" for themselves or others. Self control consistently assisted in optimizing vocational strengths for all participants regardless of workplace. While the process required considerable energy and challenges to their sense of freedom, the rewards were considerable for our participants. Kathy described what she called her *"second occupation"* of managing her symptoms and self as she discussed the process of self control: *"Happy. To be happy. I must control. For others, I must control. To be happy, I shouldn't control. Me or them?"* Self control was desirable, though again, demanding of attention for Stan who explained:

W*hen you're around people at work you have to control yourself and the number one thing you can't*
be doing is being heard swearing and stuff in an office or something.

4.5 Wishing

Participants said that "wishing", and a practice of longing for something different and hoping for work success in the future were important to them in navigating through disappointments and planning for the future. This process of wishing was useful if it produced positive fantasies, and most productive if focused on achievable goals. Janet described this tension of fantasy and practical goal setting in her reflection on imagining things could be different:

I'm always imagining that I'm going to be rich, or imagining that I'm going to have a big paying job,
or imagining that people are actually going to like me and I'm going to be popular. It's like a thing all
the time in my mind: always; I always want to be better; I always feel as though I'm not good enough.
No matter what, I feel very self critical, I guess.

For some participants the goal setting aspect of their wishes and career aspirations assisted them in being more resourceful or prepared for the workplace. For others, the process of wishing helped them maintain hope as they struggled to achieve goals. Dean's wish for independence, being able to support himself through holding a job was a valuable part of his career navigation:

> *I have this wish for me to be more independent, in all aspects of my life it's kind of like um… uh, encourages me to keep going. And not give up even though sometimes you really want to.*

4.6 Managing People Around You: Support from Family, Colleagues and Friends

Navigating peer relations was another process in optimizing vocational strengths. Having family, colleagues or friends to confide in was viewed as essential, and those who had an early diagnosis reported better abilities to address their immediate needs and long-term goals owing to better support. In terms of the process of wishing, we found many participants wished they had been diagnosed earlier in their lives/careers; they felt they could have accessed more support and achieved greater self-control. Participants declared emphatically that it was the *people around you* that can also help with *resolving conflict* and *managing your symptoms*. This was often a process of discernment and finding allies. Shirley illustrated the point:

> *It is still an iffy thing with disclosing as it is a really touchy thing. Ummm, allies, oh my God that made a big difference [finding a colleague with a similar condition] because we help each other.*

Donald went on to emphasize that:

> *Validation is the word. And so, validation of any sort, as an adult even now, for any creative endeavors or whatever matters and that does a lot for me. It makes me a happy worker.*

4.7 Finding an Audience for Vocational Strengths and Uniqueness

The vocations of participants in our study were many and varied and included: nursing student, tradesperson, farmer's market manager, high school teacher, artists, college instructors, writers, parents, early childhood development student, retired realtor, self-employed businessperson, clerk/administrator, customer service representative, and persons who were, at the time of the study, unemployed or accessing social assistance. A number of participants indicated they felt they were not in their ideal careers. Many were self-employed or in occupations that had a degree of predictability or control over contact with larger groups of people, including people who taught or conducted contract work. A few of our participants indicated a preference for managing other people, although this was noted as an area that needs further investigation.

Despite their challenges, longings and struggles, participants indicated there were many positive workplace attributes of individuals who have TS/TS+. These attributes included high energy levels, attention to detail, creativity, strong word skills, quickness of thought, and divergent or lateral thinking. It was suggested that with forethought and planning, these skills could be harnessed and put to good use in jobs and careers.

> *\I have, in many ways, tried to find jobs where I knew I could work my particular shift, my particular way, or alone, or whatever; I have literally tried to select jobs that I could do that kind of thing with because I know what I can and can not do and I know my capabilities.*

This quality of self-awareness contributed to achievement by way of "finding the right audience." Early diagnoses and appropriate treatment were thought to support this process of finding the right audience to optimize vocational strengths. Their unique attributes and habits made our participants particularly adept at certain workplace tasks. People with TS/TS+ or OCD are likely to have qualities that include checking and attention to detail. Julie described this practice in the following account:

> *I over-focus sometimes and I just will re-format something until it is absolutely perfect. So if I find a department that wants that kind of attention to detail then that is a good audience for my strength in that vocation.*

Although perfectionism was a double-edged sword for participants, prompting obsessive thought for work that required high degrees of accuracy, some of our participants considered themselves at a distinct advantage. Finding the right setting and audience enabled our participants to maximize their productivity in their workplaces and moderate clinical symptoms. Jan explained how she struggled with finding the right audience and space:

> *In the past I used to stay late after work on my own time when there was nobody around and I would get to work at my own pace and at my own intensity but they don't like that because it is a labour job (I mean it is a labour union job). So I am going to be demanding more of myself in that area because I am going to be working 8:00am to 4:15pm with a half an hour for lunch and two fifteen minute breaks like a bloody robot, but I can do it. With meds I can do it.*

Noise, light and the size of a workplace were all sensory and environmental factors that, when participants could understand them and select them for their needs, reduced conflict. Some participants were hypersensitive to many sensory stimulants, often even a small level of stimulation felt like "too much." Considering workplace size, many participants expressed distinct preferences for privacy, working alone, or occupations that had a degree of predictability as to when contact with larger groups of people would occur. Smaller settings were described as supportive of reducing triggers, and of decreasing conflict and alienation while increasing concentration and confidence.

5. A Theory of "Optimizing Vocational Strengths"

A theory of "Optimizing Vocational Strengths" emerged from the categories and analysis. This was visually articulated by as a tripod-mounted video camera and screen, shown in Figure 4 (In Camera Projection).
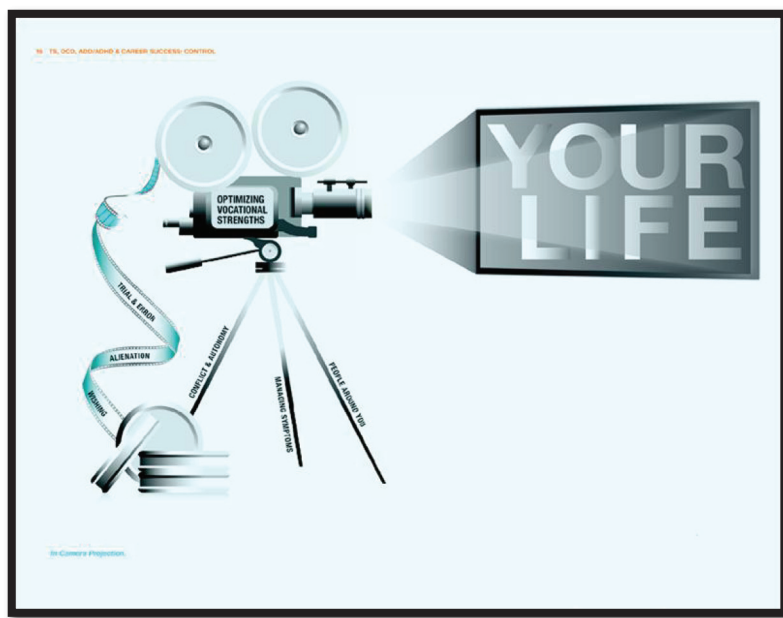

Figure 4: Participant Artwork "In Camera Projection"

The camera demonstrates the need for *Finding an Audience,* one of the social processes brought out by the participants. Participants preferred to be "*in camera*", and not automatically disclosing their conditions and needs in their educational or workplace settings. The screen of "*Your Life"* represents an image of successful career or workplace events deserving of projection onto the silver screen.

The film spooling from the back of the camera represents the three illustrated categories that need to "hit the cutting room floor" of one's career process. *Wishing* will not make things right, *Trial and Error* is endemic to a healthy process of education, training and career searching, and *Alienation* can be countered by the stability afforded via the categories represented by the tripod legs. The tripod legs keep the camera balanced and directed towards a clear and successful vision of *Your Life*. In setting up the tripod, if one leg extends too far or another gets stuck, it upsets the camera's balance and the picture is going to be impaired. Health educators, career trainers, as well as persons with TS and/or co-morbidities, need to work towards supporting the balance of each of the three legs: *Managing Symptoms,* moderating *Conflict and Autonomy,* and *Managing People Around You.*

6. Discussion and Implications

This study has taken a first step towards a wide open canvas, deploying art workshops, a technique rarely used to gather information in health sciences research. The art workshops established as a data gathering tool for this research enabled participants to visually communicate their process of career navigation. These workshops were not intended to be art therapy and there was no clinical treatment component to the research, however participants appeared to find the creative outlet a therapeutic experience. The participants in this study said that the art workshops and the research process assisted in their personal development and awareness of vocational optimization. Art, while not identified as an optimal career necessarily, was an important data gathering tool and means of *discovering* possibilities for optimizing vocational strengths.

Through self-awareness for people with TS/TS+, as well as employers and counselors awareness, the uniqueness of individuals with TS/TS+ can be better supported for vocational optimization. Nadeau (2005) also found that interventions for career counseling for adults with ADHD required a focus on self-awareness and awareness of the kind of "finding a shoe that fits" (p556), or what we uncovered as "finding an audience." Features of "optimizing vocational strengths" can be related to the learning disabilities and ADHD findings of Garber (2001) who identified particular resilience factors including the management of internal and external environments.

Overall, our theory of *Optimizing Vocational Strengths* has provided functional and creative recommendations for individuals, employers, educators and health care workers involved with TS/TS+ so that we can all work with uniqueness in ways that optimize vocational strengths.

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