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A Phenomenological Exploration of Young Adults Who Self-Identify with Primary Complex Motor Stereotypies

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Walden University
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Abstract

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MPhil, Walden University, 2019

MS, Mercy College, 2008

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

The School of Psychology

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Abstract

Primary complex motor stereotypies (p-CMS) are repetitive, rhythmic, and predictable involuntary movements which occur in typically developing individuals. To date, research has focused on observational data involving parents, leaving a lack of first-hand information about the effect of p-CMS on experiencers' quality of life and wellbeing in adulthood. This phenomenological study, grounded in Bronfenbrenner's ecological theory, explored lived experiences of six young adults, ages 21 to 29 years, who self-identified with p-CMS, through in-depth telephone and Zoom interviews. I aimed to answer how p-CMS affected participants in academic, work, and social settings, what meaning participants assigned to their p-CMS, and what participants wished family, doctors, and teachers would know about p-CMS as a social phenomenon. Data were analyzed through the application of Colaizzi's method of data analysis in combination with open and axial coding. Participants viewed p-CMS as mostly positive and serving a definite purpose in terms of emotional and learning processing, while indicating that p-CMS manifestations needed less focus from caregivers and medical/mental health personnel and underlying comorbidities required more focus. Results of the study revealed unobservable firsthand experiences of p-CMS, the role of p-CMS in processing and regulation of emotional and academic information, and effect of comorbidities. Implications for positive social change include more informed insight by caregivers, family, medical personnel, and teachers into the role of p-CMS on experiencers' lives and development of future treatments and approaches.

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Dedication

This study is dedicated to all the children whose talents and genius we are yet to understand, yet who hold the potential for all to live in a more diverse and inclusive society – I owe you.

This study is also dedicated to all the parents whose persistence and resilience is pushing scientific frontiers world-wide – I feel you.

This study is dedicated to all the educators who see past the barriers, and despite the lacking resources make learning meaningful for all students – I see you.

Finally, this study is dedicated to all the scientists who were courageous enough to look into primary complex motor stereotypies before they even became of “scientific importance”; and who continue to contribute to this area of research in meaningful ways – I look up to you.

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Chapter 1: Introduction to the Study

Primary complex motor stereotypies (p-CMS) present rhythmic and repetitive involuntary movements, which are predictable and stop with distraction (Singer, 2009). They occur in children who are typically developing, which means that they do not experience the presence of any additional psychoneurological symptoms (Mahone et al., 2014; Singer et al., 2018), but their peculiar motor behaviors are obvious enough to raise concerns in parents and educators and energize a relatively new area of scientific research (Hedderly, 2017; Mirabella et al., 2020; Oakley et al., 2015; Singer et al., 2018; Specht et al., 2017). Although motor stereotypies are typically observed in large numbers among children with autism, p-CMS occur in 4% of otherwise typically developing children (Singer, 2011).

Stereotypies vary in expression and have been categorized according to which body segments they mobilize (see Table 1), but each child displays a unique set of movements which are specific to him or her (Temudo & Melo, 2015; Wijemanne & Jankovic, 2017). As a form of movement, motor stereotypies can be viewed as a transient part of a child’s development (Cardona et al., 2016). But what makes p-CMS a source of concern is the fact that they occur intermittently throughout the day and last from several seconds to several minutes (Martino & Hedderly, 2019; Mackenzie, 2018; Wijemanne & Jankovic, 2017); and tend to be persistent throughout one’s lifetime (Oakley et al., 2015). Due to their repetitive nature and the involvement of the same body parts, they give off the impression of rhythmicity and peculiarity, and are visible to others (Martino & Hedderly, 2019).

Table 1

Most Common Examples of Stereotypies

Common motor stereotypies	Complex motor stereotypies
Nail biting	Hand flapping
Hair twisting	Arm waving
Leg shaking	Arm rotation at wrists
Nail biting	Foot rotation at ankles
Teeth clenching and grinding	Grimacing
Finger drumming	Hands opening and closing

Children often express p-CMS in a variety of ways when they are excited, fatigued, or bored (Harris et al., 2008). For example, a child may jump up and down while flapping hands when shown an object that he or she likes. An infant may twist and rotate both hands simultaneously while twisting and rotating his or her feet. In younger children, p-CMS do not interfere with daily tasks (Wijemanne & Jankovic, 2017). They often experience stereotypies during play, and even when movements are disruptive, children easily regain focus (Sanger at al., 2010 as cited in Wijemanne & Jankovic, 2017). But, as children with p-CMS grow and their involvement with society becomes greater, so do responses from their environment, exposing them to risks of social stigmatization, as well as academic and social challenges (Bronfenbrenner & Morris, 2006; Singer et al., 2018; Specht et al., 2017).

To date, scientific efforts on this topic have been directed at discovering the causes of p-CMS, testing the ways that p-CMS can be managed, and how the knowledge can be systemically organized. To date, no studies have been conducted to address the gap between how p-CMS are observed and how they are experienced by individuals who present with p-CMS. Because of this, past research on p-CMS remains largely one-sided, based on parental interviews and observations, with little attention given to the experiencing individual.

I explored the lived experiences of young adults, ages 21 to 29, who present with p-CMS in order to bring voices of experiencing individuals into the scientific discourse and add more depth and overall understanding regarding the essence of this phenomenon. Additionally, I addressed cognitively abled young people who present with p-CMS which may aide researchers in deeper understanding of nonverbal autistic individuals who experience CMS.

In the following sections of this chapter a general overview of p-CMS is provided along with the defining properties of p-CMS through relevant literature. That is followed by the problem statement where gaps in scientific literature are addressed, as well as core issues related to p-CMS. Finally, towards the end of the chapter, the focus of this study is described along with research questions.

Background

P-CMS presents as a subgroup of motor stereotypies. Motor stereotypies have been defined as rhythmic, repetitive, predictable, and involuntary movements which occur in typically and atypically developing individuals (Singer, 2009). They range from simple behaviors such as nail biting and hair twisting to more complex movements that include body rocking, head nodding, hand twisting, hand flapping, and grimacing (Freeman et al., 2010). Simple motor stereotypies affect 20% of typically developing children in the United States (Singer, 2009).

Motor stereotypies are divided into primary and secondary classifications. Primary stereotypies appear in typically developing children, while secondary stereotypies appear in children who present with developmental delays and neurological disorders (Barry et al., 2011; Gao & Singer, 2013; Mackenzie, 2018). The most common neurological disorder associated with motor stereotypies is autism, but they also occur in the presence of other conditions such as Tourette syndrome, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), and some neurometabolic disorders (Barry et al., 2011; Gao & Singer, 2013; Mackenzie, 2018).

Primary motor stereotypies are further divided into three subgroups, which are: complex arm and hand, common stereotypies, and head nodding (Barry et al., 2011). Common stereotypies include hair twisting, nail biting, rocking, thumb sucking, teeth clenching and grinding and finger drumming, while complex motor stereotypies include hand flapping, arm waving, rotating hands and feet at wrists and ankles, opening and closing the hands, mouth opening, grimacing, and finger wiggling (Barry et al., 2011; Cardona et al., 2016; Mackenzie, 2018). For the purposes of this study, research is focused on p-CMS.

The phenomenon of p-CMS is not fully understood, yet it presents a significant challenge for parents, teachers, and caregivers (Barry et al., 2011; Gao & Singer, 2013; Ricketts et al., 2013). Repetitive movements associated with p-CMS typically appear before 3 years of age during periods of excitement, focus on activities, stress, or fatigue, but remain absent during sleep (Barry et al., 2011; Gao & Singer, 2013; Martino &

Hedderly, 2019). P-CMS are specific to the child, mainly considered purposeless, and stop with distraction (Oakley et al., 2015; Specht et al., 2017).

The exact prevalence of p-CMS is unknown, but it is postulated that p-CMS affect approximately 4% of children in the United States (Singer, 2009). Even though a significant number of studies have been conducted to uncover the neurological underpinnings and effects of secondary complex motor stereotypies, very little is known about CMS among healthy individuals.

Due to its similarities with other conditions, p-CMS can be difficult to diagnose, which leads to unnecessary testing of children, incorrect diagnoses, and inappropriate therapeutic approaches (Freeman et al., 2010; Freeman & Duke, 2013). Children with motor stereotypies should be properly assessed and diagnosed, and when that is not possible, they should be referred to expert authorities for further examinations (Barry et al., 2011).

There is not a single appropriate way to treat p-CMS, as there are large variances in terms of how they are expressed among individuals (Ricketts et al., 2013). What works for one child with p-CMS may not work for the other. Common approaches to treating stereotypies are in many ways inadequate for children with p-CMS. For example, medications that are usually prescribed for motor stereotypies do not help to reduce stereotypies among children with p-CMS but do come with undesired side effects (Barry et al., 2011). Freeman and Duke (2013) said that a non-pharmacological, behavioral-based approach required a great deal of effort and training from the child’s primary caretaker to be correctly and effectively implemented. Barry et al. (2011) said behavioral interventions for treating p-CMS can be beneficial, but when delivered in a school setting can be inadequate and ineffective, because they require hundreds of prompts in a school day, warranting the use of medication.

There is an increase in comorbidities in older children and adolescents with p-CMS that require attention and could possibly be prevented (Hedderly, 2017). Approximately 92% of 49 participants (ages 9 to 20 years) in a longitudinal study had at least one comorbid disorder with p-CMS (Oakley et al., 2015). The highest rates were found for anxiety (73%), followed by ADHD (63%), OCD (35%), and motor tics/Tourette syndrome (22%; Oakley et al., 2015). Hedderly (2017) suggested further study into personal feedback from individuals experience p-CMS. Lemiere (2014) said p-CMS could be the sign of deeper psychomotor issues, and their proper diagnosis and treatment warrants interdisciplinary approaches.

Literature on p-CMS reflects the gap between how children with p-CMS experience their stereotypies and how those in their environment perceive them. Parents of researched children with p-CMS reported that levels of stress that they encounter while raising a child with p-CMS is significant, showing that stereotypies impair their overall quality of life, as they appear to dominate all activities (Hedderly, 2017). These parents worry that their children’s p-CMS will lead to bullying and social stigmatization, interfere with learning and disrupt school activities. When asking for professional help, parents of children with p-CMS often cannot receive support that they need, as knowledge about diagnosis, treatment, and management of p-CMS is not yet widely distributed among physicians and educators. When parental input and observations are used as a source of data for studies on p-CMS, they sometimes lead to higher scores of parent ratings of stereotypies and behaviors typically observed in autism (Mahone et al., 2014).

Reportedly, subjective experiences of children with p-CMS do not seem to resonate with the parental concerns. Children interviewed without the presence of their parents described feeling deep enjoyment during episodes of p-CMS (Freeman et al., 2010; Ricketts et al., 2013). These children were often unaware of the stereotypies until the episode ceased and could not detect any signs that the stereotypical episode was on its way (Ricketts et al., 2013). Children ages 13 and older revealed that they could stop the stereotypies if they wanted to but suppressing their stereotypies in the long run was challenging (Ricketts et al., 2013). Even at that age, some older children with p-CMS opted to engage in stereotypical behaviors in public, regardless of social implications (Ricketts et al., 2013). Additionally, Robinson et al. (2014, 2016) found that there are children with p-CMS who experience a phenomenon called intense imagery movements (IIM). IIM is the expression of conscious engagement in acts of deep imagination, where the subjects feel that they are in a real-time video game, with stereotypic movements occurring simultaneously (Robinson et al., 2014, 2016). P-CMS-induced pleasure has been shown to be so intense that some children prefer it to any other activity, and dislike being interrupted, making therapeutic interventions challenging and frustrating for both parties (Freeman et al., 2010; Hedderly, 2017).

These differences in terms of how p-CMS are perceived and how they are reported by experiencing individuals are only increased by the current paradigm through which motor stereotypies are studied. Currently, p-CMS is regarded as purposeless movements which only appear to have a purpose (Mackenzie, 2018). The DSM-V defines stereotypies as nonfunctional movements (APA, 2013). Researchers have focused on this definition in researching stereotypies, and this focus seems to have created a one-sidedness in research. This one-sidedness is demonstrated in the lack of studies focusing on the viewpoint of individuals who experienced p-CMS. Literature on lived experiences of individuals with p-CMS remains scarce.

A study on 57 children with p-CMS showed that typically developing children who present with CMS have intact neuropsychological profiles, which according to Mahone et al. (2014) means that they scored in the average range on neuropsychological assessments of IQ; but the same children scored significantly lower on motor skills assessments in comparison to their peers who did not present with p-CMS. Lemiere (2014) asserted that researchers have not yet determined the extent to which p-CMS affects the mental, physical, and social functioning of experiencing individuals. In their study regarding long-term life’s outcomes for children with p-CMS, Oakley et al. (2015) said that 89% of their 49 participants with p-CMS, reported experiencing some level of difficulty in school. More needs to be learned about how much p-CMS affect the wellbeing and quality of life of experiencing individuals.

There are several studies dedicated to examining the neurological and psychological underpinnings of secondary complex motor stereotypies, but focused research on p-CMS remains modest. Most p-CMS research has focused on uncovering causes of p-CMS, developing theoretical viewpoints, testing the therapeutic approaches to treating p-CMS, and data collection for classification, categorization, and distinguishing characteristics of p-CMS. No studies have been undertaken to examine the lived experiences of young adults (21- 29 years old) with p-CMS from a firsthand perspective.

This qualitative study aimed to bring voices of young adults who identified with p-CMS into this scientific discourse in order to bridge the gap between how p-CMS are viewed by observers and how they are experienced by young adults who present with p-CMS. Through in-depth phenomenological interviews, lived experiences were explored involving how these young adults described their p-CMS relative to their academic and social environments, what meaning they gave to their conditions, and what they thought society surrounding young adults should know about p-CMS which had not yet been investigated. Additionally, this study held the potential to uncover what nonverbal autistic individuals were experiencing, and lead to new directions in scientific research involving motor stereotypies.

Problem Statement

Children with p-CMS reported enjoyment while engaging in repetitive movements, were not aware of them, and disliked being interrupted, but parents and teachers shared common concerns about negatively perceived manifestations of stereotypies (Barry et al., 2011; Freeman & Duke, 2013; Oakley at el., 2015), as they could be seen as odd and “socially offensive” (Péter et al., 2017, p.2). Additionally, frequent occurrences of p-CMS sometimes led to interruption of daily activities and interfered with learning (Singer et al., 2018; Specht et al., 2017).

Children in Mahone et al.'s (2014) study, that experienced p-CMS and were given neurological and psychological assessments, reported also experiencing difficulties in school, motor expression, and overall emotional distress. Further difficulties, later described by Oakley et al. (2015), varied from focus and attention problems to social concerns and anxiety.

Oakley et al. (2015) found that p-CMS were more observable in younger children, as older children learned how to control p-CMS in social situations. Not only were p-CMS persistent throughout adulthood, but participants reported also experiencing associated comorbidities such as anxiety (73%), ADHD (63%), OCD (35%), and tics/Tourette syndrome (22%; Oakley et al., 2015). This raised the question of whether p-CMS were just a visible sign of deeper neurological and/or psychological issues that science had yet to understand in terms of impact on quality of life among typically developing individuals with p-CMS (Lemiere, 2014).

Past research efforts to study p-CMS relied heavily on observations of movements by parents and not on experiencing individuals, yielding one-sided data. This qualitative study aimed to bridge that gap via in-depth phenomenological interviews with six young adults who presented with p-CMS in order to explore the following: (a) how stereotypies affected experiencing individuals in academic, workplace, and social settings; (b) what meaning young adults who presented with p-CMS gave to their stereotypies; and (c) what was it from their perspective that others should know about p-CMS as a social phenomenon.

Purpose of the Study

In this qualitative study, I used in-depth phenomenological interviews to explore the lived experiences of young adults between the ages of 21 and 29 who self-identified with p-CMS. I focused on the subjective views that young adults with p-CMS expressed in reference to their academic and social lives, what stereotypies meant to them, how they individually experienced them, and what they felt that society surrounding young adults with p-CMS and science should learn about their authentic life experiences. My main goal for this study was to bring the voices of young adults who presented with p-CMS into the scientific discourse to add more depth to the current body of knowledge, which appeared to be one-sided, as current studies were based on parental interviews and outsider observations.

Research Questions

RQ1: How do young adults who present with p-CMS describe inducing events of CMS movements as related to their social, academic, and personal environments?

RQ2: What meaning do young adults who present with p-CMS give to their stereotypies?

RQ3: What is it that they think that society and science should learn and understand about typically developing individuals who present with p-CMS?

Theoretical Framework

The theoretical framework for this study was Bronfenbrenner's (1977, 1994) bioecological model of human development which was the mature version of his original ecological systems theory. Specifically, the aspect utilized was the Process-Person-Context-Time (PPCT) model, which describes the role of the individual as active influencer on the individual’s environment and on the responses of others in that environment. PPCT will be discussed further in Chapter 2.

Bronfenbrenner’s theory allowed for a wide exploration of factors which influenced the lived experiences of young adults with primary motor stereotypies. It involved the idea that human development takes place through bilateral interaction between a developing person and his or her environments (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge et al., 2009). Environment was defined to include families, schools, and communities, all of which directly and indirectly affect the developing individual (Bronfenbrenner, 1994). Bronfenbrenner’s theory was multidimensional, as it also included the element of time. This theory is discussed and explained in greater detail in Chapter 2.

Eisenbach et al. (2018) explained that society provides a wide framework for developing a personal identity. Initiation into the societal norms and cultural values, as well as first learning steps, begin at home (Carrère & Bowie, 2012; Ceka & Murati, 2016). The family system is the primary educational environment through which children gain numerous life skills before they enter a broader social environment (Bronfenbrenner & Morris, 2006; Ceka & Murati, 2016).

As they grow, children’s engagement shifts from simple forms of play at home to more complex societal interactions (Bronfenbrenner & Morris, 2006), and peer relationships become an additional source of influence on personal development (Vandenbroucke et al., 2018). Once they enter the school system, children gain additional authority figures, such as educators, coaches, and service providers. These children then begin to participate in a wider societal framework, where rules and expectations appear in a more organized and structured way (Ceka & Murati, 2016).

As children grow, they become aware of societal roles and stereotypes, which further influence their identity development, sense of self, and academic performance (Eisenbach et al., 2018; Vandenbroucke et al., 2018). Children with p-CMS publicly display atypical and persistent behaviors from an early age, thus eliciting responses from their environment (Péter et al., 2017). These children enjoy their stereotypies (Freeman et al., 2010), but their parents reported experiencing high level of stress, as children's p-CMS seemed to dominate all activities (Hedderly, 2017).

Prior research on p-CMS relied heavily on parental observation while not focusing on the subjective information from the children experiencing p-CMS (Ricketts et al., 2013; Cardona et al., 2016; Freeman & Duke, 2013; Freeman et al., 2010; Mahone et al., 2014; Valente et al., 2019). To date, I have found no studies which inquired as to the meaning that individuals with p-CMS give to their stereotypies, and how they are affected in social and academic settings. It is of great importance that their experiences be viewed in the larger context.

Bronfenbrenner's ecological systems theory advised that people are active agents in their environments. According to Darling (2007), this is demonstrated by individuals shaping their environments, eliciting responses from others, and expressing personal reactions. P-CMS are not a phenomenon that happens in isolation, but rather factors which affect not only the child, but the child's wider community as well. Through their behavior, children first influence the behavior of their parents, and later the behavior of others that they meet. These interactions provide a venue for a variety of psychological triggers which could affect a child's development and learning in positive and negative ways (Ceka & Murati, 2016).

A child's developing character and traits influence how he or she will be seen by others. In turn, the views that others have of the child often influence how the environment responds to their behaviors. For example, parents who perceived their young children as active and emotionally dysregulated were more likely to engage in parent-child aggression (PCA), or increased violence expressed by the parent towards their child (Rodriguez & Wittig, 2019). Further, children's ability to read positive emotional cues from their parents often resulted in these children responding with similar positive behaviors (Cole et al., 2003).

In this study, I used the mature version of Bronfenbrenner's ecological systems theory, called the bioecological model to gain a deeper understanding of how young adults who presented with p-CMS experienced their stereotypies in different academic and social environments. I also investigated what meaning young adults gave to their p-CMS, how the society surrounding young adults influenced their own perceptions of stereotypies, and what it was these young adults felt that their society should know about p-CMS that had not been discussed yet.

Nature of the Study

I chose the qualitative phenomenological design to study lived experiences of young adults between 21 and 29 who self-identified with p-CMS. Phenomenology is the study of subjective experiences which takes into account that people experience life individually, through a prism of factors unique to each person as well as factors that are shared collectively (Titchkosky & Michalko, 2012). In order to study authentic experiences of young adults who self-identify with p-CMS, phenomenology was the most appropriate choice because phenomenology examines p-CMS as a phenomenon to be explored and understood rather than another problem to be solved. Phenomenology defines the role of p-CMS experiencing individuals as givers of subjective information and the role of researchers as elicitors of these individuals' voices.

The study was conducted via in-depth phenomenological interviews with participants over the phone and/or video conferences. Colaizzi's method was applied for data collection and analysis. There are seven parts to Colaizzi's method: reading the entire content of interviews, finding and highlighting pertinent responses, determining what those responses mean, sorting those responses into categories, sorting the categories into themes, be able to use the themes to describe the phenomena, and use the participant's responses to support your description (Colaizzi, 1978).

Interviews made it possible for study participants to share their stories through open-ended questions and allow safe opportunities for exploration of the phenomenon of p-CMS. Collected data were further analyzed via open and axial coding.

Operational Definitions

Academic Environment: A broad term which encompasses human interactions, patterns, relationships, societal roles, and activities which influence a person's development and take place at or are related to the educational institution that the person attends (Bronfenbrenner, 1994).

Education: A lifelong process of learning which occurs via human interactions, patterns, relationships, societal roles, and activities (Bronfenbrenner, 1994).

Primary CMS: A term that refers to CMS which occur in otherwise typically developing individuals (Singer, 2009).

Self-Identification: Self-identification is the personal definition of a person by claiming attributes that they consider associated with their ideas of who and what they are. For example, throughout this paper, the terms "self-identify" or "present with p-CMS" are used interchangeably to describe those individuals who experience p-CMS whether they have an official diagnosis or not.

Social Environment: Human interaction, patterns, relationships, societal roles, and activities which influence a person's development as an active member of the society (Bronfenbrenner, 1994).

Socially offensive behavior: Any behavior that can be perceived negatively by observers (Péter et al., 2017).

Stigma: A process of labeling, separating, and stereotyping a member of a community through which he or she is exposed to prejudice and discrimination, and as a result of that may suffer the loss of social, economic, or political power (Link & Phelan, 2001).

Typical: A body that is developing psycho-biologically in line with societal norms of what is considered normal (Titchkosky & Michalko, 2012).

Young adult: A person who is 21 to 29 years of age (Herry et al., 2019).

Assumptions

This study was designed with consideration of several assumptions regarding the participants, who were gathered from Facebook p-CMS support groups.

The first assumption was that young adults who presented with p-CMS and participated in Facebook groups involving p-CMS would be more likely to be proactive members who sought to gain and provide support for themselves and other p-CMS experiencers. It was assumed that they would thus be more likely to be motivated to volunteer and participate in the study.

It was also assumed that since these young adults were already communicating with other members of these Facebook p-CMS support groups via the internet, they were more likely to be comfortable participating in interviews via video conferencing and/or phones instead of requiring in-person contact.

It was thirdly assumed that these young adults gathered from Facebook p-CMS support groups also had consistent access to the internet and knowledge of technology used in the interviews such as computers or smart phones.

Fourthly, it was assumed that as members of p-CMS support groups, these young adults would likely already be used to sharing personal information with others and would therefore be more likely to answer interview questions openly and honestly.

It was assumed that semi-structured in-depth phenomenological interviewing was the optimal way of exploring the lived experiences of the participants, by allowing their opinions and views to emerge naturally while also considering my personal opinions and biases.

While it was assumed that the experiences of the individuals self-identifying with p-CMS would be diverse, it was also assumed that the participants would share common aspects to their experience. For example, while one tradition or culture focuses on ability in sports and another on ability in academics, both cultures and societies will share the same tendency of children to “pick on” children who are different from the social norm.

Finally, it was assumed that while the possibility of memory bias in participants’ stories exists, the presence of this potential bias will not alter their current perspectives regarding issues they’ve experienced. Memory retrieval, even with potential bias, would still represent the accumulation of the impacts of participants’ past experiences. For example, a participant avoids a specific social setting situation. Whether the participant “remembers” a substance being spilled on them purposely by peers or accidentally spilling a substance on themselves, the avoidance of that type of situation clearly demonstrates that there are emotionally charged responses associated with those situations.

Scope and Delimitations

I aimed to explore lived experiences of young adults, ages 21 to 29, who presented with p-CMS. No children, adolescents, or older adults with p-CMS were in the study. A second delimitation concerned how participants were recruited for the study. Given that sampling was conducted in Facebook groups that connected Facebook members who were interested in the topic of p-CMS, findings of this study could not be generalized to all young adults who presented with p-CMS. Young adults who did not actively engage in Facebook groups or were not interested in connecting with other people who shared the same conditions might not have shared the same views as those in this study.

Limitations of the Study

Presently, this study appears to be the first attempt to research the lived experiences of young adults who self-identified with p-CMS qualitatively, and as such, it was open to several limitations.

Firstly, this study involved young adults who self-identified as having p-CMS movements but did not necessarily have a confirmed clinical diagnosis.

The second limitation to the study involved memory recall bias. When people are asked to retrieve their autobiographical memories, much of their views are tainted by present emotions (Meyer et al., 2015). For example, people who are generally sad retrieve unhappy memories faster with greater accuracy than those who are happy. Also, those who are happy retrieve happy memories faster than the unhappy ones (Meyer et al., 2015). This could have posed a challenge, given high rates of anxiety among adolescents who presented with p-CMS in a way that they had difficulties retrieving personal memories, and exaggerated or diminished the perceived importance of their stereotypies. This difficulty retrieving personal memories and/or exaggeration or diminishment of the importance of their stereotypies could potentially cause inaccurate responses to interview questions.

Despite limitations, this study appears to be the first attempt to include voices of young adults who self-identified as having p-CMS. In order to deal with limitations, I stayed aware of the fact that present emotions affect memory recall. I followed the natural flow of the interview, built good rapport with participants, and maintained a non-judgmental stance free from interviewer bias to the best of my ability. Additionally, I was aware that during the interviewing process, making participants feel welcome and appreciated could easily blur boundaries and lead to solicited personal information from participants that they might later regret. I stayed aware of my role as a researcher doing my best not to slip into a quasi-therapeutic interviewer role.

Finally, I made sure that all participants understood clearly what my role in the process was, how interviews would proceed, and for what purposes data were obtained, which may have helped alleviate anxiety in those participants who experienced it.

Significance

Results of this study potentially give a voice to young adults with p-CMS which have been absent from the past studies. Adults generally have a more complex and comprehensive grasp of language and communication skills than children do and can describe subjective experiences in various social and personal environments. As a professional educator, mainly working with adults, I have had occasional opportunities to informally discuss how adults with p-CMS use their episodes in proactive and creative ways to generate ideas and solutions to real-life problems and alleviate stress.

Results of this study could involve how parents view and treat their children with p-CMS in the future. In turn, children may gain space to express themselves freely, embrace their uniqueness, and be more cooperative in instances where therapeutic interventions are needed. This may result in lower anxiety rates and improved overall wellbeing later in life.

Additionally, results of this study could influence how educators, counselors, and service providers approach children who present with p-CMS. Deeper understanding by researchers, caregivers, parents, teachers, and medical/mental health personnel of what a p-CMS episode means and how it is experienced internally could bring changes of perspective, which is necessary in terms of alleviation and reduction of social stereotypes. And lived experiences of typically developing young adults with p-CMS could also lead to better understanding of information regarding non-verbal children with autism and children with other severe neurological problems who experience episodes of CMS.

Finally, findings of this study hold the potential to address aspects of p-CMS that have not yet been investigated but can energize future research efforts for children experiencing CMS, regardless of their verbal status.

Summary

P-CMS are repetitive, involuntary, and rhythmic movements which are predictable and occur in distinct patterns among otherwise typically developing individuals (Singer, 2009). Past research attempts to study p-CMS primarily relied on parental interviews, reports, and observations, which resulted in a one-sided view of p-CMS. Current literatures on p-CMS seems to be void of the voices of those who experience the very phenomenon that researchers attempt to study.

In Mahone’s (2014) study, in which neurological and psychological assessments of participants both with and without p-CMS were compared, it was found that participants with p-CMS performed worse in terms of motor skills and IQ tests. Additionally, although children with p-CMS learn to control their stereotypies as they mature, p-CMS has a persistent course to adulthood in most cases (Oakley et al., 2015). Studies indicate that there is insufficient data on how p-CMS impacts experiencers' quality of life and wellbeing in the long term. Research findings have shown that among adolescents and adults with p-CMS, there were often associations with comorbidities. For example, in one study, 73% of the 49 participants were diagnosed with anxiety disorders, 63% were diagnosed with ADHD, 35% were diagnosed with OCD, and 22% were diagnosed with tics/Tourette syndrome (Oakley et al., 2015).

In Chapter 2, a more thorough review of current literature is provided, which explains in detail how p-CMS is defined and diagnosed, what treatment options exist, and what the main challenges and gaps in research exist. Also, a detailed review of Bronfenbrenner's ecological systems theory is presented.

Chapter 2: Literature Review

The main purpose of this study was to explore the lived experiences of young adults who presented with p-CMS. Previous studies on p-CMS predominantly used parental interviews and observations as their main sources and did not include the experiences of the individuals with p-CMS on whom the studies were performed. The aim of this study was to explore the lived experiences of young adults (ages 21 to 29) who presented with p-CMS.

P-CMS represent repetitive involuntary movements which occur in typically developing individuals who do not suffer from major neurological disorders, such as autism, Tourette syndrome, and intellectual disabilities (Barry et al., 2011; Singer, 2009). These repetitive movements occur rhythmically in fixed and predictable patterns and are often expressed through bilateral motion (e.g., hand flapping, wrist rotation) during periods of excitement, boredom, and/or fatigue (Gao & Singer, 2013; Harry et al., 2008).

A common episode of p-CMS lasts from several seconds to several minutes and involves mobilization of different parts of the body. This combination of movements may make the episode to seem more complex than expected (Martino & Hedderly, 2019). Reportedly, young children enjoy their p-CMS and express them freely even though to an uninformed observer the movements may seem unconventional and socially offensive (Freeman et al., 2010; Hedderly, 2017; Péter et al., 2017). Due to their frequent occurrence, there is a common concern that p-CMS expose children to social stigmatization, interfere with learning, and disrupt classroom activities (Singer et al., 2018; Specht et al., 2017).

Even though p-CMS tends to be persistent over time, children learn to suppress stereotypies as they mature, giving off the impression that p-CMS are transient in nature (Cardona et al., 2016; Freeman et al., 2010; Oakley et al., 2015). Children who present with p-CMS may have neurological and/or psychological assessments that indicate no comorbidities present, and yet these children are more likely to perform significantly worse in terms of motor skills and IQ tests than typically developing children without p-CMS (Mahone et al., 2014). This literature review is focused on presenting outcomes of past scientific inquiries in order to identify informational gaps on this topic, demonstrate the importance of filling this particular gap, provide justification for this study, and suggest practical uses for knowledge. Hence, the goal of this literature review is to integrate findings across multiple domains and address defining properties of p-CMS, differentiation, responses, and adaptations to p-CMS, while including different and at times opposing views. The aim for this literature review is to provide exhaustive coverage, which seems necessary, given the paucity of information in the realm of p-CMS. I attempted to locate every possible source of data on the particular topic.

This chapter involves synthesizing current literature on p-CMS. The literature search strategy is explained, followed by a detailed overview of the theoretical framework. Finally, a literature review related to key concepts of p-CMS is presented, and it includes definitions and diagnosis of p-CMS, responses and adaptations to p-CMS, p-CMS in academic and social settings, and expanded meaning of p-CMS. Throughout the chapter, informational gaps in current research are identified and addressed.

Literature Search Strategy

This literature review had been in preparation since year 2018. I first focused on locating sources involving the phenomenon of p-CMS and determined there was a lack of research. As I expanded my search about motor stereotypies among autistic and non-autistic individuals, new findings began to emerge. I read and analyzed over 200 articles, but in order to demonstrate my knowledge of this field of study, I chose to present a review that was focused on research outcomes concerning typically developing individuals with CMS.

I used the online library of Walden University, which included the following databases: Thoreau, Academic Search Complete, ProQuest Science Journals, PsycINFO, PsycARTICLES, and PubMed. Keywords that were used in those searches were: *complex motor stereotypies*, *non-autistic motor stereotypies*, *primary stereotypies, primary complex motor stereotypies*, *motor stereotypies*, and *stereotypies* and added the qualifier “not” *autistic*. However, primary searches yielded an inadequate number of relevant sources. Secondary searches came from reference lists in retrieved articles. This process was repeated for all incoming articles until a point of saturation was reached.

All sources were peer-reviewed journal articles that were published in English between 2011 and 2021. Sources that did not meet these requirements were considered in some cases but generally excluded from this review. Document Delivery Service was used on several occasions for sources that were unattainable through online databases.

Theoretical Framework

The theoretical framework for this study was Bronfenbrenner’s bioecological model of human development and its corresponding process-person-context-time (PPCT) model. Bronfenbrenner’s bioecological model of human development represented a mature version of his well-known ecological systems theory. This model represents a dynamic, evolving theoretical framework for the scientific study of lifespan development (Bronfenbrenner, 2005).

Bronfenbrenner (1977) maintained the view that the developing individual is an active agent who by engaging in exchanges with others shapes the environment and influences behavior of others. Due to the complexity of this theory, as well as its misuses in the past (Tudge et al., 2009) Bronfenbrenner’s theory will be further discussed in detail.

Distinguishing Properties of the Bioecological Model of Human Development

According to Bronfenbrenner (1977), all human development takes place through proximal processes between a developing individual and his or her environment. These proximal processes get progressively complex as the developing individual matures and influence development outcomes. Examples include mothers caring for an infant, children playing with others and learning new skills, and engaging in problem solving (Bronfenbrenner & Morris, 2006).

There are four defining properties of Bronfenbrenner’s bioecological model: proximal process, person, context, and time.

Proximal Process

At the core of the bioecological model are proximal processes. They represent all interactions between a developing person and environment and constitute “the driving engines of effective development” (Bronfenbrenner & Ceci, 1994, p. 572). It is through these processes that a developing child learns his or her place in the world and makes sense of the world (Tudge et al., 2009).

Proximal processes are bidirectional in nature (Bronfenbrenner & Morris, 2007). From birth onwards, a developing child’s focus is on the external world: people, objects, and symbols in the environment (Bronfenbrenner & Ceci, 1994). As the child interacts with them, he or she influences the environment, provokes responses from the environment, and internalizes experiences through personal transformation over time. This requires active participation of the developing individual, as all development comes from engaging in activities (Bronfenbrenner & Morris, 2007).

It is also suggested that effective proximal processes take place on a regular basis over long periods of time. Theoretically, activities that take place on a regular basis and are not interrupted tend to grow in complexity and stimulate development (Bronfenbrenner & Morris, 2007). Such activities do not necessarily have to include other people, as they can be played out using objects and symbols. However, proximal processes involving these activities should be reciprocal and provoke a developing individual’s learning, thinking, creativity, and discovery of their surroundings and social world (Bronfenbrenner & Morris, 2006).

Proximal processes have the following properties. There is psychological content, which is related to one's perceptions, cognitive, and emotional states; and motivation, or the level of curiosity and engagement in one's environment (Bronfenbrenner & Ceci, 1994). Proximal processes also appear to influence a person's development biologically, theoretically linking a person's genetic inheritance and the phenotypes that manifest over time. As proximal processes become increasingly complex, a developing person learns to build relationships, to sustain increasingly prolonged and focused attention to learning and environment, to generate knowledge as well as apply that knowledge in his or her widening physical and social world (Bronfenbrenner & Ceci, 1994). Through the quality of proximal processes developing person's genetic potentials for intellect, creativity, and physical capability may be realized (Bronfenbrenner & Ceci, 1994).

Person

The extent to which proximal processes influence development depends in part on the characteristics of the developing person. Regardless of possible memory bias in participants' stories, their current perspectives regarding issues represented accumulation of their past experiences. Three characteristics were defined as most influential in terms of guiding the direction and power of proximal processes. They are demand characteristics, resource characteristics, and disposition (Bronfenbrenner & Morris, 2006).

Demand characteristics include features of a person that are easily noted, such are age, sex, and race, but also those that are subjective to other people's opinions such are appearance, behavior, and temperament (Bronfenbrenner & Morris, 2006). Central to demand characteristics is that they influence how a developing person is perceived by others – whether the person will seem inviting or not, which in turn affects the nature and quality of the respective proximal processes with them (Rosa & Tudge, 2013).

Not as obvious are *resource* characteristics, as they relate to a developing person's inner landscape – one's life experiences, skill set, the level of knowledge and intelligence, but are also linked to a person's access to material resources (Bronfenbrenner & Morris, 2006; Tudge et al., 2009). Central to this set of characteristics is the supposition that these resources influence the biological and psychological traits, both positive and negative, which potentially determine the person's ability to effectively engage in proximal processes (Bronfenbrenner & Morris, 2006). For example, a person who is born with a physical disability tends to be more purposefully challenged from birth to perform activities of increasing complexity. Whereas someone who is born able-bodied tends to become resourceful, learns skills, and acquire knowledge over time. These both expand the depth and reach of proximal processes (Bronfenbrenner & Morris, 2006,).

The characteristic of *disposition* represents the internal force that is most likely to affect a person's development in one of two directions, as it pertains to issues of temperament and personal expression. When a person carries a generative force, he or she is curious and responsive to others. He or she tends to engage in solitary activities, as well as in group activities, and has a good level of impulse control (Bronfenbrenner & Morris, 2006). A person who presents with disruptive force experiences difficulties in activities with others, as he or she is often impulsive, explosive, and easily distractible.

Unlike a person with generative force, he or she cannot delay immediate gratification, and more readily engages in aggressive and violent behaviors (Bronfenbrenner & Morris, 2006). Also, developmentally disruptive characteristics include other emotional and behavioral challenges, such are “apathy, unresponsiveness, lack of interest in the surroundings, feelings of insecurity, shyness, or a general tendency to avoid or withdraw from activity” (Bronfenbrenner & Morris, 2006, p. 810).

Context

Bronfenbrenner defined the environment as four interconnected systems (Bronfenbrenner, 1994). These four environments are microsystem, mesosystem, exosystem, and macrosystem. One of the defining features of Bronfenbrenner’s understanding of environment is that it transcends beyond physical surroundings to include human interaction, patterns, relationships, societal roles, and activities which move from simple to complex and influence a person’s development in a meaningful way (Brofenbrenner, 1994). The impact of the environment is so great that it drives the very content of the proximal processes (Bronfenbrenner & Ceci, 1994).

The *microsystem* is where most of the activities and processes take place for a developing person (Bronfenbrenner, 1994). The basic microsystem is the family, with all the activities and proximal processes that take occur there, such are mother-child interaction, child play, solitary play, caring for the child, etc. Another microsystem is school or peer group, where a different set of activities and proximal processes occur and influence the development of a child.

When all microsystems in one’s life are connected, they form the next structure, which Bronfenbrenner (1994) calls the *mesosystem*. If these four systems were viewed as concentric circles with children at the center, then the mesosystems would be the second circle. This system still directly affects the child but does so more indirectly than microsystems. For example, a child may not be directly involved in parent-teacher communication, but the quality of parent-teacher relationship could have a direct influence on the quality of the child’s life.

Beyond microsystems and mesosystems are *exosystems,* which include interconnection between the systems which indirectly effect the developing person. For example, a child’s mother may be experiencing stress at work. Even though mother’s workplace does not include the child into the mother’s microsystem, it does influence the child’s development as the mother comes home tired and irritable (Tudge et al., 2009).

Finally, the *macrosystem* would be the outermost concentric circle, including all mentioned systems through the patterns of culture, tradition, beliefs, education, external resources, socio-economic status, religion, hazards, and available opportunities (Bronfenbrenner, 1994). The macrosystem is of great importance for human development, as it influences the functioning of its subsystems. Through its belief system and ideology, a macrosystem serves as a “societal blueprint.” Because of that, most activities for children in a given society tend to be similar on a daily basis (Bronfenbrenner, 1994; Rosa & Tudge, 2013).

Bronfenbrenner focused on defining *context* only in his earlier work, even though it remains one of the most misunderstood and misused parts of his theory (Tudge et al., 2009). As the bioecological model evolved, Bronfenbrenner dedicated more attention to proximal processes to the point that they became the core of Bronfenbrenner's theory in its mature form, yet many scholars surpass this and present the bioecological model in its simplified form (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge et al., 2009).

Time

The characteristic of Time is what expanded Bronfenbrenner's work into a third dimension (Bronfenbrenner, 1994). This is evident in textbook illustrations which attempt to depict the bioecological model, placing the above-mentioned environments on a space-time continuum.

The defining feature of Bronfenbrenner's work is that he challenged the notion of time beyond the chronological age, which had been a traditional view in developmental psychology (Bronfenbrenner, 1994). Instead, Bronfenbrenner applied a multi-dimensional chronosystem to the biological model, which allowed for three distinct levels of time, and their respective effects on human development (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013).

As mentioned before, Bronfenbrenner insisted that to have any effect, all activities must take place on a regular basis over periods of time. In this postulate, we can differentiate between *microtime*, which refers to continuity and discontinuity of proximal processes; and *mesotime*, which refers to larger time periods during which proximal processes take place (days, weeks, and months). Finally, *macrotime* refers to the larger historical picture, as a chronological feature of a particular era, which influences current lifespan outcomes, but also outcomes of future generations (Bronfenbrenner & Morris, 2006). Bronfenbrenner’s *chronosystem* takes into consideration not only consistency and changes over time of a developing individual, but also of the entire macrosystem, giving the component of time not only chronological, but also ontological and historical value (Bronfenbrenner 1994; Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013).

PPCT Model

In order to avoid misuses of the bioecological model, it was recommended that PPCT model be used in studies which attempt to apply this theoretical system (Tudge et al., 2009). Bronfenbrenner and Morris (2006) defined PPCT as a research design which allows the exploration of the multidimensionality of human development.

In PPCT the characteristics of the person serve two roles – first as an active producer who affects the environment through actions and proximal processes, and second as the product of the environment, as all proximal processes are bidirectional (Bronfenbrenner & Morris, 2006).

Proximal processes are given central role in human development, and their concept has several explicitly stated properties in PPCT. First, human activity is a precursor for development. Development is defined as “stability and change in the biopsychological characteristics of human beings over the life course and across generations” (Bronfenbrenner & Morris, 2006, p. 796). For activities to be developmentally relevant, they must be performed regularly over a span of time. For example, occasional horseback-riding lessons do not qualify as effective activities unless they become part of a child’s schedule on a regular basis. Further, activities must continually expand from simple to complex, as repetition of learned tasks does not qualify as development. Also, the proximal processes that the developing individuals engage in must be bidirectional, even when they involve objects and symbols. Finally, significant persons in a child’s life are those who maintain a steady level of presence in a child’s life (e.g., parents, relatives, peers, teaches, coaches; Bronfenbrenner & Morris, 2006).

It is presumed that through PPCT human development can be studied as taking place through activities and proximal processes, which become increasingly complex as the person matures, and extend across multiple environments over time. When development takes positive direction, a person gains the abilities and opportunities to realize his or her genetic potential (Bronfenbrenner & Morris, 2006).

Background on the Application of the PPCT Model

Bronfenbrenner’s (1994) ecological systems theory (EST) was first introduced in the 1970’s. Bronfenbrenner continued to update EST until his death in 2005, The result is the bioecological model of human development as its mature and final form (Rosa & Tudge, 2013; Tudge et al., 2009). In their analysis of 25 research papers, Tudge et al. (2009) named only four distinct studies that used Bronfenbrenner’s PPCT model correctly. Due to the sensitivity of this issue, two studies from Tudge et al.’s (2009) list were chosen to depict how Bronfenbrenner’s PPCT model was used appropriately in ways similar to the design of this study.

Tudge et al. (2003) posited that Bronfenbrenner’s ecological theory was an ideal approach to studying a child’s transition to school, as it involved continuous interplay between a child and its contexts. In their study they used the ecological PPCT model to examine the relationship between the activities that pre-school children engaged in that were relevant to school and the subsequent teachers’ perception of their competence after they have started school (Tudge et al., 2003).

In PPCT, Tudge et al. (2003) defined Process as the everyday activities that the preschoolers engaged in, Person as the tendency of the participant-children to initiate the activities in which they were engaged, Context as two social classes from which the participant-children were sampled from (e.g. middle- and working-class families in the United States), and Time as those periods when the participant-children were observed (e.g., three points in time: as preschoolers, at the end of first grade, and at the end of second grade in school).

Campbell et al. (2002) conducted a longitudinal study to examine what early childhood factors among African American adolescents from low-income families were significant predictors of self-perceptions of academic competence and overall self-worth. Campbell et al. (2002) utilized Bronfenbrenner’s PPCT model by linking it to the aspects of the participants’ early childhood in order to examine their longitudinal interactions (Tudge et al., 2009). They defined Person through the participants’ academic performance which served as a predictor of the perceived academic competence and self-worth (Campbell et al., 2002). The Processes of interest were defined as interactions between the participants and their parents as well as the quality of family environment. The factors which defined the Context were “the quality of the early home environment and the provision of full-time educational childcare” (Campbell et al., 2002, p. 278).

Finally, the study incorporated the concept of Time by adding the later academic achievements and the elements of the interactions between the participants and their parents at later.

Rationale for Choosing Bronfenbrenner's Ecological Theory

Bronfenbrenner's ecological theory of human development presented an appropriate theoretical framework for this study on several levels. First, the aim of this study was to include the voices of young adults who presented with p-CMS in the discussion about CMS among typically developing individuals. Viewed through the lens of Bronfenbrenner's work, young adults with p-CMS are active agents in their development who engage with their academic and social environments bidirectionally – they influence the environments through actions and receive the feedback from the environment (Bronfenbrenner, 1977; Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006). In that light, a person is both the producer and the product of the environment.

P-CMS is a phenomenon that does not occur in isolation. Reportedly young children and some adolescents freely express their stereotypies in public and have some awareness of the attention that they get from others (Ricketts et al., 2013). As they mature, they learn how to suppress the stereotypies and manage them in private (Mackenzie, 2018). Little is known from the previous studies regarding how the feedback from others relating to their p-CMS affects them internally, especially in academic and social settings where the possibility is high that their CMS will be perceived as unconventional and socially offensive (Hedderly, 2017; Péter et al., 2017).

Bronfenbrenner highlighted that through interactions individuals internalize what they perceive in the external world so that the external becomes the internal (Bronfenbrenner & Morris, 2007). Bronfenbrenner’s work provided an appropriate framework to explore the following curiosities: if individuals who presented with p-CMS enjoyed their CMS, but were continuously reminded that the expression of their condition made them different from others, how did that shape their internal views of themselves? What meaning did they assign to their CMS?

Secondly, there was a wealth of information about motor stereotypies among autistic individuals, and CMS were considered to be the hallmark of this neurological disorder (Barry et al., 2011; Cardona et al., 2016). Studies on CMS among typically developing populations were modest (Hedderly, 2017; Lemiere, 2014). Young adults with p-CMS live in an era where research on their condition was promising to bring more answers, yet there was little social awareness that not all who presented with CMS were autistic. In order to explore lived experiences p-CMS engaging young adults, it was necessary to reflect on their past while at the same time discussing their present quality of life and well-being. Viewed through Bronfenbrenner’s (1994) concept of time, observed multi-dimensionally through the three layers of microtime, mesotime, and macrotime, allowed me to explore the lived experiences of young adults who presented with p-CMS in more depth.

In the last two decades there have been more systemic initiatives towards inclusion of populations deemed as different into all levels of the society. This was evident in the passing of the No Child Left Behind Act (NCLBA) in 2001 (Heise, 2017), and the Employment Non-Discrimination Act (ENDA) in 2007 (Robinson et al., 2009). Although these acts referred to different social environments and protected the rights of different populations, they provided a legal framework for society at large to embrace the differences among its social groups. Young adults with p-CMS who were included in this study had lived with their condition before these acts were passed, as they were older than 21 years. Yet they had had the experiences with the changes through academic and/or work environments. Bronfenbrenner’s ecological systems theory accounted for the influences of both the macrosystem – societal beliefs and ideologies, and macrotime – the particular historical era in which an individual lives (Bronfenbrenner & Morris, 2006) and provided a rich theoretical framework for the delivery of this study.

Literature Review Related to Key Concepts

Differentiation and Diagnosis of P-CMS

Not all stereotypies are the same. Most people engage in some form of stereotypical behavior, such as playing with hair and fingers, moving to music, biting nails, etc., depending on individual preferences and culture (Freeman et al., 2010). But stereotypies become noticeable when their manifestation is out of the cultural norm, when their pattern is unusual, intense, self-injurious or when it interferes with daily activities (Freeman et al., 2010). In the DSM-V, p-CMS is not categorized. The term “stereotypic movement disorder” (SMD) is used to describe clinically relevant repetitive movement when it interferes with daily activities and threatens to result in self-injury (American Psychiatric Association [APA], 2013). This will be explained in detail in Chapter 5.

According to Singer (2009) p-CMS has been reported in 4% of typically developing children in the United States with an early onset – usually before the age of 3 years.). Proper clinical diagnosis of p-CMS is necessary (Barry et al., 2011), but often difficult to obtain (Freeman et al., 2010; Freeman & Duke, 2013). Parents who seek professional help look for explanations of their child’s peculiar movements, seeking reassurance and diagnosis and expecting relevant information from their pediatrician (Mills & Hedderly, 2014). Many of them share concerns towards seizures (Mackenzie, 2018), but also towards autism spectrum disorder (ASD), as stereotypies are typically seen in autistic children (Cardona et al., 2016).

A correct diagnosis of p-CMS is, in its essence, “a diagnosis of exclusion” (Barry et al., 2011, p. 981) as it is required that p-CMS be differentiated from other conditions (Freeman & Duke, 2013; Mills & Hedderly, 2014; Valente et al., 2019). Additional diagnostic challenges are posed by a vague clinical definition of stereotypical movement disorder, making it difficult to determine when a specific stereotypical movement can be classified as a disorder.

In typically developing children, conditions such as intellectual disability and autism are easily ruled out, but difficulties arise when p-CMS must be differentiated from high-functioning autism spectrum disorder (ASD; Cardona et al., 2016). To produce a correct diagnosis, p-CMS must be differentiated from tics, seizures, and compulsions, as each of these conditions requires a different therapeutic approach (Barry et al., 2011; Freeman & Duke, 2013; Mills & Hedderly, 2014;). When correct differentiation has not been established, an individual is more likely to be incorrectly diagnosed with ASD and/or Tourette's syndrome (Freeman et al., 2010).

In the literature, the most importance is given to differentiation of p-CMS from tics, as they can sometimes both be present in a person (Temudo & Melo, 2015), yet require a different management approach (Mills & Hedderly, 2014). In this regard, there are several distinguishing characteristics of p-CMS. The first is that children with p-CMS report no premonitory urge to perform their stereotypies and describe those movement episodes as pleasant (Barry et al., 2011; Mackenzie, 2018). Premonitory urge is defined as a sensation that rises before the involuntary movement and is consciously detectable by the experiencing person (Mackenzie, 2018). In contrast to children with p-CMS, children with tics experience a premonitory urge as an unpleasant sensation which passes as they engage in tics (Barry et al., 2011; Mackenzie, 2018; Mills & Hedderly, 2014).

Additionally, tics involve specific muscle groups such as eye muscles, facial muscles, and muscles in the head and shoulders (Freeman & Duke, 2013). These muscles are mobilized in recognizable patterns, such as "blink and then head nod to the right, blink and then head nod to the right" (Mackenzie, 2018, p. 22), whereas p-CMS can be expressed in a variety of ways (Barry et al., 2011; Mackenzie, 2018; Mills & Hedderly, 2014). There is a tendency for tics to change over time, while stereotypies tend to be person-specific and constant over time (Barry et al., 2011; Mackenzie, 2018). Both tics and p-CMS can be suppressed, but the main difference is that the presence/absence of the premonitory urge determines how this is executed (Mackenzie, 2018; Mills & Hedderly, 2014). Tics are usually internally managed, while the suppression of p-CMS in children requires external intervention by the parent or teacher (Mackenzie, 2018; Mills & Hedderly, 2014). Finally, stereotypies differ in the age of onset. Typically, p-CMS appears before the age of 3 years, whereas tics often appear after the age of 3 (Barry et al., 2011; Freeman & Duke, 2013; Mackenzie, 2018; Mills & Hedderly, 2014).

Correct diagnosis of p-CMS also involves differentiating motor stereotypies from seizures (Barry et al., 2011; Freeman & Duke, 2013; Mackenzie, 2018). While movements of both seizures and stereotypies may appear similar at times, seizures usually require psychopharmaceutical intervention while stereotypies usually respond to cognitive behavioral therapy (Barry et al., 2011). The distinguishing characteristic of p-CMS is that stereotypies are usually situationally dependent on internal triggers such as boredom or excitement (Mackenzie, 2018; Mills & Hedderly, 2014). Seizures are rarely suppressible without medication, while stereotypies typically cease with distraction (Mackenzie, 2018). Finally, stereotypies tend to be persistent and occur many times a day, whereas seizures tend to occur less frequently with distinct episodes (Freeman et al., 2010; Mackenzie, 2018).

Freeman and Duke (2013) posited that stereotypies should also be differentiated from compulsions. Compulsions present ritualistic behaviors which are reported to reduce stress and are as such purposeful (Mills & Hedderly, 2014), unlike stereotypies which are deemed as purposeless (Barry et al., 2011; Gao & Singer, 2013; Singer, 2011).

Individuals who experience compulsions perform a variety of behaviors which are peculiar and seem to be energized by a desire to relieve the compulsion (Mills & Hedderly, 2014). For example, a person who may feel the compulsion to wash hands in fear of infection, or to count and/or arrange objects in a specific way (Mills & Hedderly, 2014).

Stereotypies, which are both characterized by the lack of premonitory urge and stop with distraction, are unlike compulsions which are reported to be driven by the need to be performed in fear of “impending doom” (Mills & Hedderly, 2014, p. 27). Compulsions often occur within a set of inflexible rules and intrusive thoughts (Mahone et al., as cited in Mills & Hedderly, 2014), while p-CMS occur freely and bring enjoyment (Barry et al., 2011; Mackenzie, 2018).

Management of P-CMS

Little is known about how individuals with p-CMS adapt to their condition and how individuals manage them over time. According to a longitudinal study (Oakley et al., 2015), 49 individuals who experienced p-CMS had a persistent course into adolescence and adulthood, showing that 23% of the participants experienced stereotypies in the range between 10 and 15 years, while 19% of the participants reported experiencing the stereotypies for more than 15 years. Most of the participants (77%) shared that their stereotypies decreased in severity and frequency, becoming more manageable over time, but the study did not reveal the depth of their experiences – specifically how the participants learned to manage their stereotypies, and what implications that had on the quality of their lives. It has been speculated that forced attempts to manage the p-CMS in childhood may be stressful, but that as a child’s nervous system develops, their ability to suppress and manage the stereotypies at will emerges, possibly bringing them a sense of gratification and freedom (Hedderly, 2017).

Ricketts et al. (2013) conducted a series of case-studies which involved two 13-year-old girls, each with a distinctive stereotypical pattern. These young adolescents' parents sought treatment options, as the girls' stereotypies interfered with their social and academic lives. In the first case, parents shared that their daughter tended to stop her regular activities to perform her stereotypies, regardless of the circumstances. She performed her stereotypies in public, during class, at the time of school recess, at her friend's house etc. at the expense of the opportunities to socialize with peers and/or to study (Ricketts et al., 2013). In the second case, the adolescent's father shared that his daughter expressed her stereotypies when she was stressed or engaged in physical activities and had no recollection that the episode of her p-CMS had occurred unless someone brought attention to it. It was noted in both cases that these young adolescent girls appeared to be in a trance-like state while performing their respective stereotypies. Ricketts et al. (2013) discovered that in these two cases, their subjects had not developed adaptive abilities to manage their stereotypies at age 13, but that they responded well to individualized behavioral therapy.

It should be mentioned that both the longitudinal study (Oakley et al., 2015), and the case-study (Ricketts et al., 2013) reported significant levels of anxiety among its older participants, the oldest being at the age of 20 years. Oakley et al. (2015) noted that anxiety was present in 73% of their participants, while Ricketts et al. (2013) reported significant levels of anxiety in both young adolescent participants.

P-CMS in Academic and Social Settings

To explore the effects of p-CMS over time, several longitudinal studies had been undertaken. These studies were based on primary and secondary data through adolescence of young individuals with primary motor stereotypies (Freeman et al., 2010; Oakley et al., 2015). Oakley et al. (2015) conducted a large longitudinal study involving 49 participants, ages between nine and 20 years in order to assess the life course of p-CMS as well as its comorbidities. The study brought to light many significant features of complex motor stereotypies among typically developing children, but most importantly, discovered that the manifestation of p-CMS was persistent throughout adolescence with a significantly small resolution in only 2% of the participants (Oakley et al., 2015). This showed that even though children learn to manage their p-CMS as they become more aware of them, the expression of p-CMS does not cease with time (Oakley et al., 2015). This is similar to the findings of Freeman et al. (2010) who were the first to report that contrary to the popular belief, p-CMS are not transient. P-CMS seem to have a persistent course but become less noticeable to others as individuals learn how to manage their stereotypies in public, and express them in private (Freeman et al., 2010).

Oakley et al.’s (2015) study showed that p-CMS decreased in frequency and duration as children got older, causing them no functional impairment. But researchers found an alarming prevalence and magnitude of comorbidities in more than 90% of their 49 participants. Anxiety raised the most concern as it was detected in 73% of the participants. Although anxiety was also found on a concerning level in an earlier case study series involving young adolescents with p-CMS (Ricketts et al., 2013), Oakley et al. (2015) noted that up until their study anxiety had not been assessed by other researchers, yet it appeared significantly prevalent among children with p-CMS. Other important comorbidities that Oakley et al.'s (2015) study uncovered among individuals with p-CMS included ADHD (73%), OCD (35%), and motor tics (22%).

Oakley et al. (2015) discovered that most participants in the study performed well academically and were placed in age-appropriate classrooms. Of the 49 participants 84% reported that they earned grade average of B and above, and/or were on honor roll. It was also found that some participants in the study received Special Education services at some point in time, and three out of 49 participants received services for speech/language disability. Even though this study showed high level of academic functioning among children and adolescents with p-CMS, 59% of the participants reported having experienced some level of challenges in school, primarily with focus and attention.

Manifestation of p-CMS in public can be deemed as unconventional and socially offensive (Hedderly, 2017; Péter et al., 2017), leading to social stigmatization of a child who presents with p-CMS (Singer et al., 2018; Specht et al., 2017). Research shows that children with p-CMS are not aware of their stereotypies, experience no premonitory urge, and do not learn how to suppress the stereotypies until later age (Freeman et al. 2010; Oakley et al., 2015). This leaves children with p-CMS vulnerable to stares of others, questions and comments, as was reported by Ricketts et al. (2013). Additionally, in some cases children with p-CMS feel the need to perform their stereotypies for hours at a time at the expense of academic and social activities (Ricketts et al., 2013), risking to miss developmentally important milestones (Robinson et al., 2014).

For example, a case study involving a 13-year-old girl with p-CMS showed that she engaged in stereotypical behavior not only at home, but also at school during recess, and at her friend’s house. (Ricketts et al., 2013). Her parents were concerned that the amount of time their daughter invested engaging in her stereotypies were detrimental to her social and academic development (Ricketts et al., 2013).

It is difficult to assess to which extent children with p-CMS are affected by their stereotypies in a social context, as p-CMS vary in frequency and intensity, but are also individual to person. No studies have been undertaken to examine to which extent p-CMS affect the social life of an experiencing person, but to describe this variance, the easiest way is to look at the two extremes that have been recorded. Oakley et al. (2015) found that a relatively small number of participants – 3 out of 9 - in their longitudinal study reported issues with teasing at school, but an earlier case-study showed that bullying of children with p-CMS can be internalized as so extreme that it warrants a change of school (Ricketts et al., 2013). It remains unknown how individuals with p-CMS interpret these social experiences.

Meaning of P-CMS

The American Psychological Association (APA, 2013) deems all stereotypic movements nonfunctional. In literature p-CMS are described as “purposeless” although scientists noted that they may seem to have a purpose (Barry et al., 2011; Gao & Singer, 2013; Singer, 2011). In contrast, compulsions, which include a variety of ritualistic behaviors (e.g., hand washing, arranging, and counting objects, etc.) are defined to have a purpose as they reportedly relieve stress (Mills & Hedderly, 2014). Barry et al. (2011)

attempted to expose that viewing stereotypies as nonfunctional is one-sided as it only takes into account the observable "nature of the action, rather than the person performing it" (p. 980).

This one-sided view in the past research efforts in the realm of CMS has been consistent with a view that CMS is a problem in need of a solution. This uncovers a hidden framework, which Titchkosky and Michalko (2012) call "disability as a problem," and which is defined by the following questions: "what went wrong, how can it be fixed, and brought back to normalcy" (pp.127). A number of studies on p-CMS focused on uncovering biological sources which are the possible causes of stereotypies in typically developing children (e.g., Harris et al., 2016; Mahone et al., 2016), which reflects the first question. Another volume of research was dedicated to testing various therapeutic interventions (e.g., Singer et al., 2018; Specht et al., 2017; Freeman & Duke, 2013), which reflects the other question. Inspiration to look for a solution to the problem of p-CMS is natural and well-needed; however, what has been missing is the attempt to investigate the authentic life experiences of those who present with p-CMS.

Several studies have uncovered some subjective experiences (Oakley et al., 2015; Ricketts et al., 2013) of children with p-CMS, but it remains unknown what the presence of p-CMS brings to those who experience them in social and academic settings, what personal meaning individuals with p-CMS give to their stereotypies, and what there is still to learn from their subjective experiences.

If science continues to view p-CMS as a problem in need of a solution, then it will continue to produce one-sided results that are based on the observer's understanding of what these movements are and not on the understanding of the person performing them (Barry et al., 2011; Titchkosky & Michalko, 2012). This study aims to include the voices of the experiencing individuals in the scientific discourse.

Summary and Conclusions

Primary complex motor stereotypies (p-CMS) are repetitive, rhythmic, and predictable involuntary movements which occur in typically developing individuals and stop with distraction (Singer, 2009). Although p-CMS are typically observed in the presence of other neurological disorders such as autism and Tourette syndrome, they occur in 4% of otherwise neurologically healthy children (Singer, 2011). An episode of p-CMS usually lasts from several seconds to several minutes and it mobilizes different parts of the body, which is why they are considered complex. Studies show that young children have no awareness of the stereotypy until the episode has ceased, experience no premonitory urge, and have no control of their stereotypies, but report it as pleasurable experiences (Ricketts et al., 2013). Parents, however, describe p-CMS as a stressful aspect of their life, as their child's stereotypies appear to "dominate all life activities" (Hedderly, 2017, p.117).

Past studies on p-CMS have mainly been focused on studying its defining properties, neurological underpinnings, and the effects of various treatment approaches to manage p-CMS. Most of the studies were based on observations of children and young adolescents and relied on parental reports and interviews. This approach to studying p-CMS mainly produced observational data, with scarce amounts of insight into the subjective views of the experiencing individuals. This study aimed to approach this informational gap in the literature by exploring the lived experiences of young adults who presented with p-CMS. The goal was to move the experiencing individual from being an object of research to becoming a primary source in research in order to bring the voices of young adults with p-CMS into the scientific discourse. Theoretical framework for my study was the mature version of the well-known Bronfenbrenner's ecological systems theory (1994), which is called the bioecological model of human development (Bronfenbrenner & Morris, 2007).

In the following chapter research design is further explained along with the rationale for the design of the study. Also, the role of the researcher is defined followed by detailed overview of the study methodology, procedures for recruitment, participation, and data collection. Finally, data analysis plan is presented followed by consideration of ethical procedures.

Chapter 3: Research Method

In order to study the lived experiences of young individuals who presented with p-CMS, I chose the qualitative design with a phenomenological approach. The purpose of the study was to explore how p-CMS were expressed subjectively, what they meant to those who experienced them, how these stereotypies affected them in terms of academic, social, professional, and personal issues, and what it was that p-CMS experiencers felt that society surrounding young adults with p-CMS should know about individuals who present with p-CMS. Past scientific research involved parents and small children as primary sources, as well as public records as secondary sources. However, there is a paucity of studies which included the voices of young people who experienced p-CMS. The purpose of the study was to bring these young people into the scientific discourse, as any attempt to fully grasp p-CMS without an understanding of how they are experienced and what they mean to those who experience them is futile.

In the following chapter, I first provide the rationale for the current research design, then describe the role of the researcher and methodology. In the latter section, I define targeted population, sample size, procedures, instruments, and data analysis plan. Finally, in the last part of the chapter, I explain issues of trustworthiness as well as ethical concerns.

Research Design and Rationale

P-CMS are repetitive, rhythmic, and predictable involuntary movements in otherwise typically developing individuals (Singer, 2009). They tend to have fixed patterns, which often involve multiple parts of the body (e.g., hand flapping, ankle, and wrist rotation, waving, grimacing), and last from several seconds to several minutes throughout the day. CMS are considered hallmark of autism, even though they also manifest among typically developing children. P-CMS are easily confused with tics and compulsions and present a challenge not only in terms of diagnosis, but also management and adaptation.

Children who present with p-CMS are at risk of stigmatization; but children and young adolescents prefer their stereotypies to other activities and are often unaware of them (Ricketts et al., 2013). They also learn how to control their stereotypies as they grow, giving off the impression that p-CMS goes away on their own (Oakley et al., 2015). Currently, there is an unaddressed gap in literature involving how p-CMS are perceived and experienced, with little firsthand information from experiencing individuals. Additionally, p-CMS tends to have a persistent course, and shares comorbidities with other neurological disorders such as anxiety, ADHD, OCD, and tics/Tourette syndrome (Oakley et al., 2015). Hedderly (2017) said not only should more scientific investigations include voices of experiencing individuals, but researchers should investigate what happens to children with p-CMS in adulthood.

This qualitative study involved bridging the gap between how p-CMS were viewed and experienced by interviewing young adults who presented with p-CMS. It was assumed that young adults were cognitively able to recall, explain, and verbalize their lived experiences in more detail and richness than children were. The study was delivered via in-depth phenomenological interviews exploring the essence of their lived experiences involving how these young adults described their p-CMS relative to their academic and social environments, what meaning they gave to their condition, and what these young adults felt that society surrounding young adults with p-CMS should know about p-CMS which had not yet been investigated.

Research Questions

RQ1: How do young adults who present with p-CMS describe inducing events of CMS movements as related to their social, academic, and personal environments?

RQ2: What meaning do young adults who present with p-CMS give to their stereotypies?

RQ3: What is it that they think that society and science should learn and understand about typically developing individuals who present with p-CMS?

Role of the Researcher

According to Kvale (2006), qualitative researchers explore various levels of human experience. Creswell (2014) saw researchers as instruments in qualitative studies.

So, when defining my role as a researcher, I followed 3 steps suggested by Havercamp (2005), Kvale (2006), and Qu and Dumay (2011). Firstly, to serve as an empathetic listener; secondly, to be aware of power asymmetries that exist when interviews are used as instruments in research and thirdly, to avoid common mistakes that well-meaning interviewers often make.

My biggest concern was that my empathetic presence may induce some participants to reveal more intimate details which they might later regret (Kvale, 2006). I addressed this vulnerability in several ways: (a) by staying consciously aware of my role in maintaining the natural flow of interviews; (b) by making clear my role as a researcher at the beginning of the study; and (c) by giving an opportunity to subjects to withdraw any information from the study which they regretted sharing.

In that regard, my role in this study was to design the study, develop protocols and questions for interviews, recruit and select participants, collect, and analyze data, and present findings to the best of my ability. I viewed myself and participants as equals in the study.

Research Methodology

Sampling

The study was designed to explore data among non-autistic young adults who presented with p-CMS in the US. In determining the sample size and frame, I held the view that in qualitative studies, the process of sampling is multidimensional, as it refers not only to participants in the study but also to quality of future data. Therefore, it represented a reflective process and series of decisions on my part that could affect outcomes of the study.

Participants in this study were young adults who presented with p-CMS and were active in social media groups involving motor stereotypies. There were several online communities on Facebook which were created to connect parents of children with p-CMS with others who were interested in this subject. Through public posts, members of these groups shared their ideas, resources, questions, and mutual support. Many active members of these groups were adults who self-identified with p-CMS and willingly engaged in discussions to encourage and support parents of young children with p-CMS.

I applied purposeful sampling for this study. I assumed that those who participated in online communities were in some way actively interested in the topic of p-CMS; that they found it important and/or enjoyable to discuss. Potential participants were recruited through a series of informal invitations posted in forums of these communities to ensure voluntary participation and accessibility. Each post explained necessary details of the study, my involvement, and characteristics of the ideal subject. All interested volunteers who felt that they fit these profiles were instructed to email me. The sample was drawn from volunteers who further qualified for the study.

Purposeful sampling was used to determine the best fit for the study. The targeted sample size was seven participants (age 21 to 29), but the final number of participants was ultimately determined based on the concept of saturation and was reached at six participants. The concept of saturation means the researcher should continue to collect data until no new information are obtained (Morse, 1995). When deciding the final sample size of the study, I considered that in qualitative studies large samples could complicate the data coding process while not yielding much new information, hence the final number of six participants.

Exclusion/Inclusion Criteria

Participants were young women and men between the ages 21 and 29, years who presented with p-CMS and were aware of their condition. These criteria excluded younger children and teenagers. Also, they excluded any individuals whom I personally knew or had worked with in the past in order to ensure that there were no blurred boundaries between me and subjects.

Table 2

Sample Interview Questions

Examples
Can you tell me a little bit about yourself?
Can you tell me a little bit about your stereotypies?
What is your earliest memory of the stereotypies?
What is your earliest memory of someone noticing your stereotypies?
Can you recall how that comment made your feel?
In your opinion, how does the rest of the world perceive primary CMS?
What is it that the rest of the world should know about the CMS?
What is it that the rest of the world should know about the children and adults who present with primary CMS?

Procedures

To recruit participants for the study I first composed a list of Facebook groups involving the topic of p-CMS. Next, I located and directly messaged the groups' administrators. In those messages, I clearly explained the intended nature of my involvement in their group and requested the administrators' approval to post information about the study.

Then, I began posting IRB-approved information about the study, inviting all interested volunteers to email me for further information. For those Facebook group members who responded to my posts I initiated further email exchange to ensure the members' privacy. I began scheduling and conducting 15-to-45-minute screening calls via online Zoom meetings. Upon the completion of all screening calls, I emailed consent forms to those volunteers who expressed willingness to partake in the study.

For the purposes of data collection, I scheduled video interviews via Zoom meetings for all confirmed volunteers. I also emailed each participant a private individual link to the call along with the preliminary interview questions.

Next, I conducted and recorded the interviews. I offered to email a copy of the recording to each participant. I transcribed the interviews personally to avoid misunderstanding and errors. Finally, I collected all the transcriptions into Microsoft Word documents. For the purposes of data analysis, I uploaded each transcript into NVivo software platform and continued with this phase of the study according to the steps outlined later in this chapter.

Furthermore, I scheduled and delivered follow-up (member checking-in) calls with each of the participants to confirm to which extent my interpretations reflected their lived experiences. Finally, I analyzed the new data which emerged from the follow-up calls, and I made the appropriate adjustments and corrections to my interpretations of the findings, according to the participants' input.

Data Collection

Interviews are the most used data collection tool in qualitative research, as they provide an opportunity for researchers to gather information of various depth and thickness. Depending on the level of inquiry, interviews can be unstructured, semi-structured, or structured (Knox & Burkard, 2009). I used semi-structured phenomenological interviewing to explore the essence of lived experiences of young adults with p-CMS.

Interview questions were designed using a semi-structured format to reconcile the emergent nature of qualitative designs with the necessity that all participants be given an equal chance to share their life experiences in detail. The idea was to develop a uniform protocol using open-ended questions but remain flexible and creative to ensure that each participant had an equal opportunity to share their story in depth.

All interviews were conducted via Internet video and phone conferencing, except for one telephone call. Video conferencing enabled access to the study for the participants who lived in remote locations, while maintaining safety, comfort, and convenience for all. With participants' consent, all interviews were recorded. Original recordings were converted into MP3 format and stored on a password-protected hard drive specifically assigned for this study to ensure privacy and protection of data. All participants were offered recorded copies of their interviews.

Interview recordings were transcribed using transcription software. Details about this transcription software will be discussed in Chapter 4. Relying on automated transcription services did not guarantee that this convenient service would yield rich quality data, as the computer cannot detect nonverbal cues present in interviews such as the tone of voice, pauses, and emotion. Therefore, follow up transcriptions of interviews allowed me to hear participants again, allowed for intuitive connections to emerge, and reflect on interviews as I transcribed them.

In deciding the number of interviews per participant and their duration, I reflected on two opposing concerns. Firstly, I wanted to ensure that I had enough contact with participants to build rapport and trust. It is common knowledge that participants are more willing to disclose difficult or emotionally charged experiences to those with whom they have had established some level of trust and contact. Secondly, I did not want to invest too much time in relationship building, which could lead to “blurred boundaries” and affect outcomes of the study (Knox & Burkard, 2009, p. 8). Therefore, I decided to use two 60-minute interviews per participant. The first interview allowed participants to tell their stories and share experiences, and the second interview allowed them to share their thoughts regarding the meaning of their experiences involving p-CMS. Time between interviews allowed for reflection and potentially led to additional information.

Finally, after two private interviews were conducted with each participant, all participants were invited to participate in follow up calls in which I shared my findings and suggested additional reflection. Participants were given the option to exit the study after the call or add to or remove statements made during the first interview.

Data Analysis Plan

The data analysis plan was designed with consideration of the role that the researcher’s subjectivity played within qualitative design. According to Giorgi (2002), someone using a phenomenological approach in a study should not try to eliminate subjectivity, as subjectivity cannot be divorced from knowledge, but to clearly define the role of researcher’s subjectivity in the study. In that regard, a researcher should try to understand under which conditions he or she is perceiving the participants’ responses as they are, as opposed to the conditions under which he or she is allowing their subjectivity to distort the participants’ responses (Giorgi, 2002). In order to utilize my subjectivity in service of the study, I decided that study data would be analyzed via open and axial coding with the use of NVivo software for data analysis.

Open coding is a tool used in qualitative studies to enable the researcher to systemically organize and analyze the raw data (Mills et al., 2010). Through open coding, researcher converts the raw, gathered data into a broad list of categories, starting with age, gender and occupation. This process requires a combination of theoretical knowledge and intuition on part of the researcher, as it is required that the researcher interacts with the raw data first to analyze it and categorize it, but to then question and compare generated categories to the original data (Mills et al., 2010).

In phenomenology, intuition is defined as “being present to consciousness” (Giorgi, 2002, p.9). In this way, both my technical knowledge and intuition were used to access the initial data, but through open coding my subjectivity was limited in the study (Mills et al., 2010). In this study, I intended to explore the lived experiences of young adults who presented with p-CMS by gathering data on how the participants described their p-CMS episodes relative to academic and social environments, what meaning they gave to their p-CMS, and what it was that they felt society should know about p-CMS from their point of view. Given that this study was conducted through in-depth phenomenological interviews, a significant amount of raw data was initially collected. Open coding enabled me to approach the initial data in a systemic way and organize it into relevant categories, without reducing the data (Mills et al., 2010). After all the initial data was analyzed, identified, and categorized I proceeded with axial coding.

Axial coding is also a tool used in qualitative research, which further examines the interrelationship among categorized data (Mills et al., 2010). Whereas open coding reveals to a scientist a number of meaningful categories generated from the raw data, through axial coding one central phenomenon is defined, which represents the axis. The researcher then engages into a multi-layered process of studying the categories and subcategories of the phenomenon to identify the conditions that are related to the phenomenon, its interactions with other elements of the study, and the consequences of the phenomenon. Finally, through axial coding a researcher observes relationships and interactions that could have gone unnoticed during open coding (Strauss & Corbin as cited in Mills et al., 2010).

Issues of Trustworthiness

Qualitative studies in large part rely on the researcher's intuition for collection and interpretation of data and have been traditionally vulnerable to criticism (Giorgi, 2002). There is a common understanding that qualitative researchers should demonstrate that the inferences drawn from their study are trustworthy or credible (Hammersley & Atkinson, as cited in Creswell & Miller, 2000). In the following passages four categories of trustworthiness will be discussed and they are: credibility, transferability, dependability, and confirmability (Creswell & Miller, 2000).

Validity of a study is defined by how accurately its findings represent "participants' realities of the social phenomena and is credible to them" (Creswell & Miller, 2000). The two types of validity are internal and external.

Internal validity refers to the accuracy of the conclusions the researcher reaches from the data gathered (Mills et al., 2010). To ensure internal validity, I used member checking: a process of transcribing the first interview and following up with a second interview to allow the participant to review, approve, or change their statements in order to more accurately reflect their meaning (Creswell & Mills, 2000).

External validity relates to the concept of transferability – that the results of one study could be transferred and generalized to a larger group or population (Mills et al., 2000). In order to ensure external validity, I used the process of thick rich description, which means that I explained various aspects of the study in great detail in order to enable the reader to experience the state of affairs as they were narrated (Creswell & Miller, 2000).

The third quality of trustworthiness is dependability, which is concerned with how findings of the study can be consistently applied to other contexts, social groups or settings (Noble & Smith, 2015). In this study I used the process of triangulation to ensure dependability. Triangulation is a process of approaching the data in a systematic way to define themes and categories among multiple sources (Mills et al., 2000).

Finally, confirmability is the fourth quality of trustworthiness, and it ensures that the findings of the study are consistent with the participants' input and not with the researcher's subjectivity (Noble & Smith, 2015). In order to ensure confirmability, I used the process of researcher reflexivity to account my personal opinions, biases, views, and beliefs (Creswell & Miller, 2000).

Ethical Procedures

The aim of this study was to explore the lived experiences of young adults, ages 21 to 29 years, who presented with p-CMS. Participants were recruited from Facebook groups committed to gathering members around the theme of p-CMS of which I was not a member to ensure equal participation and the absence of any conflict of interest. Participation in the study was voluntary. Participants were informed of the purpose of the study, its main features, and design, and their right to withdraw at any time through briefing and debriefing (Mills et al., 2000). Additionally, all participants were informed of the potential risks and benefits involved in participation in the study (Mills et al., 2000).

Confidentiality in the study was handled on a case-to-case basis. Participants had the opportunity through informed consent to decide whether they wanted to participate anonymously or if they wished to be fully accredited for their participation in the study (Mills et al., 2000). Since the participants of the study are of legal age, information from their respective interviews were only available to them and to the researcher. All collected data was stored in a separate hard-drive and password protected. It will be kept for five years after the submission of the dissertation and then deleted.

To ensure that participants were protected from harm, the proposal of this study was sent to the Institutional Review Board (IRB) of Walden University for approval. Although this study was designed to ensure that the ethical principle of beneficence is met, there were several potential risks for participants such as emotional distress and unintended disclosure. Emotional distress may occur because of the participants' recalling of painful memories. Although it was unlikely that participants would be exposed to emotional distress during the study, this topic was included in the informed consent and discussed with the participants. Additionally, a licensed professional psychologist was made available in case any participant felt that he or she needed professional help as a result of the interview. Finally, in-depth interviews have been known to lead the participants to over-share personal information, which they may later regret (Mills et al., 2000). In case this happened, any data that participants decided should not be included in the study was excluded from the raw data. To ensure the privacy of all the participants, their names were coded, with the original list of names and nicknames kept in a password-protected safe box at my office.

In defining my role as a researcher, who conducted all the interviews, I reflected on the power asymmetry that is usually present in qualitative interviewing (Kvale, 2006; Qu & Dumay, 2011) and on my intention to serve as empathetic listener (Qu & Dumay, 2011). I realized that there was an added risk to the participants which happens when the participants trust their interviewer too much, reveal sensitive data, and the interview crosses over research into counseling and therapy (Mills et al., 2000). I approached this issue in two ways: (a) by stating clearly my role as a researcher during recruitment and before the interview to clear any possible expectations from the participants that they may receive therapeutic feedback; and (b) by consciously refraining from making any therapeutic interventions during the interview (Mills et al., 2000).

Summary

In this qualitative study, I explored the lived experiences of young adults, ages 21 to 29 years, who presented with p-CMS. In this chapter I provided a detailed overview of study design, as well as ethical concerns. Purposeful sampling was applied to recruit six volunteers for the study from Facebook groups gathered around the theme of p-CMS. Data was collected online through in-depth phenomenological phone/video interviews and analyzed via open and axial coding. To ensure that four categories of trustworthiness, which are validity, transferability, dependability, and confirmability, were met I applied member checks, thick rich description, triangulation, and reflexivity, as I saw best fit throughout the study.

Chapter 4: Results

In this phenomenological study, the focus was lived experiences of young adults who self-identified as having p-CMS. Throughout this exploration, I focused on participants' individual journeys through life with p-CMS, seeking to understand what it is like to live with p-CMS, what personal meaning they assign to their stereotypies, how stereotypies influence participants' lives in social, academic, and work settings, and what it is that society surrounding young adults with p-CMS should know about their stereotypies.

The literature review showed that firsthand experiences of those who live with this phenomenon are lacking in terms of research, and the purpose of this study is to address their authentic voices to add more depth and understanding about p-CMS in the scientific discourse.

To realize the purpose of the study, the following research questions were developed:

RQ1: How do young adults who present with p-CMS describe inducing events of CMS movements as related to their social, academic, and personal environments?

RQ2: What meaning do young adults who present with p-CMS give to their stereotypies?

RQ3: What is it that they think that society and science should learn and understand about typically developing individuals who present with p-CMS?

All data were collected via semi-structured in-depth interviews which were conducted privately with each participant on Zoom. Results of this study are presented in this chapter. Chapter 4 starts with an explanation of participants' demographic information, followed by the setting for this study and data collection procedures. I explain the process of coding, procedures for categorizing codes, and emergence of themes.

Setting

Purposeful sampling was used to recruit participants for the study from several online Facebook groups involving p-CMS. Upon the approval of administrators of groups, information about the study was made public in Facebook groups, and I invited potential participants to contact me at my university email. Three of the study participants were recruited this way. They voluntarily contacted me and scheduled their screening calls. The other three participants contacted me upon learning about the study from a friend and a close relative who had read the post about this study.

Participants were given two options to participate in the study, depending on their personal preferences: Zoom or telephone calls. Out of six interviews, five were completed via Zoom and one via a telephone call. All Zoom calls were conducted face-to-face with the video option turned on, except for one participant who enjoyed having the option to turn her camera off during the interview to let her stereotypies express freely. All interviews were conducted in quiet locations, with participants logging in from their rooms, and I used my home office. All interview arrangements, follow up appointments, and rescheduling were done via email.

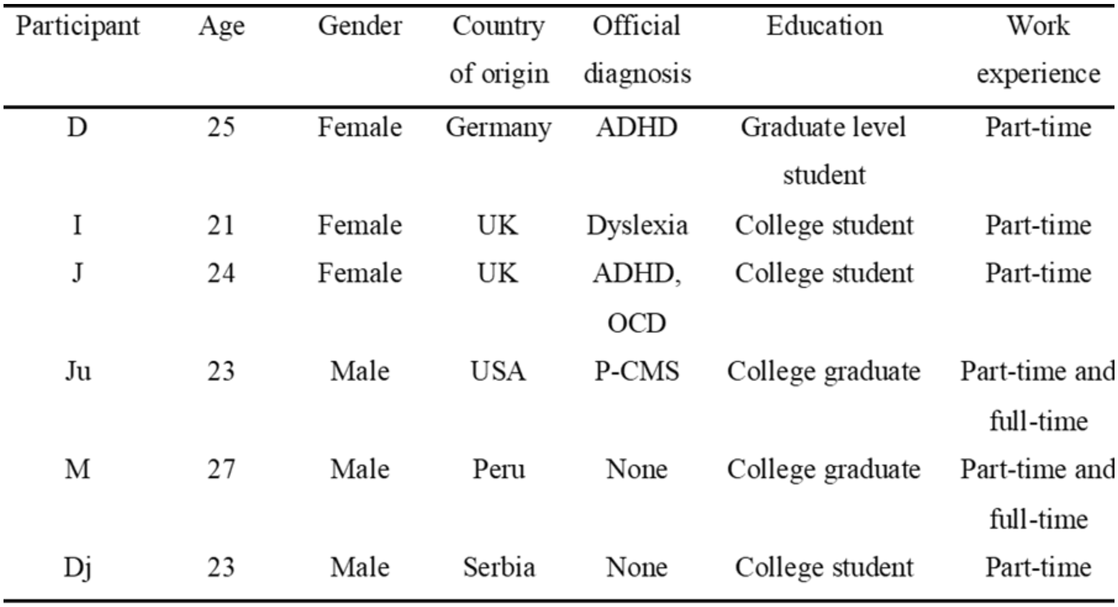
It is important to note that this study was conducted during the COVID-19 global pandemic. It is difficult to clearly assess to what extent circumstances involving the pandemic influenced participants and their experiences at the time of this study. The global pandemic was an unusual circumstance in this study and will be discussed later in the chapter.

Demographics

Participants were recruited from several Facebook support groups for those who experienced p-CMS and through word-of-mouth. The participant pool for the study consisted of three females (I, D, J) and three males (Ju, Dj, M). Their ages ranged from 21 to 29. All participants were either college graduates or in the final year of college, with part-time and/or full-time work experience. None of the participants were married or parents.

Table 3

Participants' Demographics



Participant	Age	Gender	Country of origin	Official diagnosis	Education	Work experience
D	25	Female	Germany	ADHD	Graduate level student	Part-time
I	21	Female	UK	Dyslexia	College student	Part-time
J	24	Female	UK	ADHD, OCD	College student	Part-time
Ju	23	Male	USA	P-CMS	College graduate	Part-time and full-time
M	27	Male	Peru	None	College graduate	Part-time and full-time
Dj	23	Male	Serbia	None	College student	Part-time

All six participants had been experiencing p-CMS since early childhood. Five of them had at some point in their lives committed to researching the topic of p-CMS through medical journals, literature, online forums, and networking with others who self-identified with p-CMS in attempts to understand this condition better. One participant had received an official diagnosis for p-CMS as a child, while three other participants held the official diagnoses of dyslexia, ADHD, and OCD. Five participants reported receiving support from counselors, psychotherapists, and psychiatrists around the issues of anxiety, ADHD, and OCD at some point during their teenage and adult years.

Participants in this study came from different cultural and ethnic backgrounds, as well as geographic locations. One participant was from the US, two participants were from the United Kingdom, one participant was from Peru and residing in India, one participant was from Germany and studying in Finland and the United Kingdom at the time of the interview and member check-in, and one was from Serbia. All participants were fluent in both written and spoken English. There were three participants for whom English was not their first language. Two participants chose to speak English during interviews, while the other participant opted for Serbian. There was no need to engage the help of a professional interpreter because Serbian is a native tongue for both myself and the participant.

Data Collection

All decisions regarding the data collection, from initial contact of prospects for the study to screening calls to interviews and follow ups, were made in consideration of the comorbidities among adults with p-CMS. Kuzujanakis (2021) said that it is important to use supportive language and to “keep an open line of communication” (p. 59) with young adults who are prone to anxiety, so I strove to provide this throughout the study.

Prospective participants were given all relevant information about the study via email before they decided if they wanted to participate in screening calls. Upon agreeing to participate in screening, each participant received a private Zoom link with an invitation to join the call and notification that it would be recorded. Participants were reminded in both emails and during screening calls that they could ask questions about the study, share any concerns and worries that they have, and contact me afterwards with any additional input. All six qualified participants decided to participate in the study after their screening calls. Consent forms and invitations for interviews were emailed with instructions to choose times and dates that best suited them. The participant who opted for a telephone interview was asked to provide a phone number so that I could contact him directly.

Once interviews were scheduled, all participants were emailed twice more before their interview. The first email was sent a day before the scheduled interview, and the second email several hours before the interview. Emails included supportive language to confirm interview appointments, offer the option to reschedule, if necessary, explain the interview agenda, offer the choice of using video or audio during interviews, and list the interview questions. This was done to minimize anxiety and give a sense of order and predictiveness.

These steps were reported by participants to have helped with anxiety, organization, and time management as well as easing the natural flow of interviews and building rapport, as some participants reported struggling with these factors. Having the necessary information for meetings right before interviews reportedly helped with the natural flow of interviews and rapport building.

Interviews were originally estimated to take approximately 45 minutes, although some took as long as 120 minutes. All questions were open-ended in order to explore the study topic in-depth (Weller et al., 2018). While this led to long narratives, it also yielded a wealth of information about the topic, leading participants to feel heard, to be more open about the topic, and to give richer detail in interviewing (Brubacher & Powell, 2019). To reduce anxiety, the 23 open-ended questions were shared with participants, to answer in whichever order they chose.

Participants were frequently reminded they were able to withdraw any information gathered during interviews, in whole or in part. During interviews, participants were informed and reminded of member-checking follow-up calls in the months following the interview, in which they would be able to review data and add to their original answers.

Once each interview call was complete, the recording of that call was converted into MP4 file and stored on a password-protected hard drive in the researcher's home office.

Unusual Circumstances Encountered in Data Collection

The Institutional Review Board (IRB) of Walden University approved this study (#01-24-20-0309690) on January 22, 2020. Upon receiving approval, I began the process of participant recruitment and screening.

During the first two months of actively attempting to make the study visible in online forums on Facebook, I only received one qualifying inquiry for the study. The administrator of a Facebook group informed me that a better idea would be that the administrator posts the information about the study in a group that is closed to the general public, and only includes adults who self-identify with p-CMS. A few weeks later, the administrator additionally informed me that he had received multiple inquiries about the study, but these inquiries were all from people who were older than 27. Only three potentially qualifying participants expressed interest in the study, and these potential participants were instructed to contact me directly.

As I was expecting to receive emails from prospective participants in March 2020, the global COVID-19 pandemic started, and all activity ceased. Given that most of the world was homebound and online, I decided to begin actively recruiting for the study again.

This time, three qualifying participants emerged who not only seemed eager to participate in the study, but also promoted the study among their peers who also self-identified with p-CMS. However, only one prospect was from the US. I soon filed a request for a change in procedures to expand the sampling frame to include international participants and received an approval from the IRB.

During this stage, two more prospects contacted me due to their friend's recommendation, and I began scheduling screening calls. From that point on, a month passed before I heard back from prospects. I decided not to be forceful with my follow up emails given the context of the pandemic, trusting that participants would email me back. All participants eventually returned emails, and I began conducting the first screening calls in mid-May. This nonforceful approach on my part proved beneficial to the study, even though it delayed the study's timeline. When participants did reestablish contact with me, they shared with me that lifestyle changes caused by the pandemic had impacted them in various ways, mainly in terms of increased anxiety levels, and they needed some time to adjust before they could join the study.

Initial data collection was completed with five participants. During this phase, I encountered multiple issues while attempting to recruit more participants for the study. This resulted in two additional requests for changes in procedures being filed with and approved by the IRB, which allowed me to join the Facebook groups in which I was attempting to recruit participants and post information about the study on both Facebook and other social media platforms.

I conducted the next stage of the study using NVivo, a qualitative and mixed methods software designed for coding and analyzing qualitative interviews. Using this software, I examined five interviews from which I obtained rich information about participants' lived experiences with p-CMS. Not only was this the first qualitative study of its kind to my knowledge, but it was also an international study, so I wanted to ensure that all details, commonalities, and differences in data among participants were accounted for, without discarding any information as irrelevant. This process yielded a wealth of codes (see Appendix D).

I also continued to recruit during this stage of coding. At that time, the participants who took part in the study came from four countries (the United States of America, Peru, the United Kingdom, and Germany) and three continents (North America, South America and Europe). To expand the international nature of the study, I located a Facebook group in Australia and began posting the official information about the study. Additionally, I expanded my activity to another social media platform called Reddit. My recruitment efforts remained within the procedures previously approved by the IRB, which consisted of the following: (a) join the online forum; (b) inform the administrator of the forum about the study and ask for a permission to post; and (c) refrain from directly engaging with the members of the forum unless they contact me first. These efforts did not bring about any new contacts.

At that point I had been actively pursuing the recruiting efforts in all the relevant Facebook groups which were publicly available to anyone searching for the term complex motor stereotypies. I refrained from venturing into online forums which thematically gathered around broader themes such as motor disorders, with the assumption that if the potential participants self-identify with p-CMS they are more likely to be active in the Facebook groups which are focused on the p-CMS. Instead of continuing to post in the existing Facebook groups, I decided to file another change in procedures with the IRB, requesting to expand my recruiting efforts to include paid Facebook ads. My request was approved.

In the following weeks, a professional marketing agency in Belgrade, Serbia was hired to help me with the placement of the Facebook recruitment advertisement. I provided the marketing agency representative with the copy of the IRB approved text for the advertisement, along with the funds for the campaign in the amount of 80 euros (€80.00), which had covered the cost of the marketing services in the amount of 30 euros (€30.00). These professionals had already been collaborating with the local universities and had had a profound experience in the recruitment of the study participants online. Collaboratively, we launched a marketing campaign, which consisted of paying Facebook for my previously IRB-approved information about the study to be visible to wider audiences on Facebook platform. A close relative of a young adult in Serbia who experiences p-CMS saw the ad and initiated contact with me. Soon, the screening call was scheduled with the sixth prospective participant, and upon mutual agreement, he joined the study.

The interview with this participant was completed via a telephone call and recorded using the Zoom recording feature. Even though this young adult is fluent in English, the interview was conducted in Serbian as it felt the most natural for the flow of the interview, because Serbian is the native tongue of both the researcher and the participant. The interview was transcribed and coded in the same manner as the previous five interviews in the study.

Further data analysis showed that even though it would have been fruitful to add more participants to the study, data saturation had been reached on all the main points of the study. The sixth participant added little in the way of new data other than expanding the depth of the existing information. Given that determining saturation in qualitative research is a complicated task, as it depends on the experience and personal judgment of the researcher (Guest et al., 2020), I contacted both the IRB and my chair to consult about ending the study.

However, data collection did not end here. At this point, a year had passed from the time that the COVID-19 pandemic had started, and I was aware that there was a large possibility that the collected data from the interviews had been influenced by these unusual global circumstances. Young adults in the United States have been vulnerable to increases in psychiatric symptoms due to the circumstances of the pandemic, mainly due to a fear of suffering from the corona virus (COVID-19) as well as due to the school-related issues (Hawes et al., 2021) and job insecurity for them or someone else in the household (Ganson et al., 2021). For many young adults, including four participants of the study, the pandemic led to sudden changes in schooling from on-campus to online format. For two participants this meant that they had to leave their colleges and/or place of residence and return to live with their parents, which had been identified as one of the common occurrences among young adults in the United States and a contributing factor to an increase in anxiety and other psychiatric symptoms (Hawes et al., 2021; Ganson et al., 2021).

To ensure that this phenomenological study remained true to the exploration of the phenomenon of the *p*-CMS, I decided to invite all the participants for detailed member checking calls.

To prepare for these calls, I had already compiled all the relevant data that were accounted for the results of the study. I separated the data into Word files according to each participant and emailed the six participants invitations to participate in member checks, detailing the reason for our call. I added a dimension to the usual nature of the member checking which involved going over each item with the participants and asking them if that was a truthful representation of their lived experiences. The goal of this process was not only to check if my interpretation of their accounts was truthful, but also to provide space for the participants to reflect how much of their statements had been influenced by the unusual circumstances at the time of the interview.

This proved to be a beneficial process for several reasons. Firstly, for four participants the initial engagement in the study was the first opportunity to voice and discuss their lived experiences with *p*-CMS. Reportedly, having the interview questions beforehand allowed them to reflect on their life prior to meeting me on the interview call. Some participants chose to discuss their early memories with their parents to clarify when they first began expressing their stereotypies and what they looked like to the observer at the time in preparation for the interview. Secondly, when the time for the interview arrived, it provided the participants with an additional opportunity to verbally share their lived experiences, which to some brought an expanded level of integration, reportedly. Finally, for the first five participants a year had passed before they engaged in member checking calls, which provided an ample amount of time to reflect on their statements and views previously given during the initial interviews. These member checking calls played a crucial role in data collection and the goal of staying true to the phenomenon despite the unusual circumstances during which the study was conducted.

Variations in Data Collection from the Plan Presented in Chapter 3

As previously noted, there were multiple changes to the original plan in data collection. I originally intended to study the lived experiences of young adults who self-identify with *p*-CMS in the United States. With the IRB's approval, the study was expanded to include international members. This decision proved beneficial as it exposed the essence of the phenomenon of *p*-CMS across the different cultures and geographical locations.

Next, the original design of the study did not include a variance in how the participants will be recruited online, limiting the researcher's recruiting efforts to posting only in designated Facebook groups. With multiple approvals from the IRB, the original design was expanded to include engagement on other social media platforms, as well as conducting the targeted Facebook marketing campaigns.

Initially, I proposed conducting 15-minute screening calls with the prospective participants. This showed to be unrealistic in practice, as the time required to explain the nature of the study, to discuss with the prospects if they qualify for the study, as well as to answer the questions was much longer than that, and it ranged anywhere from 30 to 60 minutes for four of the participants. Given that this was the first qualitative study among young adults who presented with p-CMS, I was unaware that the participants differed in the amount of time that it took them to build rapport, as well as that the screening calls were, for some participants, the first opportunity to discuss the phenomenon of p-CMS.

Also, I had proposed that the recordings of the interview be shared with the participants. This was taken out of the study, as the participants did not express interest in having the interview recordings for personal records. I also offered to manually transcribe all the interview recordings. From the practical side, this proved to be labor-intensive and unnecessary work. With the approval of the IRB, an automated online transcription service was used (www.sonix.ai) for the rough draft of the transcripts. I listened to the recordings again and edited the errors in the transcripts.

Lastly, I proposed that the summative group call be conducted with all the participants once all the data was analyzed, to provide space for reflection, new insights and corrections. This, too, proved to be impractical for two reasons. The first being the time difference across several continents in which the participants live. The second being that due to the unusual circumstances of the global COVID-19 pandemic, the researcher felt it more appropriate to conduct the member checking calls with each participant privately.

Data Analysis

Analysis of the data was conducted using NVivo, a qualitative and mixed-methods software designed for coding and analyzing qualitative interviews. This software was used to examine the transcripts, develop the codes and search for patterns and themes in the participants’ responses.

In analyzing the data for the study, I followed Giorgi’s (2002) view that in phenomenological research subjectivity of the researcher should not be minimized or discarded, as it is in direct relationship with knowledge. Instead, the researcher should remain aware of the conditions under which she or he is perceiving the participants' statements as they are, and not allow for his or her subjectivity to corrupt the data (Giorgi, 2002). To ensure that both the researcher's subjectivity and objectivity were utilized in this study, I used Colaizzi's (1978) method of data analysis in combination with open and axial coding.

Colaizzi's seven-step-method has been recommended for data analysis in phenomenological studies as it provides researchers with a logical sequence of operations when organizing and analyzing the data (Wirihana et al., 2018). In comparison with other data analysis methods, Colaizzi's method requires that the participants validate the researcher's findings, thus increasing reliability and dependability of the study. Colaizzi's method provided a strong framework for data analysis in this study, as its application required me to read the transcripts multiple times and get familiar with them, code the data and formulate meanings, develop categories and themes, formulate the essence of the phenomenon, and validate the findings with the participants to complete the analysis (Wirihana et al., 2018; see Appendix D).

In the first step of data analysis, I had to transcribe all six interviews. To transcribe the recordings with high fidelity, I used a two-step strategy. The first step involved using the services of a paid online transcription service platform named Sonix, which yielded a rough draft of the transcript. The second step involved listening to the recording before making the necessary corrections to the transcript. According to Hepburn & Bolden (2017) this process also helps the researcher get attuned into the participants' speaking style and accents, aiding in accurate transcribing. Participant privacy was maintained throughout this process by using the participants' pseudonyms in the transcripts and all the related materials in the study (e.g., Zoom links, codes, titles of the documents, researcher's notes, etc.).

When all the transcripts were ready for further data analysis, they were uploaded into NVivo portal and the second and third steps of Colaizzi's (1978) data analysis method began, which involved me conducting open coding. Open coding is the process used as a tool in qualitative studies which enables the researcher to organize the original transcripts into concrete units (codes) to further analyze the data (Mills et al., 2010). This process is two-fold, as it combines both the researcher's logic and intuition in the way that the researcher first examines the raw data and decides which parts of the interviews will be systemically organized into codes (Mills et al., 2010). Then, the researcher scrutinizes his or her choices, comparing them to the original data for accuracy (Mills et al., 2010).

Table 4

Starting Interpretations, Codes, and Participants' Examples

Interpretations	Codes	Examples
How p-CMS is observed externally differs from how p-CMS is experienced by young adults	P-CMS episode	*Other people see it as a movement disorder, but movements are what I do. What is important to me is what goes on internally. P-CMS is how I think* (Participant I)
Young adults control, manage, and privatize their p-CMS	Control of p-CMS	*I had a pretty good ability control [p-CMS] by the time I started high school.* (Participant Ju)
P-CMS does not prevent the participants from engaging in social activities	Social activities	*I don't really feel generally hesitance to attend anything or go anywhere because of it.* (Participant D)
P-CMS can affect how the participants relate to others (e.g. issues of shame, secrecy, fear of rejection)	Shame, secrecy, self-esteem	*I think it impacted my relationships and my sense of identity and a lot of other things because I was living a lie.* (Participant I)
P-CMS do not present an obstacle at the workplace	P-CMS and workplace	*No one at my work would care if I could just do it [p-CMS], and it would be better*. (Participant Ju)
Participants struggled with comorbidities in school	Comorbidities	*For me what's most pronounced is the attention deficit, and that has been an issue when it comes to doing individual school university work.* (Participant D)
P-CMS is involved in the learning processes	P-CMS and learning	*If you are doing the movements [p-CMS], it's like hyper attention.* (Participant I)

During this phase, I first extracted the basic demographical information, such as: the participant's age, country of origin/residence, occupation, education level, frequency of p-CMS occurrence, and the presence of the official diagnoses relative to the study, as per Mills et al.'s (2010) suggestion. These data were grouped into a category of codes named "Demographics."

Then, I set off to analyze each full transcript in a chronological order in which the interviews were conducted, and to group the data into codes. At this stage, I did not use any *a priori* codes, but instead I allowed myself to interact with the raw data analytically to develop the codes inductively (APA, 2013) without reducing the data (Mills at al., 2010). This yielded a detailed systematization of the raw data into more than 40 individual codes, which are listed in the Appendix E.

Finally, I compared the codes to the original data and checked for accuracy (See Table 5).

Table 5

Examples of Categories, Codes, and Participants' Experiences for Theme 1

Category	Codes	Examples
P-CMS in School	P-CMS and learning (C1)	*And so, in third grade they were teaching us latticed multiplication. What happened at the time in my head was I was sitting trying to solve the problem* (C1). *My teacher came up to me, grabbed me by the wrist, said – 'You don't belong in this class'* – (C2) *took me down the hall and dropped me in like the remedial math class* (C5). *Probably I spent the rest of the year doing my CMS while they played school and learning absolutely nothing. And what I'm pretty sure happened in retrospect is I was trying to solve the problem. I started doing my CMS because I was trying to solve the problem* (C1) (C3)*, because the thing is, she always perceived my CMS as meaning that I wasn't caring and wasn't trying - I wasn't paying attention. So, she saw that, took me down the hall and then I wasted a year.*
	Reprimands (C2)	
	Control (C3)	
	Special Ed (C4)	
P-CMS and Social Activities	P-CMS and friendships (C5)	*Doing these movements is not unusual to people who would stick around* (C6). *Even though I do them [p-CMS], I guess, that would be around open-minded people, so those are people I make friends with* (C5). *But I mean, that is not just because of the movements. I do appreciate open minded people, for other reasons as well* (C5).
	P-CMS and romantic relationships (C6)	
P-CMS and Workplace	P-CMS and workplace (C7)	*In that job CMS was an advantage* (C7) *because if I got bored, I could just CMS* (C8).
	Control of p-CMS (C8)	

Once all the transcripts went through the process of open coding, I moved on to the fourth step of Colaizzi's method, which required me to look for patterns and themes among the codes (Wirihana et al., 2018). I first noticed how the codes combine into larger categories and how categories combine to answer the research questions. Then, I organized codes and categories by research questions into three main groups (see Appendix D). Further analysis showed the emergence of the three main themes: (a) experiences; (b) perceptions; and (c) messages.

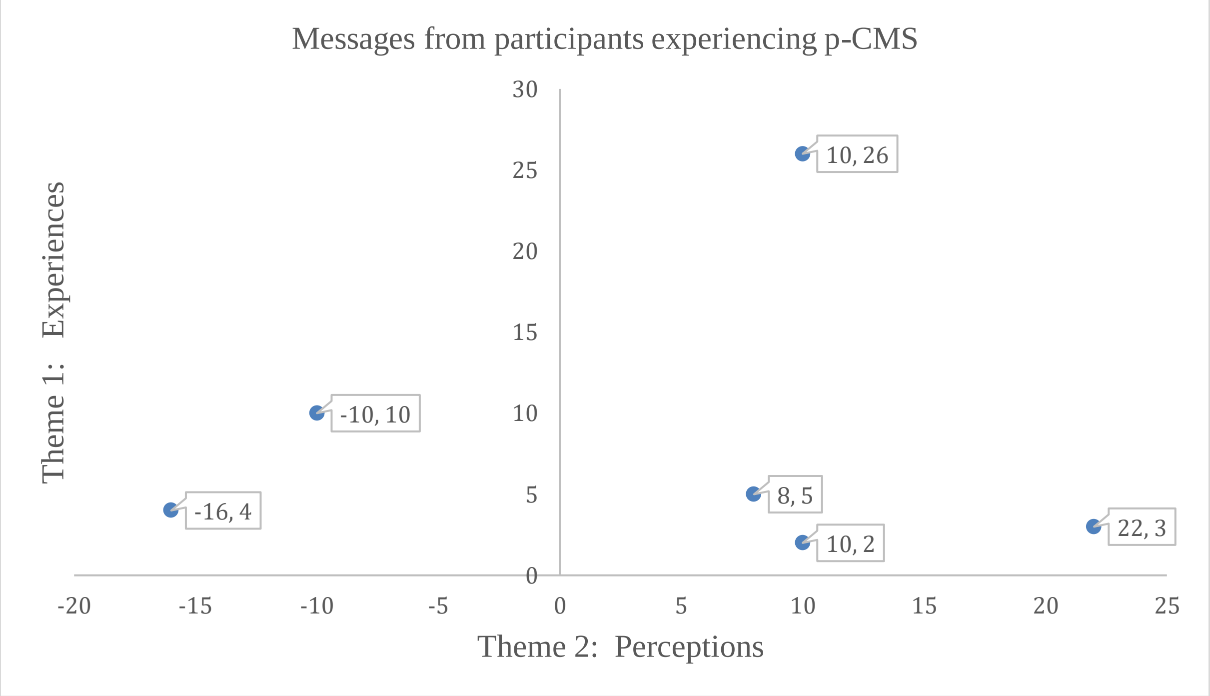
For example, codes such as "physical manifestation of p-CMS," "the internal experience of p-CMS," "triggers," "visions," and "control of the p-CMS" naturally led to a category named "p-CMS episode." Also, codes such as: "p-CMS and learning," "reprimands," "peer bullying," and "special education services" evolved into a category termed “p-CMS in school” (See Table 5). Codes such as: “p-CMS and friendships,” “p-CMS and romantic relationships,” and “p-CMS and social activities” led to the formation of a category named “p-CMS and relationships.” When analyzed together, these three categories of codes – “p-CMS episode,” “p-CMS and school,” “p-CMS and relationships” - showed the emergence of the theme of “experiences.” The same inductive process was used for other codes and categories to define the other the themes of “perceptions”, and “messages.” All six participants’ responses reflected the impact of culture on their p-CMS movements and adaptations/attitudes to those movements. The interesting part of this theme emergence was that there were similarities across culture as well as differences. Therefore, this theme of “culture” was included in the study.

Next, I analyzed the main four themes and I noticed that the themes of “experiences” and “perceptions” serve to support “messages” as the overarching theme. The goal of the study was to contribute to the existing body of knowledge by bringing the authentic voices of young adults who self-identify with p-CMS into the scientific discourse. The theme “messages” showed to do just that, with the themes of “experiences” and “perceptions” helping the reader understand the deeper context out of which these messages emerged from.

To further analyze the interplay of the themes of “experience” and “perception” and their support of the theme” message” I engaged in axial coding. Axial coding is an analytical process which helps the researcher to further examine the relationships which exist among the coded data (Mills et al., 2010) that could be otherwise overlooked by the researcher (Strauss & Corbin, as cited in Mills et al., 2010). Axial coding enables the researcher to define one central phenomenon, represented by the axis, which is then studied in interaction and relationships with the categories, subcategories, and themes of the phenomenon (Mills et al., 2010). In my study, examination of codes led me to sort a total of 27 codes into the theme of "experiences" and a total of eight codes into the theme of "perceptions." During this process, the themes suggested by the research questions were developed: Experiences, Perceptions, Message, and Culture. The content of each participants' responses to the open-ended questions was examined to determine the level or valence of the participants responses (from -5 for very negative to +5 for very positive) in both theme-groups for each participant for each code. Then those evaluative numbers were added up by valence (e.g.-all positive numbers in that theme and all negative numbers in that theme), the negative numbers were subtracted from the positive numbers, and the remaining result (whether positive or negative) represented the participants placement along the XY axis. Then, I identified those participant's statements which corresponded with the identified valence and selected the most representative statement to show the reasoning for the participants location on the axis. For example, participant D held the value of 2 for "experiences" and 10 for "perceptions." These values were used as the (X,Y) coordinates on the graph to show the point D (2,10).

Figure 1

Axial Coding Graph: Messages from Participants Experiencing p-CMS



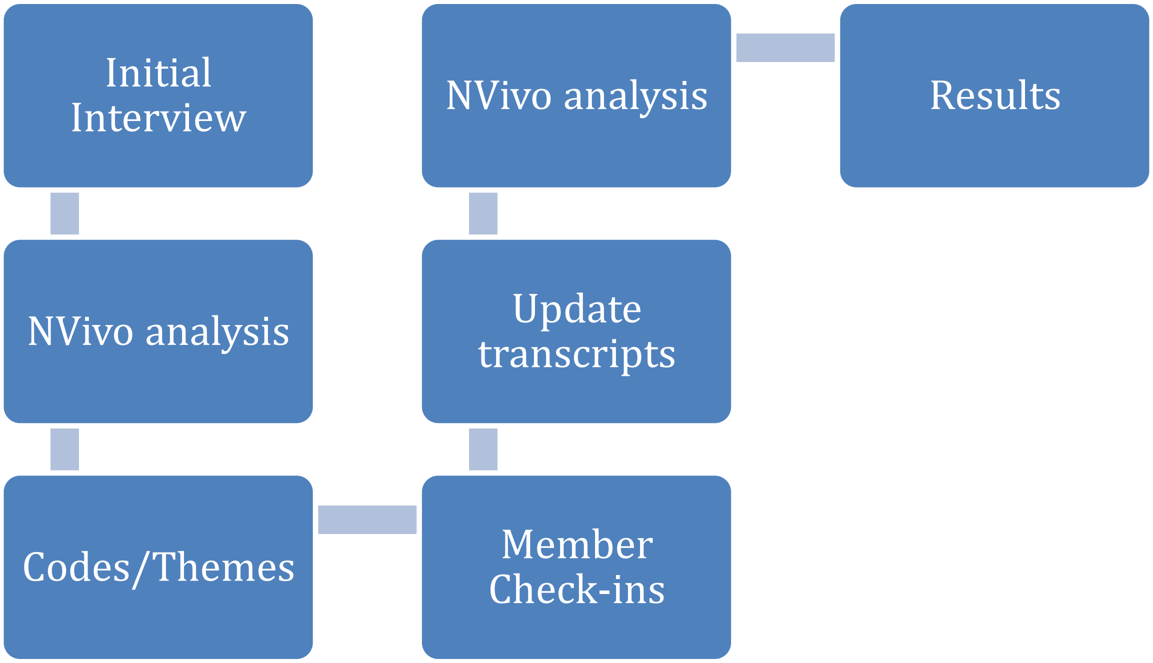
The next step of axial coding was to design the graph in Excel software program for a visual depiction of how the themes of "experiences" and "perceptions" interacted to support the overarching theme "messages." Values for "experiences" were placed on the X-axis, and values for "perceptions" were placed on the Y-axis. Each of the participants' (X, Y) values were named by the participants pseudonyms, and color coded for easier visual representation.

After I conducted open and axial coding, I was ready to move to the fifth step of Colaizzi's method for data analysis, which is development of the essential description of the studied phenomenon (Wirihana et al., 2018). To complete this step, I created individual Word document for each participant, and I transferred their most significant statements categorized by codes. For example, the first code in the document was “PERSONAL DEFINITION OF P-CMS” and under this code I placed all the statements from the transcript that helped to define each participant’s personal definition of the phenomenon. I studied all these statements in detail refining the list of those which describe each code closely.

This stage of data analysis enabled me to move to the sixth stage of Colaizzi’s method (1978), which is a description of the studied phenomenon. In the case of my study, during this phase I clarified my findings and interpretations by each code in the previously created Word documents. Under each code I wrote my interpretation which I wanted to check with the participants. After I completed this step for all six participants, I began scheduling member checking calls with the participants. These steps are illustrated in Figure 2, which visually demonstrates the process flow.

Figure 2

Flowchart: Data Analysis Procedures



Conducting member checking calls marked the completion of the seventh stage of Colaizzi's data analysis method, as I validated all the findings with each participant individually (Wirihana et al., 2018). Six member-checking calls were conducted via Zoom and telephone to allow participants to review their prior responses, to allow participants to decide whether my interpretations and assessments of their responses accurately reflected the participants intended meaning, whether any participant responses needed changing or removing from the study, and any influence that the pandemic or other ongoing events had on the participants responses. For four of the participants of the study, the pandemic led to sudden changes in schooling from on-campus to online format. For two participants this meant that they had to leave their colleges and/or place of residence and return to live their parents, which had been identified as one of the common occurrences among young adults in the United States and a contributing factor to an increase in anxiety and other psychiatric symptoms (Hawes et al., 2021; Ganson et al., 2021).

These member checking calls ranged in length from 30 minutes to 120 minutes and were not recorded. The participants did not note any erroneous conclusions on the researcher's part. The participants did provide fresh additions and clarifications, which added to the depth of the study. Two participants requested that some minor information be completely taken out of the study, as they felt that the data that they had provided during the initial interview did not accurately describe their lived experiences with p-CMS and were influenced by the COVID-19 circumstances at the time. All the additions, clarifications, and removal of data were made by the researcher manually, directly into the allocated Word documents and confirmed by the participants for accuracy. Additional statements given by participants were integrated into original transcripts, analyzed, and coded.

Evidence of Trustworthiness

Qualitative studies have long been vulnerable to criticism as they depend on the researcher's intuition for collection of data, data analysis and data interpretation (Giorgi, 2002). In phenomenological research, intuition has been defined as the researcher's ability to remain "present to consciousness" (Giorgi, 2002, p.9). As intuitive abilities vary among researchers, there is a commonly accepted understanding that researchers should present proof in qualitative studies that the inferences that they drew from data are credible and trustworthy (Hammersley & Atkinson, as cited in Creswell & Miller, 2000). Trustworthiness of this study will be discussed in the following passages, based on the following four criteria: credibility, transferability, dependability, and confirmability.

Validity of a qualitative study depends on how accurately researcher's interpretations represent the participant's representations of the studied phenomenon (Creswell & Miller, 2000). Validity is examined on two levels. The first level is called internal validity, and it serves to determine the credibility of the study, as it refers to the researcher's interpretations of the relationships which exists among the variables (Mills et al., 2010). The second level is the external validity, which determines the level of transferability of the data from the group of participants to a larger population (Mills et al., 2010).

To ensure credibility of this study I used member checking. Member checking is a process of presenting the researcher's conclusions and interpretations of raw data back to the participants to confirm that the presented data accurately represent "participants' realities of the social phenomena and is credible to them" (Schwandt as cited in Creswell & Miller, 2000, p. 124-125). To ensure credibility of this study, I conducted private meetings with each participant, after I had completed all the data analysis. The meetings varied in length from 45 minutes to 120 minutes, depending on how much each participant felt it was necessary to be heard, to go over my interpretations and conclusions, and to make any necessary adjustments to the data. As explained earlier in this chapter, member checking was an integral part of the data collection process too, as it helped to clear the participants' input given during the initial interviews from the influence of the unusual circumstances of the COVID-19 pandemic. During the member checking call, each participant was given the autonomy to decide whether there was any information that they had previously stated which did not accurately represent their view, as well as to clarify and correct the researcher’s interpretations to accurately represent their statements. Member checking allowed the participants to not only share their lived experiences, but also to influence the credibility of this study and have their comments included in the study’s final results (Creswell & Miller, 2000).

To make sure that this study met the criterion of transferability, I used thick rich description and variation in participant selection. Thick rich description is met when the study is explained in detail so that the readers can experience the state of the study as it is narrated (Creswell & Miller, 2000). Due to the unusual circumstances of the global COVID-19 pandemic, not only did I aim to use thick rich description in composing the final report of the study, but also continued to use it throughout my communication with the participants in both written and spoken language. I wanted to ensure that the participants were informed in rich details to clearly understand the aim of the study, the researcher’s role, the procedures, interview questions, agenda for the calls, as well as the current state of the study. Also, I used a variation in participant selection which was present in two ways: (a) equal ratio of men to women among the participants; and (b) the international nature of the study.

The third criterion of trustworthiness of the study is dependability. Dependability refers to the level at which the findings of the study can be applied with consistency to other situations, populations, and settings in which the studied phenomenon is present

(Noble & Smith, 2015). To ensure dependability, I used triangulation of data, which is a process in qualitative research that requires that the data be approached systematically to define codes, categories, and themes (Mills et al., 2010). Also, the process of data collection and data analysis was explained in detail to ensure that the information from the study could be understood, used, and shared by others.

Finally, to ensure trustworthiness, I aimed to meet the fourth criterion, which is confirmability. Confirmability serves to ensure that the findings of the study accurately present the participants' lived experiences free from the researcher's subjective tainting (Noble & Smith, 2015). To meet this criterion, I used reflexivity. Reflexivity refers to the researcher's ability to remain aware of his or her internal thought processes, metacognition, and meaning making throughout the study, and how these affect the flow of the study at all its stages (Haynes, 2012).

"Researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and the universal" (Berger, 2015, p. 220, as cited in Dodgson, 2019). For this purpose, I used several strategies. The first one is reflective journaling which was utilized throughout the study to allow my own biases, attitudes, and quick conclusions to be exposed. I also remained transparent in the writing of this study of what my role is as a researcher, as well as what limitations such a role brings to this study. My role as a researcher was clearly defined in all the information about the study, on the consent form and it was further clarified during the screening process.

Additionally, in the writing of this dissertation, I explained the process of data collection and data analysis in rich detail to expose my thought processes and meaning to the reader. Finally, I have provided definitions of all the relevant terms and research strategies in my writing with the proper citations, so that the reader who is unfamiliar with them can easily explore these on their own (Dodgson, 2019).

Results

In this section, I will discuss the results of this phenomenological study, which was designed and implemented to examine the following questions from a first-person perspective:

RQ1: How do young adults who present with p-CMS describe inducing events of CMS movements as related to their social, academic, and personal environments?

RQ2: What meaning do young adults who present with p-CMS give to their stereotypies?

RQ3: What is it that they think that society and science should learn and understand about typically developing individuals who present with p-CMS?

In the following pages four main themes will be discussed: (a) the participants' lived experiences with p-CMS in social, academic and relationship contexts; (b) the participants' perceptions of their p-CMS and issues relative to p-CMS; (c) messages to others about p-CMS; and (d) the participants' experiences in their cultural contexts.

Figure 3

Word Cloud

Theme 1: Experiences

Experiences is the theme which embodies the information sought in RQ1: How do young adults who present with primary CMS describe inducing events of CMS movements as related to their social, academic, and personal environments? In other words, what impact did the p-CMS behaviors or events have on the participants' social, academic, and personal environments.

The following passages reveal how much there is about p-CMS that we are yet to find out, and to which degree those things that observers (e.g., parents, teachers, service providers) see fail to reveal what is being experienced internally by the young adults who self-identify with p-CMS. Understanding how an episode of p-CMS is experienced and what it entails is extremely important as a sudden interruption of it can have "jarring" consequences (participant Ju). This viewpoint will be explained more fully later in this chapter. Testimonials shared by the participants also uncover that the internal experiences of p-CMS vary from person to person in the depth, the complexity, and the polarity, as well as in the application of p-CMS for concrete tasks (e.g., studying, proof-reading, creating something new, writing, designing, etc.). Whereas for some participants p-CMS is just a positive daily practice which serves as a “battery charger” (participant Dj), “part of fun” (participant M) and a way to “revel in excitement” (participant D), to others it is the interplay between “the conscious and the unconscious” (participant I), a complex immersive “thing that brain does” (participant Ju), and the time-consuming source of concern (participant J).

In explaining the difference in the experience between what the observer does and does not see during an episode of p-CMS, Ju said the following:

> The core of the movement is the same – the same muscles, but slight variations – the force, duration, and number of repetitions based on a trigger. There is the hand movement, and there is the thought process. CMS is a movement that is triggered by a high energy emotion or a complex thought. CMS as an emotion triggered movement – I am fully aware of my surroundings, not aware that I am doing my stereotypy, but I am fully aware, just excited. CMS as a movement triggered by a thought process (e.g., proofreading) – I am hyper-focused, somewhat aware of what I am doing with light visualizations. CMS triggered by IIM [Intense Imagery Movements] – I am gone. I have lost all the awareness of my surroundings. I

> become the character. I am fully immersed in the world of IIM, whatever that is in the particular moment.

The results of this study added more depth to the existing understanding that individuals with p-CMS learned to control and manage their stereotypies in response to their environments, giving off the impression that p-CMS disappeared with time. Three participants noted that as young adults, they never experienced their p-CMS in the company of others (participant J, participant M, participant Dj) because their stereotypies only occurred when they were alone (participant M, participant Dj) or because they had chosen to make their stereotypies "a completely privatized affair" (participant J). One participant noted that her p-CMS did get activated in public, but that she blocked them out if she was not comfortable with how people might respond to her stereotypies (participant D). Two participants noted that they had developed a variety of skills in how they controlled and navigated their stereotypies in front of others so that they did not have to always suppress their p-CMS (participant I, participant Ju). In this context, all the participants shared that the presence of their p-CMS did not prevent them from engaging in social activities.

However, three participants did disclose that the presence of their p-CMS in social life did influence how they related to others (participant I, participant J, participant Ju). For participants I and J, issues of secrecy, shame, and fear of abandonment were closely related to their p-CMS and added more complexity to how they viewed themselves relative to others.

Participant I shared,

> So, I think when I was younger, I didn't tell anyone about it [p-CMS]. I think it impacted my relationships and my sense of identity and a lot of other things because I was living a lie. I think it made it difficult to be properly close to people because there was always this barrier where it feels like no matter how well they know you, because they don't know about the CMS and they haven't seen it, then it's like if you're anxious like I am, you can rationalize in your head like they wouldn't really be my friend if they knew who I actually was. I felt unusual in many ways, so CMS made me feel disconnected from people.

During member check-in call, I stated that she no longer felt that the presence of p-CMS in her life affected her relationships in any negative manner. She shared that “it tends to bring me closer to people when I tell them about CMS, and they can reveal information about themselves.”

Participant J said the following:

> Maybe because I don't feel I'm being completely honest with people because I don't really talk about it [p-CMS]. I did go through a phase where I told a lot of people about it. So, I started a blog on my social media. And people found it interesting. But I think that's almost forgotten because it was such a quick - like ‘I have this.’ It’s that feeling of not being my full, true self because I can't be; like that [p-CMS] sounds bad. I called people then to try explaining it properly [p-CMS], because it so weird and difficult to explain. Usually, I just wouldn't mention it at all.

During her member check-in call, when asked to confirm the researcher's interpretation of the above statement, the participant J clarified that in young adulthood she did not feel "being whole."

On a more positive note, the participant Ju disclosed that his openness about his stereotypies helped him to invite people in conversations and gain new acquaintances and friends. Participant Ju said,

> Honestly, it's an ice breaker. People who I haven't really talked to will see me doing it and ask me what I'm doing and then I'll explain it to them, and they'll think it's cool and interesting and then we'll end up talking about it more. And I go on to being friends with that person out of just CMS, because that's what started the conversation. In general, I find that when I'm talking about it with whoever, I can decide exactly what they're going to think about it by the way I framed [p-CMS] describing it. I can make them think it's cool and I can make them think it's just kind of weird and interesting. I can describe it in a way where they think - 'Oh, that seems like a pain'- just on how I frame it. But yeah, other than it being like a fun fact, it's pretty irrelevant [p-CMS].

Five out of six participants rated suppression of p-CMS as a negative experience, which is unpleasant and taxing on emotions and cognition. One participant who did not share this sentiment had stated that he never felt the need to suppress his stereotypies because they only occur when he is alone. He also stated that his stereotypies are so intense in a positive sense that "if there were any negative experiences, I don't remember them, because the enthusiasm was so intense, it overwhelmed them" (participant Dj). Two participants attempted suppressing their p-CMS for an extended amount of time, both rating it as a negative experience which they would never repeat.

Participant Ju said that

> When I was first learning to suppress it [p-CMS], it took a lot of energy into suppressing it. The reason why I stopped suppressing as much as I did in high school, was that there was an energy like I would be more tired at the end of the day if I suppressed it. I would be a bit grumpier. I would have more trouble focusing because I was pulling focus and pulling energy into suppressing.

Participant I said that

> It's not nice. Yeah, it's quite, it's quite unpleasant. It's like holding your breath or the feeling of this buildup that isn't released. It's like a desire to sometimes run away. I get a desire to start running somewhere. But it isn't a like a desire to get away. It's not anxiety generated. It's just like there's this electricity and it's not going anywhere. And then I kind of, it makes me a bit sort of like, oh, God, I need to do them [p-CMS].

When asked to discuss if p-CMS affected their romantic relationships in young adulthood, all six participants shared that they did not see their stereotypies affecting their dating life. For example, participant D shared that she preferred investing her time in open-minded people and that those are the people that would be open to her p-CMS anyways. Some of her social had been observers of her p-CMS episodes and she felt comfortable expressing her stereotypies around them, not feeling any different about her p-CMS in intimate relationships.

However, participant I did state that in the past she used to live under the impression that she could not have a romantic relationship because of her p-CMS, mainly due to unresolved issues of shame and low self-esteem surrounding her p-CMS. She stated that having disclosed her stereotypies to her boyfriend early in the relationship led her to a vulnerable place in that relationship, which affected her sense of personal power and esteem, but that with that experience she grew to a more integrated place. To put it in her words: “It was not my CMS that were the problem – it was the shame that was the problem”.

In terms of their work experience, all the participants stated that their p-CMS did not present any obstacles at the workplace. The participants for whom the stereotypies were not as pronounced at work waited until they got home to perform p-CMS episode (participant D, participant J, participant M, participant Dj). The participants who tended to have more persistent daily courses of p-CMS either suppressed them until they found a private place to let their stereotypies freely express, or they performed a smaller type of p-CMS at work (participant I, participant Ju). Even though none of the participants stated that p-CMS kept them from progressing at work, participant Ju’s statement stood out as a reminder of how necessary it is to view and understand p-CMS from the first-person perspective. In his case, it was not the p-CMS that was an issue at work, but the suppression of the stereotypies, as a reflection of the general view that p-CMS is something that should be removed from one's reality.

Participant Ju said,

> No one at my work would care if I could just do it [p-CMS], and it would be better. I would be more productive. I would have more energy. I would be able to get things done more efficiently if I just did it whenever the heck I wanted to do it at work. But there is like this like this part of me that just won't let me because I feel like I'm not supposed to.

Deeper analysis of the transcripts showed that the participants in this study did experience difficulties at work, which were not directly related to their p-CMS, but to the comorbid disorders of anxiety, ADHD, and dyslexia. Issues of zoning out, staying focused on office tasks, time management and anxiety were confirmed by the participants. Their p-CMS played an important role in management of the above issues, as p-CMS "help with anxiety at work" (participant M), served when there is "something to be released" (participant J), and contributed to the participant's "energy" and "efficiency" (participant Ju).

In describing their school experiences, the participants noted that they mainly struggled in school with issues that were less related to the p-CMS and more related to its comorbidities (See Table 6). Of the six participants in the study, three participants held the official diagnoses of the following conditions other than p-CMS: ADHD (participant D, participant J), OCD (participant J), dyslexia (participant I); while all six participants reportedly could relate to at least one more common comorbid disorder in the following order: anxiety (participant D, participant I, participant J, participant Ju, participant M, participant Dj), ADHD (participant D, participant I, participant J, participant M), OCD (participant D, participant I, participant J, participant Ju, participant M).

Participant D said that

> The CMS that I personally experience I don't think is a problem at all. ADHD is the only thing I actually have a diagnosis on. For me what's most pronounced is the attention deficit, and that has been an issue when it comes to doing individual school university work.

Table 6

Learning Issues Reported by Participants

Comorbid learning issues	Participants
Zoning out	Participants D, J, M
Difficulty staying on task when task is not engaging	Participants D, I, Ju,M
Difficulty with rote-memorization	Participants D, M, Ju
Difficulties with time management and task prioritization	Participants D, M

When describing their experiences of learning in class with p-CMS, four participants noted that they usually did not express their stereotypies during class (participant D, participant J, participant M, participant Dj) and two participants stated that they struggled to manage their stereotypies in class, mainly as their stereotypies were closely linked to their thinking processes (participant I, participant Ju).

All participants noted that they experienced other difficulties with learning such as having difficulty staying engaged on tasks that were not interesting to them and rote memorization. There were differences with learning difficulties between those who did not engage their p-CMS during lessons (e.g. zoning out, participants D, J, and M; difficulties with time management and organization, participants D and M) and those who did engage their p-CMS during lessons (e.g. participating in lessons that were interesting to them without doing the p-CMS, participants I and Ju).

In describing the reasons for engaging in their p-CMS during class, two participants stated that it helped them to sharpen their focus, think clearly, make sense of the information, and connect the information in a systemic way.

Participant I said the following:

> If you are doing the movements [p-CMS], it's like hyper attention. Parents always say that their children, if they're in class and they're doing the movement, then they're not paying attention. But the movement is so linked to the imagery that is it is literally the opposite. So, if I'm in school

and I was in a lesson and it made me like - the things I love most in the world, make me do my movements the most. And like any creative pursuit I've ever done, I have to do the movements, and the movements aid in the in the creation of it. So, it's like, yes, if you watched me at a laptop and you'd be like, I would stop typing and then I would start doing the movements, you'd be like, oh, she stopped working on the thing. But actually, it is that I'm continuing to work on the thing. It's just that it's done in a different way.

Ju shared that

When I was in elementary school and we were studying the water cycle we were going over the same freaking things. We will watch a video, and there is no new interesting anything. And at some point, my brain refuses to let me be bored. So, it would switch into IIM [Intense Imagery Movements] because like I would I like I would like switch in for a while and then there'd be a moment where, like, I would pop out of it and I listen, I thought - ‘Yep, yep, still the same stuff that's already gone over and I already know it.’ And I'd switch back to it [p-CMS] and I wanted to pay attention. I really did because I knew I was supposed to. My brain knew that I didn't actually need to. And to quote my dad, what was happening in my head was more important than what's happening in class. The weirdest one was Math because I couldn’t, and I still can't memorize my multiplication tables. I'm very bad at sort of storing what I call

> unconnected information. Like just this number and this number this number. Because part of what I realized, looking back on it, is like a lot of CMS when I was little was about, what I was learning in class. So, we'd be talking about. Like the weather system in science, we'll be talking about it or the Oregon Trail in Social Studies or whatever. And would have CMS in my head, about both of those things, like bring those things together and also this other book I like. It was always kind of pulling everything I was learning together and synthesizing it into stories. And so, if I can't take a piece of information and connect it all up with everything else, it's just bye.

When asked if they had received any special education services in school all participants provided negative answers. However, one participant noted having received extra support in school for reading, spelling, and writing, but that it was not before college that she was diagnosed with dyslexia and was able to use the appropriate testing modifications (participant I). As shown in Table 7, four participants shared that despite not having been placed in any special education support programs, it would have made a difference to their school experience had they received support for learning issues caused by anxiety, ADHD, and OCD (participant D, participant I, participant Ju, participant M). In explaining their overall school experiences some participants shared a common view that school was "a struggle" (participant D) and "the hardest part of life if you're someone with CMS" (participant I).

These findings provide more depth to the existing data which revealed that students with p-CMS often get overlooked in school for their learning difficulties. A study conducted by Oakley et al. (2015) revealed that in the sample of 49 participants, more than a half (59%) of the participants reported experiencing difficulties in school, yet only 9 of them received special education support. Of the 29 participants who reportedly experienced learning challenges in school, 23 of them stated attention and focus being the primary cause of concern (Oakley et al., 2015).

To further illustrate this issue, the following passage describes the gap between what p-CMS is understood to be by the observers and what it is to the experiencing student. It describes how a misunderstanding of p-CMS in a school environment can lead to non-beneficial outcomes for children with p-CMS, even when it is driven by the best intention of service providers.

Participant Ju shared the following:

> And so, in third grade they were teaching us latticed multiplication. What happened at the time in my head was I was sitting trying to solve the problem. My teacher came up to me, grabbed me by the wrist, said – ‘You don't belong in this class’ - took me down the hall and dropped me in like the remedial math class. And I spent the rest of the year listening to, like Schoolhouse Rock multiplication tables and learning absolutely nothing. Probably I spent the rest of the year doing my CMS while they played

> school and learning absolutely nothing. And what I I'm pretty sure happened in retrospect is I was trying to solve the problem. I started doing my CMS because I was trying to solve the problem, because the thing is, she always perceived my CMS as meaning that I wasn't caring and wasn't trying - I wasn't paying attention. So, she saw that, took me down the hall and then I wasted a year. And then in fourth grade I was back in normal math. And then by fifth grade, I was in sixth grade math.

Earlier studies on p-CMS revealed that a great number of parents worry that their children will be exposed to peer bullying and social stigmatization because of their stereotypies (Singer et al., 2018; Specht et al., 2017). The results of this study revealed that these parental worries are only justified to a certain extent. Five out of six participants in this study reported being teased by peers in elementary school for their stereotypies (participant D, participant I, participant J, participant Ju, participant M). Two reported that in instances when peer bullying was present, they were not bullied for their p-CMS, but for being different from other kids on terms other than their stereotypies.

For example, participant Ju stated that

> I was bullied, but I was bullied for being weird in terms of, like, my interests and not liking sport. Like, I was just different. CMS was probably a factor for me being a weird kid, but I wasn’t directly teased for CMS.

Participant M shared,

> I was bullied for being shy and introverted and not into sports, but not due to CMS. I was just vulnerable; my parents were splitting up. I became a target due to a combination of factors, and for three years it was really bad.

Theme 2: Perceptions

Perceptions is the theme which embodies the information sought in RQ2. One important part of this study was to explore how young adults who self-identified with p-CMS defined this phenomenon in their own terms; whether the participants considered it a positive, negative, or neutral element in their lives. This study examined perceptions of different portions of the participants' lives (e.g.- their own definition of p-CMS, the participants perception of p-CMS's impact on their lives, the role or function of p-CMS in their mental and physical well-being). These perceptions were then examined for positive or negative characteristics.

In an observer-based definition of p-CMS, the stereotypy behavior (e.g., hand flapping) that was witnessed was often considered to be the entirety of what occurs for the individual experiencing the p-CMS. Current definitions of p-CMS define it as a movement disorder (APA, 2013), only taking into the account the observed side of the p-CMS (Dantzer, ass cited in Barry et al., 2011). But what the observer sees during an episode of p-CMS may have been only a fraction of a greater, multi-layered experience that goes on internally for the individual experiencing the p-CMS event. This difference was apparent in the positive responses provided when participants were asked to give their own definitions of p-CMS.

Participant D said that “those movements [p-CMS] that I experience come from positive excitements, being able to do them means living myself out and reveling in my excitement.”

Participant I stated that

> It’s an experience and it happens when I think about stuff intensely. It happens like a means of thinking about stuff -a multilayered experience which sometimes happens intently, and sometimes it does not - like watching a movie inside of your head. It’s like if somebody changes the channel in my mind, I’m like the camera in the movie. There is a dreamlike state to it. Things just happen, I’m discovering them [during p-CMS episode].

According to the participants in this study, p-CMS was a wholesome experience and an integral part of life, because p-CMS represented how their brains worked. It is an experience which comes on when a person is: (a) expressing a positive emotional state; (b) thinking about something that is engaging; (c) thinking about difficult situations from life; (d) feeling that there is something pent up to be released; and (e) when “brain gets bored.” All the participants shared that an episode of p-CMS brings about a “rush of excitement,” “high energy emotions,” “energized positive states,” and that in that sense they perceived it to be a positive part of life.

> Participant Dj said that “[p-CMS] Movements are an integral part of my life, one of the forms of expressing an energized positive emotional state.”

Participant Ju shared the following: “It's not the most important thing about me. It's not the biggest problem I have. It's just another part of how my brain works. I would say definitely it feels pretty core to how my brain works.”

Robinson et al. (2016) said that some children with p-CMS experience heightened states of visual imagery, which makes them feel as if they are inside a movie or a video game, described in the literature as IIMs. In my study all six participants reported experiencing imagery during their p-CMS episodes, but there was a significant difference in what their statements revealed about the importance that the imagery played for them and at which intensity it was experienced. There was also a difference in how these immersive experiences were explained terminologically. The participants who actively participated in the online communities gathered around p-CMS and who reportedly research the medical literature on p-CMS regularly used the term IIM during the interview (participant I, participant Ju). The participants who were not actively engaged in the online communities on p-CMS, nor who exhibited any special interest in researching the literature on the subject opted for the following terms to describe the internal experiences of p-CMS’ visual part: (1) “vivid imagery” (participant D); (2) “fantasy world” (participant J); and (3) “fantasies” (participant M, participant Dj).

Even though imagery was noted by all the participants, for three participants the importance of imagery seemed more pronounced (participant D, participant I, participant Ju). These three participants shared that they view p-CMS as the outward manifestation of the thinking process which goes on for them internally. To say it in participant I’s words:

> Other people see CMS as a movement disorder, but movements are what I do. CMS is how I think. This is just how my brain works and how my brain has always worked. The movements are linked to the imagery. And so, I deliberately do the movements to generate the imagery, like to generate the state of mind.

> Participant Ju shared that

> CMS has a lot of different triggers. And so, what triggered it is what determines the internal experience, even though the movement looks the same. So, if it's triggered by excitement, I'm not even noticing that I'm doing the CMS. I'm just thinking about whatever I'm excited about. Same with stress and with frustration, although with stress and frustration, it calms me down a bit… Then if I'm doing it to focus on something: proofreading, solving a math problem, figuring out an Excel spreadsheet then it's just sort of this very hyper focus on the thing. Other thoughts fade away and my brain runs faster. And IIM? I'm totally gone from reality, totally gone from my sense of self and completely immersed in the world - like I'm there. I'm the characters in the world. I'm not me. So, like, if I was in a scene where I was a character with a really angry person and in an argument with someone, then when I come out of it, there's like that residual emotion for a minute. It's like being inside of a movie. Do you know who controls the scenario? My hands.

When asked to tell more about his IIM experience during p-CMS episodes, Ju said that

> It's like I walk into a movie I don't have control over when it's going to happen, no control over what the story is about. It's fed from content I see. So, if I'm reading

> a lot of fancy books about dragons, there will probably be dragons involved…
>
> My hands have their own taste in music. Certain songs they really like. It's like if I'm trying to set off certain IIM I can like put on content that my hands really like. And that'll trigger it.

When asked what the perceived function of the p-CMS was, the participants stated that during a p-CMS episode their brain worked faster, helped them to hyper-focus, helped them to come up with creative solutions, to organize information in their mind, and to learn.

Reportedly, three of these participants (participant D, participant I, participant Ju) experienced vivid imagery during p-CMS events. This vivid imagery has been noted by other researchers and named intense imagery movements (IIM; Robinson et al., 2014; 2016). The p-CMS movements themselves were perceived by participants to be irrelevant and inconvenient, while the internal processes of the p-CMS were considered by the participants to be important. Participants acknowledged that the physical expressions of their stereotypies played an important role in the entire experience of p-CMS episode. According to the participants, these physical movements were directly linked to the imagery. For example, participant I stated: “The more movement there is, the more vivid the imagery.” When asked to discuss his stereotypies, participant Ju stated that “the movement part of CMS is annoying, but the thought-process is beneficial.”

When directly discussing positive and negative perceptions of p-CMS, two participants stated that for them p-CMS was a fully positive part of life (participant D, participant Dj), three participants shared that they had mixed perceptions (participant I, participant J, participant Ju), and one participant stated neutral stance (participant M).

Upon being asked to list the positive aspects of p-CMS, the participants identified the following: (a) energizing state (participant D, participant I, participant Ju, participant Dj); (b) the use of vivid imagery as a way to engage with the subconscious (participant I); (c) the influence of vivid imagery as a way of thinking (participant D, participant I, participant J, participant Ju, participant Dj); (d) p-CMS as a facilitating part of the thinking process (participant D, participant I, participant Ju); (e) p-CMS as a playground in which life can be examined through vivid imagery (participant D, participant I, participant Ju, participant M, participant M); and (f) the mental and physical expressions of p-CMS as a way to relieve stress (participant D, participant I, participant J, participant Ju, participant M, participant Dj).

When naming the negative aspects of p-CMS, the participants shared the following: (a) the physical aspect can be inconvenient (participant J, participant J, participant Ju, participant M); (b) the reactions of others can be unpleasant (participant D, participant I, participant J, participant M); (3) social conditioning around p-CMS can lead to shame, self-esteem issues, and feeling isolated from others (participant D, participant I, participant J, participant M); and (4) engaging in p-CMS behaviors can be time-consuming (participant J). Yet when asked if they would eliminate their p-CMS if they could, four participants declined and two participants agreed, but only if they could keep the thought process and satisfaction that their p-CMS brings to them (participant J, participant Ju).

In the light of the difference between how p-CMS has been defined in the literature and how the experiencing individuals define it, the participants in this study were asked to share their perceptions of current therapies for p-CMS. Multiple studies have been conducted to test the therapeutic approaches for children with p-CMS with the goal of lessening the frequency of the occurrence of their p-CMS (Freeman & Duke, 2013; Rickets et al., 2013). Five out of six participants shared that they were aware of the attempts to develop therapy for p-CMS and indicated that they held a negative stance towards it. The participants main areas of concern were the following issues: (1) viewing p-CMS as a problem to be fixed (participant D, participant I); (2) placing the focus on something that does not need treatment instead of focusing on areas that do require treatment (participants identified issues of anxiety, attention deficit, time management, reading, writing, etc. as benefiting more from treatment than p-CMS; participant D, participant I, participant J, participant Ju, participant M); and (3) concern for what happens to the thinking process when the movement aspect of p-CMS is treated or suppressed (participant I, participant Ju).

Participant J shared: “It’s weird. This sort of treatment is strange. It’s like somebody saying: ‘How would you feel about developing a treatment for being articulate?’ To me that [p-CMS] seems like a trait that people have.”

Participant M stated: “CMS does not need treatment. Regular therapy helps with self-acceptance. CMS is not an object that you treat, it’s something you actually need to help someone integrate. The problem is when you tell someone it’s a problem.”

Participant Ju stated: “Thought process causes the movements, not the other way around. If you are managing the movements, you’re too late. Movements are the output.”

Theme 3: Messages

Messages was the theme which embodied RQ3. While the previous two themes aimed to provide a deeper understanding into the lived experiences and perceptions of the young adults who self-identify with p-CMS, the theme “Message” aimed to give the voice to those who actually experienced p-CMS, rather than the opinions of those who observed p-CMS experiencers. In short, what those who experienced p-CMS think that others should understand about this condition that, from the experiencers’ viewpoint, had not been addressed.

During the interviewing process a great deal of time was dedicated to discussing the messages that the participants had for others regarding their p-CMS experiences. These messages were clarified during member check-in calls and comprised three main messages: (a) p-CMS need not be framed as a problem to be fixed; (b) the actual problems in the lives of the experiencing individuals should be identified and addressed (comorbidities); and (c) p-CMS needs to be redefined and explained in a more relatable way to the experiencing individuals.

The first message that the participants in the study voiced directly spoke of the one-sidedness with which p-CMS had been defined in the literature, and society’s view of p-CMS. According to participants, we as observers of p-CMS need to understand what p-CMS is from the view of the experiencing individuals and consider their experiences when forming our views and definitions. Participant D described it as "...don't assume there is nothing to be known."

Instead of looking at p-CMS as a problem to be fixed, we need to understand that an onset of stereotypies in any given moment is a sign of a deeper complex thinking, reveling in excitement, stress release, or simply – learning. That the processes associated with p-CMS are not just unconventional behaviors or “socially offensive” (Hedderly, 2017; Péter et al., 2017, p.2). Participants describe these behaviors as increasing focus and learning, calming anxieties and assisting in processing overwhelming emotions, and bolstering coping skills when faced with daily challenges. Therefore, according to participants, efforts must be put into clearing out our limited focus on the stereotypies alone and expanding our focus into a more holistic view which considers the lived experiences of individuals with p-CMS.

Participant I said that

> The idea of being told not to do that part of you is the same as being told not to think, not to engage with something that is very natural to you. It leads to concluding that there is something wrong with me, I am broken in some way because I was told not to engage with my own thinking.

In that regard, in the second message participants described how more attention should be placed into defining what the real problems are in the lives of those who experience p-CMS. According to the participants in this study, p-CMs expression did not and does not pose any issues that participants would seek treatment for, but participant comorbidities do pose issues requiring treatment-seeking. Issues related to anxiety, ADHD, and OCD continue to be the source of challenges that five of six participants have sought therapeutic support for at some point in their lives. In the words of the participant Ju “anxiety and OCD are much a bigger issue than the CMS is ever going to be.”

Reportedly, discerning what is a problem and what is not in the lives of the individuals with p-CMS is of greatest importance in their academic lives, as the lack of understanding about p-CMS on the educators’ part can lead to interventions that address the movements and not the areas that require intervention (e.g., attention, reading, writing, time-management, etc.) contributing to non-beneficial outcomes for students with p-CMS.

Participant D shared that

> Schooling is such a big part of life and can be a struggle. If educators and parents understand what CMS is, what a problem is and what is not, and where to focus – these years can be different and used to help people prosper in life instead of being a struggle.
>
> Participant Ju stated: “Consider that what is happening in those kids’ heads is more important than what is happening in class.”

Participants also shared that at some point in their lives the participants began researching the topic of p-CMS in medical literature with the goal of finding medical explanations for their condition. For some participants, this quest was upsetting and traumatizing as they could not reconcile their personal experiences of p-CMS with available medical definitions. To quote the participant I: “Reading scientific literature about CMS can be upsetting because it’s so wrong.” Plainly speaking, participants stated feeling that their experiences were not “normal” because the medical definitions did not match their lived experiences. Therefore, the participants shared just how important it is that p-CMS be defined in a more relatable way to those who experience it, with a wealth of details describing the p-CMS, in order to help the seeking person organize the information for themselves in a beneficial way.

Participant J noted the following:

> I Googled it one night at age thirteen, ‘hand flapping,’ and then a lot of stuff about autism came up and I was just terrified. I think I had some sort of panic attack because I felt like there is something really, really wrong with me. From that point I used all my willpower to suppress the movements.

Participant I said that

> You have to sort of see, you know, when you're forming a definition of something or you're trying to understand something, it usually exists in the world. And so, you read stuff about it, and then you form your own opinions in your own mind. And so, I couldn't, form my own opinion, independent of the medical literature. I had to kind of read that and then interpret it, like trust them in a sense. Then that kind of helped with the idea that – ‘Oh, I should not do it.’ And the feeling of constantly trying to not do it [p-CMS] and then constantly failing at it, not doing it because this is how you think. And so, it's impossible, it's impossible to not do CMS. That was very destructive, I think, for me, because it made me feel like there was something wrong with me.

Additionally, it was noted that there is a general lack of information about what p-CMS is to children with a recent diagnosis and their parents. In the view of the participant Ju, it must be addressed that “what CMS is for a 2-year-old is very different from what it is for a 16-year-old.” The lack of this understanding often leads to parents worrying about the future of their children with p-CMS not taking into the account that stereotypies change over time and that children learn how to manage and control them.

Finally, when the participants were asked about the common definition of p-CMS which displays the stereotypies as “purposeless movements,” they provided an important layer to the above stated messages. Five participants disagreed that their p-CMS were purposeless, with the participant D noting that “purposeless makes it sound like it’s nothing.” In the opinion of the participant I, her stereotypies are “physical manifestation of the excitement so big that it needs physical manifestation.” In discussing this topic, participant I added the following: “I deliberately do the movements to generate the imagery and the state of mind, and that is the antithesis of purposeless.”

Participant I further added the following:

> So, to look at a child and say they're doing nothing right now is the opposite of what's actually going on because they're actually thinking incredibly intensely [during an episode of p-CMS]. If you saw someone pacing, if you saw like a detective pacing through a board of like a murder thing, you wouldn't say that they are doing nothing. You would be saying that they're thinking of the thing. And so, that's what's happening [p-CMS]. The fact is - I think ‘purposeless’ is a word used by people who are watching it, who don't understand what's going on.

In articulating his message to scientists, participant Ju stated that

> There is an underlying purpose that is being served for an underlying process that has value. Learn what that underlying process and purpose are, and from there on figure out if there are ways to lessen or control the movements themselves without negatively impacting the underlying purpose.

One participant stated that he was not aware that there was any research on stereotypies, and that his p-CMS behaviors were so integrated into his life that he did not think about them, which made it difficult to discuss the issue of purpose.

Theme 4: Culture

Culture was a theme that permeated all of this research, without embodying a specific research question. In this study the six participants came from different cultural backgrounds and geographic locations and the theme “culture” emerged after the previous three themes were analyzed and defined. One participant in this study was from the United States of America, two participants were from the United Kingdom, one participant was from Germany (residing in Finland and the United Kingdom at the time of the interview and member checking, respectively), one participant was from Peru (residing in India and Peru at the time of the interview and member checking, respectively). In total, six participants from this study came from three continents (North America, South America, and Europe) and five different countries. The theme of “culture” was defined in this study to embrace and address the international nature of the study. It was interesting to note that, although participants' cultures could be considered very different from one another, they had some remarkable aspects in common.

Cultural differences in this study are best viewed through the construct of individualism-collectivism, which remains the most used construct in cross-cultural studies (Santos et al., 2017). In individualistic cultures the most promoted cultural values are those of independence, self-autonomy, and separateness from others; while in collectivist cultures the most dominant cultural values are those which promote interconnectedness and interdependence with others in the community (Santos et al., 2017; Varnum et al., 2010). In this study four participants were raised in predominantly individualist cultures (the United States, the United Kingdom, and Germany) while two participants were raised in predominantly collectivist cultures (Peru, Serbia; Santos et al., 2017). It was interesting to find that two participants from collectivist cultures shared that their p-CMS were greeted with well-meaning humor among family members in instances when their p-CMS episodes occurred in the presence of others. Participant Dj shared that he used to engage in his stereotypies as a child freely during family meals and he never felt a need to privatize his p-CMS, but that with time his stereotypic movements began occurring only when he was alone. When other people were present during family gatherings, his family members explained his p-CMS to others through humor making him feel that his p-CMS were part of his family dynamics. This is in line with the collectivist values of personal connection and relatedness (Varnum et al., 2010). But the participants from the individualistic cultures demonstrated a higher level of self-direction and autonomy (Varnum et al., 2010) as can be best seen in the example of participant Ju, from the United States. Participant Ju is gainfully employed in the career of his choice, lives independently, advocates for children with p-CMS, and is a recognized community leader.

In observing the cultural differences among the six participants, it was interesting to find that all six participants shared the same essence of the experience of the phenomenon of p-CMS, regardless of where they were brought up. According to the participants, p-CMS includes the physical part, expressed through the stereotypical movements which are visible to the observers; and the internal psycho-emotional process which is not observable by others. The participants noted that p-CMS episodes are always geared towards positive outcomes, whether they are used as a thought process (participant D, participant I, participant Ju), emotional regulation practice (participant D, participant J, participant I, participant Ju, participant M) or a way of experiencing life (participant D, participant Dj); and can occur with the presence of vivid imagery (participant D, participant J, participant I, participant Ju, participant M). The three participants for whom imagery was strongly pronounced all shared that it represented the most important part of their p-CMS experience (participant D, participant I, participant Ju).

It is necessary to mention that this study was conducted during the global COVID-19 pandemic which affected all the participants in the study. Five of six participants shared their experiences with p-CMS during COVID-19 pandemic without being prompted. They noted that the mandated COVID-19 measures issued by their respective governments caused them to change their daily structure and work/study from home. For two participants these measures led to a change in residence, as they had to leave their university and move in with their parents (participant J, participant I). For one participant the measures required that he remained quarantined in a foreign country as that country was going through a shutdown for outbound flights (participant M).

What all five participants shared was that being home-bound had led to a natural increase in the frequency and volume of their p-CMS episodes (participant D, participant J, participant I, participant Ju, participant M). For some participants this was a positive experience, as observed in participant Ju's words who shared that staying at home allowed him to work from home and to engage in his stereotypies whenever he liked. Yet for some participants, the lack of the social interactions and public exposure was a negative experience as the increase in p-CMS episodes challenged their productivity and contributed to higher levels of anxiety (participant D, participant J). Participant J noted that in her experience, COVID-19 measures in her country led her to complete her college studies from home. Staying at home away from social gatherings and larger environmental stimuli led the participant J to experience more frequent episodes of p-CMS at the expense of studying, which contributed to stress around meeting the school-work deadlines.

This is in line with recent studies which showed that young adults were a population vulnerable to high levels of anxiety during the pandemic (Ganson et al., 2021; Hawes et al., 2021). The driving factors in increased levels of anxiety in these studies were fear of suffering from the corona virus (COVID-19), school-related issues (Hawes et al., 2021) and job insecurity for them or someone else in the household (Ganson et al., 2021).

In studying the theme “culture” I noticed that there were some parallels in the lived experiences of the six participants which could not be observed through the individualistic-collectivistic framework. These parallels will be explained in the following paragraphs.

Two male participants noted that in their countries of origin (the United States of America and Peru) the prevalent expectation from boys is to be athletic and engaged in sports. These two participants shared that they were impacted by this social norm by being deemed different from others because they were not interested in playing nor watching sports.

According to M:

> Basically, soccer is the official religion, the real religion in my country. So, yeah, that sucks. I really can't stand watching it that much. I guess that the example of me not being able to watch a full soccer match. I guess you could kind of infer from that. It just wasn't the best ideal environment to thrive.

In participant’s Ju’s words:

> I was not popular in elementary school. I was bullied, but I was bullied for being weird in terms of, like, my interests and not liking sport. I was just different. Like me and my friend, we would just sit on the playground and talk about ethics in second grade. The other kids weren't super about that.

It was interesting to find that two female participants who shared high levels of internalized shame regarding their p-CMS were both from the United Kingdom. Compared to participants from Peru, Germany, and Serbia – who all explicitly stated that they were not culturally conditioned to dislike p-CMS – the two participants from the United Kingdom noted that the circumstances around their p-CMS led them to feel that there was something wrong with them because of their p-CMS.

Findings from the study also showed that the participants from Peru and Germany made distinct references to their native culture in a similar way. The participant from Peru stated that he grew up in a military culture, marked by high expectations and discipline. He attended the bilingual private schools in Peru, for which he often received academic scholarships, but he often could not choose the subjects that he was interested in. Expectations laid out by his family and a larger culture were that as adult he had to be fluent in English and educated in economics so as to satisfy familial expectations and definitions of success. These expectations led the participant M to minimize his interests in psychology, literature, photography, and philosophy and to commit to pursuing a career which was considered appropriate in his culture. Similarly, the participant D shared that she grew up in Germany, in an authoritarian culture which also promoted high academic expectations. In the participant D’s experience, cultural expectations led her to spend most of her days studying the subjects in which she was not interested nor felt she was good at. Participant D struggled with ADHD related issues for which she held a medical diagnosis but had to stay engaged in tasks until she finished her homework. Participant D said that she had no regrets for the academic choices she had to make. But that she did wish she'd been given more choices than she had available. At the time of her member checking, participant D told me that she made a choice to pursue a graduate degree, which is in line with her aspirations; and that she chose a university which appeared to be a good fit for her academic needs.

Thus, it is evident (see Table 7), from the responses given by the six participants in this study, that p-CMS fulfills a number of vital roles in the connection between the participant and processing of the participants' environments. The p-CMS experienced by participants has a largely positive role to play in this processing. While there are negative aspects to the p-CMS experienced by participants, these negative aspects are reported to be far outweighed by the positive aspects. Moreover, in spite of the cultural differences in the lives of the participants, these responses to p-CMS by participants are predominantly similar despite different cultural backgrounds among participants.

Table 7

Participants' p-CMS characteristics

Participant	Frequency of p-CMS	Privatization	Physical manifestation	Imagery	Triggers	Age of onset	Age of privatization
D	Daily	Not fully privatized	Hands, body tensing fast-paced walking	Vivid imagery	Positive excitements, anxiety, environmental stimuli	Birth	Cannot recall
I	Daily	Not fully privatized	Hands, body rocking, fast-paced walking	Intense Imagery Movements (IIM)	Pleasurable activities, stimulating content (e.g. movies)	Birth	Around the age of 12
J	Daily	Fully privatized	Hands, body tensing	Vivid imagery	Stimulating emotions, solitude	Birth	Around the age of eight
Ju	Daily	Not fully privatized	Hands, body tensing, humming	Intense Imagery Movements (IIM)	Emotions, stimulating content, boredom	Birth	Around the age of eight
M	Weekly	Fully privatized	Jumping, action moves	Vivid imagery	Anxiety, stimulating content	Birth	P-CMS only occurs in solitude
Dj	Daily	Fully privatized	Jumping, action moves	Vivid imagery	Stimulating content, positive excitements	Birth	P-CMS only occurs in solitude

Summary

The results of this study revealed that young adults who identify with p-CMS have already adapted their stereotypies to match their perceived social expectations, so they either only engage in their p-CMS in private or they perform a smaller version of their stereotypies in public when they deem it appropriate. In that regard, the presence of p-CMS does not have a significant effect on their social life, relationships, academics, or work, and they mainly share positive perceptions of their p-CMS.

However, the results revealed that young adults with p-CMS struggle with comorbid disorders such as: anxiety, ADHD, OCD, and dyslexia, as well as the unresolved feelings of shame around their stereotypies. The participants' main message to the world is that what the world sees during an episode of p-CMS is only a physical sign of a much larger internal experience, which relates to their thinking, focusing, reveling in excitement, stress regulation, and making sense of life situations. In that sense, the world needs to understand what p-CMS are from the first-person view, in order to understand what is and what is not a problem for individuals with p-CMS, and seek to resolve those problems (e.g., attention issues, time management issues, anxiety management, etc.) instead of trying to minimize the stereotypies.

More effort needs to be put in reframing and redefining the phenomenon of p-CMS, not only so that those who experience it can relate to what is stated in the literature, but also so that those seeking to understand p-CMS can find meaningful information and pointers.

In Chapter 5, interpretations of findings are presented involving what ways this study’s findings confirm, disconfirm, and extend knowledge about p-CMS. Interpretation is done in the context of the theoretical framework for the study.

Chapter 5: Discussion, Conclusions, and Recommendations

This phenomenological qualitative study was a focused exploration of the lived experiences of young adults who self-identify as having p-CMS. During this inquiry, I intended to understand what it is like to live with p-CMS from participants' point of view, how participants viewed their p-CMS and how they define it, as well as to which extent p-CMS affect participants' lives in terms of relationships, social activities, and academic endeavors. Given that this seems to be the first qualitative study of its kind, I also wanted to explore what it is that young adults who self-identify with p-CMS would like society surrounding individuals with p-CMS to know about this phenomenon. The purpose of this study is to bring forth authentic voices of experiencing individuals into scientific discourse to help mitigate the current predominantly one-sided external view of p-CMS.

Participants agreed that external observation of stereotypies only presents a fraction of much larger, complex, and individually unique experiences lived by each participant. From participants' view, p-CMS are not a problem to be fixed, but a visible sign of a different way of thinking and experiencing one's reality. What young adults who self-identify with p-CMS indicated they needed help with were issues caused by comorbidities associated with p-CMS. Participants cited help was needed mainly in terms of attention, time-management, and rote memorization.

All participants began adapting their p-CMS in response to reactions and reprimands from environments in childhood. Participants reported that, since young adulthood, they learned to fully control and manage their p-CMS, only expressing their p-

CMS when they felt it safe or appropriate. In that sense, p-CMS did not present an impediment to their social life, nor to their academic and work environments. Participants' testimonials also showed how lack of understanding of p-CMS by those in the participants' environments has led some of them to internalize painful feelings of shame, secrecy, and low self-esteem. Participants noted that this lack of understanding contributed to a sense that it is wrong to engage in acts that feel natural to them.

Finally, results of this study were used to address how necessary it is to include authentic voices of experiencing individuals when forming a definition of a phenomenon. Participants noted that it is of great importance to have information about p-CMS publicly accessible and described in a way that is relatable to those who experience it. Having information about p-CMS may potentially help educate society surrounding children with p-CMS about it, as well as provide answers to individuals who experience p-CMS and who have just begun to research this topic.

Interpretation of the Findings

P-CMS are not recognized by the DSM-5 nor are they differentiated from other stereotypic movements. In the DSM-5, there is an umbrella term stereotypic movement disorder (SMD) which encompasses stereotypies in both typical and atypical populations alike.

According to APA (2013), a clinical diagnosis of SMD can be considered in cases when repetitive, purposeless movements are present in a way that they obstruct a person's daily activities and pose a threat of self-injury. Additionally, it is important to establish that these motor behaviors were present in the person from an early age, and whether or not these motor behaviors could otherwise be attributed to a neurological condition or substance use.

In the DSM-5, it has been recognized that SMD does occur among typically developing children. But the diagnosis would not be appropriate in the case of typically developing children who present with p-CMS, since complex stereotypies do not interfere with children's daily routine, do not cause distress to children, and can be suppressed (APA, 2013).

All literature reviewed in this study defined p-CMS as repetitive, involuntary, and rhythmic movements which cease with distraction or external stimuli and serve no apparent purpose. Findings of this study supported the point made by Barry et al. (2011) and Hedderly (2017), discussed in the literature review, that the current definition of p-CMS appears to be one-sided and does not seem to take into the account views of experiencing individuals. The results of my study seem to indicate that viewing and treating p-CMS as a physical stereotypic manifestation by itself, without taking into account one's internal experience, may lead caretakers and medical professionals astray in their goal to aid those who experience stereotypies. According to the participants of this study, these movements are purposeful, serving as an output of a more complex internal process for them. To paraphrase the participant Ju, if parents, caregivers, educators, medical personnel, and researchers place the importance on the observable aspects of p-CMS, they are focusing on the surface issue to the detriment of the underlying issues, whatever they may be.

This gap exists in terms of how p-CMS are viewed by parents, caregivers, educators, medical professionals, and researchers and how they are experienced by individuals with p-CMS. Findings of this study confirmed that when p-CMS is viewed externally, these behaviors serve no apparent purpose. However, when p-CMS is viewed from the perspective of experiencing individuals, they serve multiple purposes in the lives of these young adults. As expressed by participants, p-CMS movements are closely tied to their thinking processes, emotional regulation, and ways in which they experience the world. Reducing one's internal world to only what is visible to the observer – motor stereotypies – seems to bring into question which causes we are looking to serve. As indicated by Hedderly (2017), it is the job of researchers to determine whether the goal is to treat p-CMS for social reasons or to benefit those who experience p-CMS.

Oakley et al. (2015) found that p-CMS continues beyond childhood (10-15 years) into adulthood for 23% of their participants and beyond adulthood (15 years and above) for 19% of their participants in a sample of 49 participants. For 77% of those participants, stereotypies showed a decrease in magnitude and frequency of occurrence as participants learned to manage and control their p-CMS. The findings of my study confirmed this for all six participants. Five participants reported experiencing their p-CMS daily, and one participant noted the decrease of occurrences to weekly episodes.

What has not been available prior to this study is knowledge of how young adults with p-CMS adapted to managing their stereotypies and how that adaptation affected the quality of their lives. From findings of this study, young adults who self-identify as having p-CMS all have control over their p-CMS. Not only can they choose when to allow their stereotypies to express, but they can also induce them and harness their p-CMS expressions for various purposes (e.g., hyper-focus, learning, problem solving, emotional regulation). This level of mastery for some came early, and for others it took years to develop. Participants also indicated that in young adulthood, p-CMS did not negatively impact the quality of their life. However, for some participants, issues of shame and secrecy which involved p-CMS negatively impacted relating to others.

The findings of this study also added to the knowledge of when the participants became aware of their p-CMS and why the participants began privatizing their movements. For all six participants this first-time-awareness was asserted by external sources. For some participants this first-time-awareness was gained through a gentle parental approach. For others, this awareness was gained through peer interaction. One participant stated that he gained this awareness through an inappropriate teacher intervention in third grade. Data from this study showed that despite how gentle some of these experiences appeared to be for some participants they initiated a long journey of questioning what was wrong with them. These participants experienced a sudden realization that engaging in the acts that feel natural and beneficial to them – are viewed as wrong by others. Therefore, I believe that understanding the internal processes of those who experience p-CMS is of great importance.

Participants shared that having supportive parents who gently and openly allow their children to express stereotypies without interruption is often not enough. According to these participants, growing up with p-CMS and meeting condescending or reprimanding reactions, sooner or later made the participants feel the need to understand p-CMS from the perspective of others. These participants sought answers to the questions of what p-CMS is and how it is explained in medicine. For some participants, this journey for answers was not the most pleasant one, often causing emotional pain, confusion, and the conscious abandonment of p-CMS at high emotional, physical, and mental costs. Participants noted that there was both a lack of descriptive information (e.g., medical definitions and descriptions) and relatable information (e.g., applicable to them personally) which would have helped the participants internalize and integrate their p-CMS experiences in a more beneficial manner.

Oakley et al. (2015) reported that children who present with p-CMS tend to experience multiple issues in school and life when they reach adolescence and adulthood, due to the high prevalence of the following comorbid disorders: anxiety (73%), followed by ADHD (63%), OCD (35%), and motor tics/Tourette syndrome (22%; Oakley et al., 2015). In Oakley et al.' study, a sample of 49 participants which had presented with p-CMS had reported being placed in general education setting with their age-appropriate cohorts, with only nine participants receiving special education support at some point in their academic careers. However, 23 participants reported having had difficulties in school mainly related to attention/focus issues.

The findings of my study are consistent with the findings in the study conducted by Oakley et al. (2015). Of six young adults who self-identified with p-CMS, four reported having the official diagnoses of the following disorders: anxiety (17%), ADHD (33%), OCD (17%), dyslexia (17%). All six participants reported the presence of a significant level of anxiety in their experience, at least at some period in their lives. For five participants anxiety continued to have a consistent course into adulthood, being reported as an obstacle that has kept them from progressing in life. For three participants issues related to ADHD were pronounced mainly in the domain of attention and focus, time management, and task prioritization. Two participants shared that in adulthood the most pronounced issue that requires attention is OCD, but OCD viewed in combination with anxiety – as obsessive thinking patterns.

Academically, the findings of this study are also consistent with the previous findings that despite the learning challenges, the participants were placed in age-appropriate classes with little or no special education support. In the sample of six young adults who self-identify with p-CMS, five participants reported not receiving academic support for learning-related issues except for one participant who received some assistance with reading, writing, and spelling. This participant shared that she advocated classroom accommodations for herself in college allowing her to use a laptop instead of a notebook in class.

One participant reported being inappropriately placed in remedial math in the third grade due to his teacher’s perception of his p-CMS, which had led his parents to pursue an official diagnosis of p-CMS for him. Having the medical diagnosis of p-CMS for this participant was crucial in no longer being reprimanded for engaging in his p-CMS during class. This participant shared that by 5th grade he was attending 6th grade math classes.

With this study, I attempted to expand the view of the issues that young adults who self-identify with p-CMS face. Our current view of p-CMS, divorced from the lived experiences of individuals with p-CMS, points to the need to fix the stereotypies and lessen their expression from one's experience. Yet for the experiencing individuals with p-CMS, their stereotypies are not a problem until they are framed as a problem by others. Reportedly what young adults with p-CMS need to thrive is appropriate support in those areas which they personally deem problematic, and which are more related to comorbidities than to p-CMS alone (e.g., anxiety, attention, time management, task prioritization, etc.).

As shown in a study conducted by Ricketts et al. (2013), not all children with p-CMS develop management and coping skills when they reach their reach teenage years, but they may respond well to individualized behavioral therapy. Ricketts et al. (2013) cited a case of two 13-year-old girls whose experiences of p-CMS were persistently present in daily life at the expense of socializing with peers and/or academic life. This caused parents to seek treatment. Both girls were also noted to be experiencing high levels of anxiety, and both girls received treatment for their stereotypies. While the results of this study showed a significant decrease in the frequency of the movements and an increase in the amount of time their participants spent socializing and studying, it was not mentioned at what cost these improvements arrived, how they affected the participants' anxiety levels, and whether the results were sustainable on the long run. The results of my study expand on the previous findings alerting that as observers of the p-CMS episodes, we need to stay open to the idea that "what is happening in those kids heads maybe more important than what is happening in class" (participant Ju). In other words, that the stereotypies are a sign of a deeper thinking process, emotional regulation, and/or a way of experiencing life. When we attempt to treat the physical part of p-CMS, attending to the stereotypies alone, we are playing with the byproduct of a much larger internal experience and we do not yet know what effect that may have on the person that we are trying to help. Additionally, all the participants in my study noted that p-CMS helped them to relieve anxiety and to process difficult situations from life. In my opinion, the purpose that p-CMS plays in their lives must be considered when we attempt to treat the stereotypic movements by themselves.

This study also addressed another point – how young adults who identify with p-CMS view therapy for this condition. All six participants expressed negative perceptions of therapy stating that the idea that p-CMS are something that requires treatment needs reframing as it raises multiple concerns. Their first concern is ethical; when children with p-CMS are told not to do p-CMS (which feels natural to them according to some participants). In the participants' view, it feels the same as being told not to think. Participants stated that it reflects our limited scope of understanding of what p-CMS is, and to paraphrase the participant D, prevents us from looking at the whole person; how that person thinks, feels, experiences life, what talents the person has, and how his or her life can be designed so that he or she can prosper.

Participants also indicated that the lack of knowledge on how the stereotypic movements are tied into the internal experiences during a p-CMS episode can lead to negative consequences for the treated individual. We do not yet know how stopping the stereotypic movements affects the thinking processes, emotional regulation, and one's personal experience of life. To paraphrase participant J, developing treatment for p-CMS is similar to developing medical treatment for being articulate as p-CMS is more a trait that a person has than a disorder. But for severe cases of p-CMS, which warrant treatment, participant Ju noted that the scientists should start with the assumption that “there is an underlying purpose for an underlying process that p-CMS serves.” Instead of treating the stereotypic movements participant Ju stated that “scientists should learn what the underlying purpose and process are and find the ways to control or lessen the movements without negatively impacting the underlying purpose.” Additionally, the participants shared the view that individuals with p-CMS may need therapy to help them integrate their experiences with p-CMS, to deal with difficult feelings around p-CMS, and to address the issues which arise from the comorbidities (e.g., anxiety, ADHD, OCD, dyslexia).

An important contribution of this study is knowledge about how young adults with p-CMS defined this phenomenon from their perspective and which perceptions they held towards it. When their definitions were carefully compared to the current scientific definitions, it was easy to notice the gap that has been discussed earlier; that the current scientific definitions have been formed from a one-sided external view. All the participants in the study defined their p-CMS as an integral part of life, in which the stereotypic movements are the output of a much larger internal experience. To paraphrase the participant I, stereotypic movements are what the participants do, whereas the internal experience is how the participants think, process emotions, and experience life. From the participants’ point of view, when they talk about p-CMS they are referring to a wholesome experience, not just the physical movements which are visible to the observer.

Upon questioning the personal perceptions of p-CMS, participants expressed a spectrum of viewpoints. These viewpoints ranged from very positive (participant D, participant Dj); to slightly negative (participant J), to a mix of positive and negative (participant I, participant Ju, participant M). In participant D’s words p-CMS are about “living myself out and reveling in excitement and that's fantastic - I can't say anything negative about it.” Yet participant J also shared that she found her p-CMS to be time-consuming and a source of concern for her. This participant shared that she was worried about the long-term effects that the intensity of her p-CMS may have on her nervous system. For participant Ju, “right now, CMS is just a thing; mildly positive, not completely neutral.”

Previous research showed that the person’s expression of p-CMS in public can be perceived as odd and socially offensive leading to peer bullying and stigmatization of children with p-CMS (Hedderly, 2017; Singer et al., 2018; Specht et al., 2017). The findings of my study confirmed this to a certain extent. The young adults who self-identified with p-CMS shared that as children they were often aware of the reactions of others, but they were not sure what those reactions referred to as their p-CMS were a natural process to them. For some participants this brought feeling of confusion and to others internalized feelings of shame. They became more aware of the reactions of others during elementary school when most of the participants began privatizing their p-CMS. When the participants were asked about peer bullying, five of them stated that they did experience mild teasing due to p-CMS by peers. Two participants shared that in their school experience bullying was present, but they rarely attributed it to their p-CMS. These two participants noted that the presence of p-CMS did play a part in them being seen as different but was not a cause for bullying.

In childhood, individuals with p-CMS have no awareness of when their p-CMS are expressing as they feel no premonitory urge to perform the movements, but that they learn to control their stereotypies later in life (Freeman et al., 2010; Oakley et al., 2015). My study supports those prior studies while it expands our knowledge regarding the ways that young adults experienced their p-CMS episodes in childhood, what those p-CMS episodes meant to experiencing young adults, and the time and method in which experiencing young adults learned to control their stereotypies. Importantly, young adults who identified with p-CMS shared their experiences of how p-CMS were expressed in the young adults' social and academic environments across time and how those expressions have affected the young adults' lives. Participant testimonials revealed that for some, p-CMS experiences were their visible sign of the thinking process in action; of paying attention in class and of learning. Meanwhile, the participants’ educators sometimes saw these p-CMS expressions as disruptive, inattentive, and unacceptable. Researchers’ earlier attempts to collect this type of information from children, who often could not verbalize their experiences as other than enjoyable, made what seemed futile attempts (Freeman et al., 2010; Hedderly, 2017; Mackenzie, 2018; Ricketts et al., 2013). Participants’ ability to describe, define, identify, and clarify the role of p-CMS and p-CMS experiences in their lives from childhood to young adulthood may provide researchers and others with an expanded view of the role and value of p-CMS experiences in the lives of those who cannot describe their experiences for themselves.

A concern raised by p-CMS literature is that the expression of stereotypies can often be time-consuming, causing the children with p-CMS to miss out on social and academic opportunities. This concern was only partially supported by my study. Some participants noted that in childhood their p-CMS were incorporated into their daily activities and that they were only met with challenges when they did not perform their p-CMS during the day. For these participants p-CMS was part of the thinking process and engaging with information. When they were allowed to fully express their p-CMS, they could easily incorporate them in their activities. But, being asked to suppress their p-CMS in school caused some of the participants to spend hours at home making up for the lost stereotypic activity – and that was time-consuming. In adulthood, the participants shared that the expression of their p-CMS can be time-consuming if they allow it to be, but that it rarely causes them to miss appointments or social engagements. Of six participants one participant noted that she still struggles in adulthood to reconcile to which extent her p-CMS cause her to miss on other activities.

Some participants shared that as children, they preferred solitary play or play with one close friend to large social gatherings. These participants stated that in that regard p-CMS did not pose a threat to them engaging in social activities in childhood. This is an important point to consider, because as observers we may conclude that the episodes of p-CMS are keeping the children with p-CMS from engaging in life. But, from the point of view of the experiencing children, p-CMS may represent a different way of participating in and experiencing life.

Robinson et al. (2014, 2016) reported that a subgroup of children with p-CMS experience Intense Imagery Movements (IIM) as part of their p-CMS events. This term, IIM, is used to describe conscious engagement in highly energized moments of deep imagination, where the experiencing individuals feel like they are in another world, described as being in a movie or a multi-dimensional video game while engaging in stereotypic movements. In my study, the findings not only confirmed the presence of IIM among the participants, but also provided more information about their first-hand experiences with IIM, which is a novel contribution.

Four of the six participants in this study reported engaging in vivid imagery during their p-CMS episodes, but only two participants self-identified with IIM and used that term to describe their experiences. For these participants, IIM was the core feature of their p-CMS episodes, which in childhood was something that would “come at them” during the hours of play, engagement with interesting content, or when being bored. As the participants grew and matured, they learned how to control the onsets of IIM and to harness it to solve problems from everyday life, organize information in their mind, memorize, and process emotions. As young adults, they have gained mastery over both their stereotypic movements, and their IIM and they can control them and manage them in everyday life.

The participants explained that IIM is significantly different from the acts of imagining and daydreaming. IIM acts as an intense experience of being transported into another world where young adults with p-CMS report that they become characters in that world. The content of the IIM is often combined with content from the participant's daily life (e.g., music, movies, video games, books, etc.), but it includes novel adventures. To paraphrase participant D, IIM is about discovering things that are happening, like watching a movie inside her head. When asked about the experience of IIM participant Ju shared that it depends on the triggers, but that it was his hands [CMS movements] that decided on his IIM. In his words, IIM is about "the worlds" in which he does not play a character but becomes a character.

A longitudinal study on older children and adolescents showed that p-CMS have a persistent course into adulthood and that they share a high rate of comorbid disorders (e.g., anxiety, ADHD, OCD, tics/Tourette syndrome; Oakley et al., 2015). The findings of that study were important as Oakley et al.'s study represents the only longitudinal study to date focused on investigating long-term outcomes for children with p-CMS. What my study, which focused on the lived experiences of young adults who self-identify with p-CMS, brings is the first-hand information which help us not only add depth to the existing knowledge about p-CMS, but also to learn what happens to children with p-CMS in adulthood (Hedderly, 2017). All six participants in my study shared that they either graduated from college or are in the final year of college; that they are gainfully employed, and that they have the experience of living independently. Two participants shared that they had a vast international experience, as they have lived and studied in different countries.

In discussing workplace experiences relative to p-CMS, which has not been investigated prior to this study, participants shared that their p-CMS does not in any way present an impediment at work. Participants stated that they could fully manage their stereotypies and adapt their stereotypies to circumstances at work. The participants either suppressed their p-CMS until they got to a private place, or they performed the stereotypies in unnoticeable ways.

When discussing challenges at work, the young adults with p-CMS shared that they struggled with the already mentioned issues related to comorbidities of p-CMS (e.g., anxiety, time management, task prioritization, attention). These issues have been noted by participants as having been persistent since childhood in the lives of the young adults who self-identify with p-CMS. In the participants' view, p-CMS does not prevent them from performing at work – it helps them to perform better at work, relieve anxiety, and think clearly. The participants did note that it would be largely beneficial to them if they could freely express their stereotypies at the workplace for those very reasons. Three participants shared that they are considering non-traditional career venues which are more suitable to their personalities, and inclusive of their p-CMS.

To date, this is the first study on primary p-CMS which explored the messages young adults who self-identify with p-CMS have for scientists, teachers, parents, and the world at large. Their messages are clear and serve to help us understand not only p-CMS from their perspective, but also where to place our focus when discussing this phenomenon. These messages have been grouped in the following categories: (a) p-CMS need not be framed as a problem to be fixed; (b) the actual problems related to comorbidities deserve significant attention; and (c) p-CMS needs to be redefined and explained in a more relatable way to those who seek answers about it.

Theoretical Framework

In this study I used Bronfenbrenner’s bioecological model, called the PPCT model of human development, which represents the mature version of Bronfenbrenner’s well-known ecological systems theory. In this section, I address which stage of Bronfenbrenner’s theory was used and the evidence that the model was applied in its entirety.

PPCT Model

I used Bronfenbrenner’s PPCT model, which dates to the period between years 1993 and 2006 and represents the mature version of Bronfenbrenner’s bioecological model of development. The central property of Bronfenbrenner’s bioecological model is the view that all human development occurs through interactions between a person and his/her environment. These interactions are bidirectional and constitute “the primary engines of development” (Bronfenbrenner & Ceci, 1994, p. 572), as the child uses these interactions to define his/her place in the world and make sense of it (Tudge et al., 2009).

In Bronfenbrenner’s bioecological model these interactions are called proximal processes. The extent to which proximal processes will influence one’s development depends on the unique set of characteristics of the person, as humans are bio-psychologically complex organisms (Rosa & Tudge, 2013) and all proximal processes take place within a specific context (environment) and over a particular time period. In

Bronfenbrenner's PPCT model the interwoven complexity of all four of these elements – proximal process, person, context, and time – are represented.

Process

The main purpose of this study was to bring the authentic voices of young adults who self-identify with p-CMS into the scientific discourse so that more can be known about their lived experiences from the first-person perspective. In conducting data analysis, I committed a large part of my attention to the participants' individual internal experiences which occur during form them during an episode of p-CMS to uncover what has remained unrepresented in the literature to this date. Just the participants' internal experiences of p-CMS definitionally did not qualify as proximal process in and of itself. According to Bronfenbrenner and Morris (2006), for an activity to be defined as proximal process, it must take place over a period of time in interaction with others in order to provoke one's "attention, exploration, manipulation, elaboration, and imagination" (p. 798).

To apply PPCT model correctly, I maintained the perspective of how the participants' lived experiences of p-CMS occurred in interaction with those in their environments. This led me to group the data into particular segments by where these interactions took place: academic environment, social environment, and work environment. Additionally, I explored how the presence of p-CMS influenced the quality of social relationships for the participants in those environments.

Following Bronfenbrenner's definition of what constitutes a proximal process, I committed to a guideline that these processes had to be of psychological content and include cognitive and emotional states, participants' perception, and the level of participants' motivation (Bronfenbrenner & Ceci, 1994). The application of this guideline emerged as follows: the participants' experiences with p-CMS in childhood (psychological and emotional states), when the participants first became aware of their p-CMS (psychological, cognitive, and emotional states), how participants' p-CMS episodes were met by others (psychological, cognitive, and emotional states), how participants perceived these experiences (psychological, cognitive, and emotional states), and when participants began privatizing their movements (motivation). From there, the data was analyzed to include how their proximal processes grew in complexity as they matured through the years of schooling and leading to their experiences in young adulthood. Finally, the data was analyzed to include the participants' experiences with p-CMS at the workplace in young adulthood.

Bronfenbrenner maintained the view that proximal processes influence how a person's genetic potentials can be realized (Bronfenbrenner & Ceci, 1994). This part of his theory was beyond the scope of this study. Bronfenbrenner's explained that the increasing complexity of proximal processes over time motivates a person to develop relationships, build capacities to sustain attention and develop knowledge, and to apply skills in the world. In that sense, proximal processes serve as the bridge between a person's genetic heritage and the phenotypes which get to be expressed over a lifespan (Bronfenbrenner & Ceci, 1994). It was interesting to find that participant D spoke about this in a different way. Participant D emphasized that individuals with p-CMS should be viewed more holistically, with consideration of their talents and aspirations and to receive help for what they need in order for the individuals with p-CMS to “thrive and prosper in life.”

Person

In PPCT model, a person’s individual characteristics are accounted for the outcomes of proximal processes over time, and are defined as containing the properties of demand, resources, and disposition (Bronfenbrenner & Morris, 2006). All three of the defining properties of person’s characteristics were applied during data analysis in this study.

Demand characteristics include both the person’s apparent features (e.g., age, sex, race), but also those characteristics which are judged by others (e.g., appearance, behavior, temperament; Bronfenbrenner & Morris, 2006). The core element of demand characteristics is the level of influence that they have on a developing person, as they account for how the person is perceived by those in his/her environment. When analyzing the data in this study, demand characteristics were important as they explained how, in the participants’ view, the participants made their decisions about where and when to express their p-CMS, form their view of what p-CMS are, and the level of influence of others’ perceptions which they internalized over time (Bronfenbrenner & Morris, 2006).

Resource characteristics include non-obvious parts of the persons’ inner world, such are lived experiences, the person’s intelligence level, skillset, and knowledge, as well as the level of the level of material resources in the person’s life (Bronfenbrenner & Morris, 2006; Tudge et al., 2009). In this study, resource characteristics were taken into account during data analysis as it was important to consider how the participants built their inner resources to manage experiences of p-CMS as participants grew and the way participants' proximal processes increased in complexity over time. This was particularly important to consider when analyzing how comorbidities played into the quality of the participants' learning abilities, the participants' abilities to cope with learning challenges and the participants' course of adaptation to the demands of their respective environments. The results of this data analysis spoke about tremendous inner resourcefulness on the part of the participants in adapting to their p-CMS and meeting the demands from their environments despite an apparent lack of support.

Disposition represents the sets of a person's characteristics which relate to the person's temperament and one's personal expression (Bronfenbrenner & Morris, 2006). Disposition is observed as an internal force which moves in two opposite directions. When a person is curious and responsive to others, he or she can control impulses and engage in group activities and solitary activities alike. This represents disposition as a generative force in one's life. When a person is impulsive, easy to distract, and explosive then the person's disposition is a disruptive force, leading that person to experience difficulties in relating to others. Disruptive force is also present when emotional and behavioral challenges contribute to a person's feelings of apathy, insecurity, shyness, and lack of interest, leading to avoidance and withdrawal (Bronfenbrenner & Morris, 2006). In this study, the participants' disposition was considered during data analysis to a great extent as it showed to which level the presence of p-CMS in the participants' lives and their individual conditioning had led the participants' willingness to engage in social activities, to pursue or to refrain from building relationships with others, as well as to which extent these experiences affected the quality of their lives. It was especially interesting to consider disposition when analyzing the participants' lived experiences in young adulthood. As participants described events in their childhoods, it became evident as to how the participants used their disposition as a generative force to achieve the goals that they had set for themselves earlier in life, while managing disposition as a disruptive force which for some participants, remains a challenge in some domains (e.g., self-esteem).

Context

In Bronfenbrenner's view, the environment is defined as four interconnected systems: the *microsystem, mesosystem, exosystem,* and *macrosystem* (Bronfenbrenner & Ceci, 1994). These environments transcend beyond physical features (e.g., classroom, one's home, playground) to include those social interactions, societal roles and activities which influence one's development (Bronfenbrenner, 1994). Thus, the environment has a great influence on the person's development, as it fuels the content of the person's proximal processes.

The *microsystem* is the environment which is defined as the context in which most of the proximal processes take place for a developing person (e.g., family, peer group; Bronfenbrenner, 1994). When all these microsystems are connected in one's life, they form the next environment, called the *mesosystem*. When a mesosystem is observed in interconnection with others' mesosystems (e.g., mother's stress at work which impacts a child's development), then the third environment is considered which is called the *exosystem*. Finally, the fourth environment is the *macrosystem*, which extends beyond the previous three environments to include the larger cultural structures (e.g., cultural beliefs, customs, opportunities, material resources, etc.; Bronfenbrenner, 1994).

During data analysis, all four environments were utilized as the contextual background for the participants' lived experience to a certain extent. It was beyond the scope of this study to analyze each of these environments in great detail, but what I did consider is the following: (a) the family structure in which the participants were raised and how they perceived their experiences with p-CMS relative to their family members; (b) peer interaction over time and how that has influenced their lived experiences relative to p-CMS; (c) school experiences with teachers and learning relative to their p-CMS, including the level of support that they had received for challenges in school; and (d) cultural norms regarding how p-CMS is viewed in their respective cultures.

Time

It is considered that the fourth element of PPCT model, Time, gave Bronfenbrenner's bioecological model of development a third dimension (Bronfenbrenner, 1994). The element of time provided the framework to overcome the challenges of the common, linear view of time by dividing time into three distinct levels – *microtime, mesotime*, and *macrotime* (collectively referred to as a *chronosystem*). In Bronfenbrenner's chronosystem, microtime refers to continuity of proximal processes and their eventual discontinuity, mesotime refers to larger periods of time (e.g., days, weeks, months, years) over which proximal processes take place, and macrotime refers to a larger historical era during which a person lives that influences that person's development.

I applied Bronfenbrenner’s chronosystem to this study to the extent to which the scope of the study allowed for it. In that sense, microtime was considered when I analyzed the data about the level of continuity of p-CMS episodes in the participants’ lives in young adulthood and how the circumstances of COVID-19 pandemic affected the participants’ p-CMS events. Mesotime was considered when I analyzed the data which pertained to the participants’ current expression of p-CMS to show how often they experience episodes of p-CMS in young adulthood. Finally, I applied macrotime to observe the current historical period, which is characterized by an increasing amount of initiatives which promote diversity and inclusion in the Western societies. Macrotime was especially observed when I analyzed international cultural differences among the participants.

In summary, the application of Bronfenbrenner’s PPCT model to my study led me to view the participants in this study as both active producers in their environment and the products of their environment, as the proximal processes that were analyzed are bidirectional in nature (Bronfenbrenner & Morris, 2006). Bronfenbrenner’s PPCT model allowed me to explore the lived experiences of young adults who identify with p-CMS in great depth and complexity, which was necessary in this case, given that this is the first qualitative study that focused on the subjective views of young adults who self-identified with p-CMS. I strove both to provide the audience with the necessary context and depth of the participants’ experiences which birthed their important messages and to deliver this goal with academic rigor, precision and clarity without the unnecessary reduction of data.

Limitations of the Study

This qualitative phenomenological study, which aimed to explore the lived experiences of young adults who self-identify with p-CMS has been vulnerable to several limitations. The most pronounced limitation was that only one of six participants held an official diagnosis of p-CMS as the studied phenomenon. Although other participants held official diagnoses for comorbid disorders (e.g., anxiety, ADHD, OCD, dyslexia), according to these participants they were never medically examined for p-CMS.

The number of six participants is also a limitation. Morse (1995) advised that in qualitative studies the final number of the participants should be determined on the concept of saturation and that guideline was used in this study. But, having a larger sample would have brought more diversity to this study, especially given its international nature.

Data collection for this study was conducted during a global COVID-19 pandemic, which represented an unusual circumstance. Even though additional measures were taken on my part (individual member-checking calls with the participants a year after the initial interviews), the participants in this study reported being affected by a set of additional circumstances related to the COVID-19 pandemic (e.g., change in a place of residence, switching to working and studying from home, higher anxiety levels). In that regard, it is difficult to tell the extent to which these unusual circumstances affected the participants' memory recall and tainted their expressed views.

Finally, this study was conducted by a doctorate student, which poses a limitation at the level of the researcher's professional experience.

Recommendations for Future Research

Recommendations for future research, based on the strengths and limitations of my study, can be grouped in the following categories: (a) sample recommendations; (b) purposeless vs. purposeful; (c) treatment; (d) comorbidities; and (e) the participants' curiosities.

This study was based on the shared lived experiences of young adults who self-identify with p-CMS. Even though the study was international, gathering the participants from three continents and five countries, only one of six participants held the official medical diagnosis of p-CMS. Future qualitative research should include a larger sample and seek not only to interview the participants who self-identify with p-CMS, but also those individuals who already hold the medical diagnosis of p-CMS. Also, it would be beneficial that future studies explore the lived experiences of older adults with p-CMS to add more information about how p-CMS and the effects of p-CMS changes over time. This would expand our understanding of how older adults integrate and utilize their p-CMS as their life tasks become increasingly complex and societal demands grow in adulthood. Having a deeper understanding of the long-term outcomes for adults with p-CMS could potentially aid in identifying what early interventions can be developed to help children with p-CMS "thrive and prosper in life" (participant D).

More studies are needed to further explore the gap that exists between how p-CMS are observed by others and how they are experienced by those who engage in p-CMS and to address the topic of a purposeful vs. purposeless role of p-CMS in the lives of the individuals with p-CMS. One of the findings of this study was a message from the participants that the current definition of p-CMS is one-sided and non-relatable to them; that p-CMS needs to be reframed and redefined in the literature to represent this phenomenon accounting the experiences of individuals with p-CMS more truthfully. Future research should be undertaken to further explore the phenomenon of p-CMS from the perspective of the experiencing individuals with p-CMS at all ages. The purpose or lack thereof of p-CMS is the issue that should not only be explored in the physiological sense (e.g., defining psycho-neurological underpinnings of p-CMS), but also in a larger ontological sense, as p-CMS appears to be a different way of experiencing one's reality which holds meaning for participants, reportedly.

The findings of this study showed that young adults who self-identify with p-CMS hold negative perceptions towards treatment of p-CMS. In their opinion, viewing p-CMS as purposeless movements which can be treated into non-existence without possible negative consequences for the experiencing individuals is problematic on multiple fronts. Instead, participants indicated that when developing treatment for p-CMS we need to consider the internal experiences of those whom we are trying to help. More research should be conducted to address this issue. In my opinion, we need more qualitative studies which would provide information about the first-hand experiences of those individuals whose p-CMS are pronounced at moderate and severe levels, as their needs for therapeutic intervention may be different from those stated by the participants in this study.

The findings of this study confirmed and expanded on the previous research regarding a high prevalence of comorbidities among young adults who self-identify with p-CMS (e.g., anxiety, ADHD, OCD, dyslexia). In the participants' view, p-CMS experiences are not a problem that require treatment, but issues related to comorbidities are problems that require treatment (e.g., anxiety, obsessive thinking patterns, attention/focus, time management, task prioritization, etc.). It would be possibly beneficial to explore deeper the role that p-CMS plays in alleviating the negative impacts of comorbidities, as was reported by the participants in this study.

Finally, in the participants' view, more neuroimaging studies are needed to uncover what occurs physiologically during an episode of p-CMS in the bodies of the experiencing individuals, especially with the presence of vivid imagery and Intense Imagery Movements (IIM). Some participants were concerned about the long-term outcomes of p-CMS on their nervous system. Some participants were also curious to learn if the future research which involves neuroimaging could potentially uncover how the beneficial aspects of p-CMS could be utilized more for the experiencing individuals. Some participants noted that it would be beneficial if future studies explored common behavioral patterns and personality traits among individuals who experience p-CMS.

Implications for Positive Social Change

Based on previous research and findings of this study, p-CMS have been the source of concern for parents and educators and a subject of scientific interest. Parental interviews uncovered that parents of children who present with p-CMS tend to have a negative view towards their children's stereotypical behavior, stating that it negatively impacts the quality of the children's lives (Hedderly, 2017). Some of the main parental concerns included peer bullying and social stigmatization, as well as interference of p-

CMS with learning and socializing in their child’s life (Singer et al., 2018; Specht et al., 2017). It would be irresponsible on my part to state that these worries are unfounded, but to paraphrase participant Ju, parents should keep in mind that what p-CMS is for a toddler is largely different from what p-CMS is for a young adult, as children learn to manage and privatize their p-CMS episodes as they mature.

Findings of this study showed another side of p-CMS; the side which belongs to the intimate worlds of the experiencing individuals. In participants’ views, parents should not be worried about their children’s p-CMS. Instead, participants expressed that parents, teachers, and caregivers should look for ways to support children as they grow. Participants expressed that more should be done to explore how best to integrate p-CMS in children’s lives as part of who they are. Additionally, parents should pay attention to the issues related to comorbidities and help their children in that regard (e.g., anxiety, attention/focus, time management, etc.). The findings of this study hold a promise to help the parents of children with p-CMS better understand what this phenomenon is from their child’s point of view, why it is important to their child, and what purpose it serves for their child’s well-being. If parents could understand the unobservable, unseen aspect of the p-CMS in their child’s life from the child’s viewpoint, my assumption is that those parents could increase the quality of the child’s family life and relationships, which participants reported as strained due to a lack of understanding of p-CMS. In that sense, the parents can become the advocates for their children with p-CMS in an empowered and appropriate way in school and in public.

The findings of this study may also hold important information for educators at all levels who may encounter students with p-CMS in their classrooms. Instead of reprimanding students for their p-CMS episodes or providing potentially inappropriate classroom interventions, educators would be equipped to understand that p-CMS may aid in learning. Rather than focusing on stopping the outward expressions of p-CMS, educators may find (through this study) that a greater appreciation for the inward processes of p-CMS can help empower students and assist students in higher achievements. With this level of understanding of what p-CMS are for their experiencing students, educators could not only develop appropriate modifications to class instruction but become advocates for p-CMS in their schools, setting an example for student peers and others in the community.

Having understanding parents as well supportive educators, young children with p-CMS could be raised in environments in which the natural expression of p-CMS is met with approval rather than censure. Children with p-CMS could then possibly gain the opportunities to internalize more positive views of others and be empowered to freely explore the beneficial side of their p-CMS. Advocacy on parents' and educator's part could then possibly inform other parents, peers, and community members regarding what p-CMS is, leading to a more diverse, harmonic, and inclusive society.

The findings of this study could potentially be important for medical professionals who attend to children with p-CMS. Instead of dismissing the phenomenon of p-CMS as something that children grow out of or assigning it to a comorbid disorder, pediatricians could consider issuing medical diagnoses for p-CMS which would, in a legal sense, assist the parents in requesting and receiving special education services and/or appropriate support in school that their children might need.

This study could also contribute by sparking a discussion among scientists about the definitional aspect of p-CMS; how to reframe and redefine the phenomenon of p-CMS so that it is not only relatable to the experiencing individuals, but also truthful to their experience. With the findings of this study, scientist can gain a new perspective when conducting future research on p-CMS. With a more appropriate definition of p-CMS, we may then be able to address the question of how to energize changes at organizational and societal/policy levels which are supportive, inclusive and empowering for those individuals who experience p-CMS and their care providers.

Conclusion

CMS have for a long time been considered to be the hallmark characteristic of individuals with autism. This motor disorder is not exclusive to autism and other neurodevelopmental disorders, but also occurs among otherwise typically developing individuals (Barry et al., 2011; Lemiere, 2014; Oakley et al., 2015). To differentiate the terms, CMS which occurs among typically developing population has been termed in the literature as p-CMS. P-CMS have been defined as repetitive, rhythmic, predictable movements which stop with distraction, and serve no apparent purpose (Singer, 2009).

Previous studies on p-CMS have been focused on: (a) defining the p-CMS; (b) uncovering the neurological nature of p-CMS; and (c) testing the effectiveness of different therapeutic approaches to treating the physical manifestation of p-CMS episodes. These studies were mainly focused on parental reports and observations of young children who present with p-CMS; with the exception of one case-study series, which utilized the reports of two 13-year-old girls. This has led some scientists to note that current view of p-CMS in the literature is mainly one-sided, as based on the external observations; and that more qualitative studies are needed to explore what p-CMS are from the first-person view and what effects p-CMS has on the experiencing individual on the long run.

To my knowledge thus far, this is the first qualitative study aimed to explore the lived experiences of young adults who self-identify with p-CMS. The purpose of the study was to help us understand how experiencing individuals describe their p-CMS episodes, how they define and view their p-CMS, and how p-CMS affects the young adults' lives in social, academic, and work settings. Finally, this study aimed to bring the voices of the experiencing individuals into the scientific discourse by delivering what young adults who self-identify with p-CMS think that others should know about this phenomenon.

The results of this study showed that young adults who self-identify with p-CMS have gone through a tremendous level of adaptation to meet societal standards of behavior, sometimes at high emotional, cognitive and psychological costs. Even though all six participants from this study came from different cultural backgrounds, their testimonials share a common message – that there is so much that we have yet to learn about p-CMS if we aim to help individuals with p-CMS prosper in life.

In the participants' view, the current state of affairs in medical practice and scientific literature regarding p-CMS does not benefit individuals with p-CMS.

According to the participants in this study we as researchers need to consider the lived experiences of those who present with p-CMS in order to understand what p-CMS are, what purposes p-CMS serves, and what issues those who experience p-CMS need help with from the first-person perspective. Most of all, we need to understand that, to participants, p-CMS is a wholesome experience which is closely tied into the participants’ cognitive, emotional, and psychological states; and not just the physical movements, as had been determined by p-CMS experiences that had been externally observed and treated.

In my opinion, if researchers continue to view p-CMS only from the observer’s point of view, we risk reducing one’s complex inner cognitive, emotional, physiological, and psychological processes to a socially constructed disorder which presents a problem requiring treating until the experiences disappear. The lack of understanding of the fine inner webbing of p-CMS processes may lead into the application of therapeutic approaches which treat the physical aspect of the stereotypies at the expense of the well-being of the treated individuals; while, at the same time, not providing solutions to the issues that individuals with p-CMS consider to be a problem. According to the participants in this study, the current focus of research is not on the relevant obstacles in life for those who experience p-CMS (such as comorbid issues of anxiety, ADHD, OCD, learning difficulties), but only on the observable part of p-CMS, a minor to non-issue for experiencers by this study’s findings.

Even when the apparent limitations of this study are considered, it is difficult to ignore that the testimonials of these six young adults who present with p-CMS from three continents and five different countries carry a unified and important message for scientists, educators, parents, and society as a whole. It seems that if researchers seek the privilege of being allowed into the inner landscapes of those who experience p-CMS, they may not only discover “the worlds” which they observe, but “the worlds” of which the participants talk about and a different way of experiencing life. With a wider, more inclusive way of viewing p-CMS, researchers may also possibly find that those who have the clues to the p-CMS are the individuals who experience p-CMS.

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Appendix A: Interview Protocol

Interview Questions

1. Can you tell me a little bit about yourself?
2. Can you tell me a little bit about your movements?
3. When did you first notice the movements? When did you notice others noticing the movements? How did others react (parents, teachers, peers, etc.)? Do others react the same way still?
4. How do the movements manifest?
5. When do they manifest?
6. How often?
7. Are there any situations – internally or externally – that make the movements manifest?
8. What do you experience during their manifestation?
9. Have you ever researched the topic of the movements?
10. If yes, how did you resonate with the results of your research – with the way that they are defined medically?
11. What do you feel that the world should know about the movements?
12. Do the movements bring any benefits to you?
13. Do the movements bring up any unpleasant emotions or situations when they occur?
14. Are the movements any different now from when you were younger?
15. When did you become aware that the movements express through you?

16. Do you have any recollection of how people in your environment responded to your movements?
17. Have you ever tried to refrain from making the movements? If so, what effect did you feel that this had?
18. Can you tell me a bit about your experiences in school? How about work?
19. Have your CMS experiences influenced or impacted personal relationships such as friendships or romantic relationships? How has it effected these relationships?
20. Have your CMS experiences influenced or impacted your other personal or social behaviors? Do they effect your willingness to engage in social or public activities such as shopping, parties, theaters, etc?
21. Research shows that people who experience primary CMS (the movements) often have a high rate of ADHD, OCD, and anxiety – can you relate to this?
22. Have you ever been referred to a doctor for any of those conditions?
23. Research shows that the movements never happen during sleep, but I would like to ask you if quality sleep has ever been an issue for you in relation to the movements.
24. Do the movements pose any issues to your personal relationships?
25. Do the movements pose any issues to your career development?
26. What would you like scientists to understand and pay attention to when it comes to primary CMS (the movements)?

Appendix B: Recruitment Social Media Post

ARE YOU INTERESTED TO PARTICIPATE IN A STUDY ON PRIMARY CMS?

Dear Members of _______________ group,

Are you a young adult, between 21 and 27 years old?

Have you been experiencing complex motor stereotypies (CMS) since childhood?

You may qualify for a study that is focused on learning what it is like as an adult to live with complex motor stereotypies. It is important that scientists understand how you view the stereotypies, how they have affected your relationships at school, work, and home, and what you feel that the rest of the world needs to learn about the stereotypies.

The purpose of this study is to add to the knowledge scientists have about complex motor stereotypies (CMS) and how individuals adapt to CMS in their daily lives. There has been an increase in the number of studies on CMS among otherwise healthy individuals. However, these studies have been based mainly on parental reports and observations of children. What is missing from research is the perspective of those who have been living with complex motor stereotypies as adults to tell us first-hand how living with CMS affects their lives. Your participation is important as it increases information which may potentially be used for such things as determining the course of future research, creating more relevant support systems for those experiencing CMS, or streamlining therapeutic approaches already in place for those experiencing CMS.

The study consists of two 60-minute interviews that will be conducted via phone call or Zoom video call – whichever medium you prefer. Your participation is voluntary.

Those individuals who accept voluntary participation will be required to indicate their acceptance by reading the informed consent and responding to an email signifying their understanding.

Not everyone who volunteers/agrees to participate will be accepted for participation.

The researcher is inviting young adults only between the ages of 21 to 27 years, who also self-identify with primary complex motor stereotypies to be in the study.

The researcher will not include anyone who is a personal or professional acquaintance and will only draw participants from a pool of potential participants created by individuals responding to this Facebook post seeking study subjects. Also, the researcher will not include children, teenagers, and adults older than 27 years.

This study has been designed to offer no monetary compensation for participation. However, as a thank you gift for your time and effort, every participant will receive a $5 Starbucks gift card.

This researcher conducting this study is Vanja Maria Popovic, who is a doctoral student at Walden University. You may contact her at Vanja.popovic@waldenu.edu.

If you are a young adult, between 21 and 27 years of age, who has been experiencing CMS since childhood, and would like to participate in the study, please contact the researcher.

Appendix C: Colaizzi's Seven Step Method for Data Analysis

Step	Name	Description
1.	Familiarization with transcripts	The researcher listens to and/or reads the transcripts numerous times in order to familiarize with the content of the interviews.
2.	Identification of relevant statements	The researcher identifies the participants' statements which pertain to the studied phenomenon.
3.	Formulation of meaning from relevant statements	The researcher formulates meaning from the collected data, by going back and forth between the original data and his/her interpretations to check for accuracy. The researcher uses "bracketing" to note his/her personal opinions and bias in order to maintain fidelity to the studied phenomenon.
4.	Emergence of theme clusters and themes	The researcher combines his/her meaningful interpretations of the data into larger theme clusters and themes
5.	Composition of the detailed description of the structure/essence of the studied phenomenon	The researcher produces a detailed description of the phenomenon under investigation, taking into account the themes which previously emerged in step 4.
6.	Description of the structure/essence of the phenomenon	Based on the previous descriptions of the phenomenon, the researcher synthesizes his or her descriptions into short statements which explain the essence of the structure of the phenomenon
7	Verification of the structure/essence of the studied phenomenon	The researcher takes his or her findings back to the participants to check for accuracy – to see whether the results of the data analysis truthfully represented their experiences. Then, based on the feedback, the researcher goes back and makes the necessary changes.

Appendix D: Open Coding Codebook

Research Question	Codes	Description
1. How do young adults who present with p-CMS describe events of p-CMS as related to their social, academic, and personal environments	P-CMS: SOCIAL, ACADEMIC, PERSONAL, WORK	The following set of codes helps to answer the Research Question one.
	Adult view of p-CMS	How adults in the life of the person viewed his or her p-CMS
	Adult friend	The perceived view of friends in young adulthood
	Parents	The participants' experiences with how their parents reacted to their p-CMS
	Perceived others	The participants' general view of "others"
	Teachers	The participants' experiences with teachers during all stages of schooling
	Positive experiences	Positive experiences
	Negative experiences	Negative experiences
	Changes in p-CMS over time	How the participants' p-CMS evolved over time
	No	No changes
	Yes	Signifies changes to p-CMS over time
	p-CMS and creativity	Relationship between p-CMS and creativity in the participant's experience
	p-CMS and relationships	How p-CMS affected the quality of relationships in the participants' experiences
	p-CMS and friendships	How p-CMS affected the quality of friendships in the participants' experiences

Friendship preferences	Explores the participants' preferences for engaging in small groups vs. large groups
Large groups	
No preference	
One friend	
Small groups	
p-CMS and romantic relationships	How p-CMS affected the participants' romantic relationships
p-CMS and social activities	How p-CMS affected the participants' willingness to engage in social activities
p-CMS and sleep	Explores whether p-CMS affected the quality of sleep
p-CMS and workplace	How p-CMS affected the participants' experiences at the workplace
Negative	Negative view
Neutral	Neutral view
Positive	Positive view
p-CMS episode	Explores the participants' lived experiences during an episode of p-CMS
Awareness during p-CMS	Explores whether the participants have a conscious awareness during an episode of p-CMS
Conscious	
Not conscious	
Control of p-CMS	Explores when in life the participants gained control over their p-CMS episodes
High School	
Middle School	
Coping strategies	Explores coping and management strategies that the participants utilized for their p-CMS

Physical damage	Explores whether the participants' p-CMS episodes cause any physical damage to the surrounding objects in space
Energy	Explores to which extent the participants used the term "energy" to describe their experiences with p-CMS
Frequency of manifestation	How often the episodes of p-CMS occur
IIM/Vivid imagery	Explores whether the participants engage in vivid imagery during p-CMS
Internal experience	What a person is experiencing internally during an episode of p-CMS
Active participant in the experience	Explores active participation in the episode of p-CMS – being a character in the world of IIM
Creativity and innovation	Explores the occurrences when a p-CMS episode is used to harvest creativity and novel solutions
For fun	Explores the occurrences when a p-CMS episode is used for fun
Problem solving	Explores the occurrences when a p-CMS episode is used for problem solving
Relief	Explores the occurrences when a p-CMS episode is used for relief
Thought process	Explores the occurrences when a p-CMS episode is used for thought process
Missing out due to p-CMS	Whether the participants' experience a sense that they

Physical hurt	Explores whether the participants experience physical hurt as a consequence of their p-CMS episodes
Physical manifestation of p-CMS	What parts of the body are engaged during the physical manifestation of p-CMS episode
Hands	
Hands and head	
Walking	
Whole body	
Triggers	What commonly triggers the participants into an episode of p-CMS
Boredom	
Creativity	
Environmental cues	
Negative emotion	
Positive emotion	
Routine	
Thought process	
Time of day	
Voluntary use of p-CMS	Explores whether the participants induce their p-CMS episodes for specific purposes
Creativity	
Focus	
p-CMS in school	Explores the participants' experiences in school with p-CMS
p-CMS and learning	How p-CMS influenced the participants' learning experiences
Focus	
Helps thinking	

Memory	
Synthesizing	
p-CMS in childhood	Explores the participants' experiences in childhood relative to their p-CMS
Favorite subject in school	What the participants' favorite subjects in school were and why
Art	
English	
History	
Math	
Least favorite subject in school	What the participants' least favorite subjects in school were and why
English	
History	
Math	
Physical education	
Peer Bullying	The participants' experiences with peer bullying due to p-CMS
Yes	
No	
p-CMS and peers	Explores the participants' lived experiences with peers relative to their p-CMS
Negative experiences	
Positive experiences	
Reprimanding experiences	Explores the participants' lived experiences with being reprimanded for their p-CMS
At home	
In school	
Special education services	Explores whether the participants received any special education services in school for their learning difficulties

Comorbidities	Explores the presence of comorbid disorders to p-CMS
Anxiety	
ADHD	
OCD	
First time awareness of p-CMS	Shows at what age the participants first became aware of their p-CMS
0-5	
6-10	
11-15	
16-20	
21+	
Growing out of p-CMS	Explores whether the participants grow out of their p-CMS
Identification with autism	Explores whether the participants ever identified with autism or were referred to testing with the assumption that they had autism
Medication	Explores whether the participants were prescribed any medication for their p-CMS
Privatization	Explores when the participants began privatizing their p-CMS episodes
Privatization cause	Explores why the participants began privatizing their p-CMS episodes
Psychological hurt	Explores the data pertaining to the participants’ perceived psychological hurt due to their lived experiences with p-CMS
Suppression of p-CMS	Explores when the participants began suppressing their p-CMS
Elementary school	

	Middle school	
	High school	
	Suppression effects	Explores the participants' experiences with the effects that the suppression of p-CMS has on them
	Negative effects	
	Positive effects	
1. What meaning do young adults who present with p-CMS give to their stereotypies?	MEANING AND DEFINITION	The following section combines the codes which help to answer the research question two.
	Personal definition of p-CMS	Explores how the participants define p-CMS in their own terms
	Personal perception of p-CMS	Explores the participants' views towards p-CMS
	Negative	
	Neutral	
	Positive	
	Desire to eliminate p-CMS	Explores the participants' inner desire to eliminate their p-CMS
	Mixed	
	No	
	Yes	
	View towards therapy for p-CMS	Explores how the participants view therapy for p-CMS
	Negative	
	Positive	
	Therapy	Explores the participants' experiences in therapy
	Negative	
	Positive	
	Safety	Explores safety issues during the participants' episodes of p-CMS

	Secrecy	Explores the participants' issues of secrecy surrounding their p-CMS
	Self-esteem	Explores the participants' perceived views of how p-CMS affected their sense of self-esteem
	Shame	Explores the participants' issues of shame surrounding their p-CMS
1. What is it that young adults who self-identify with p-CMS think that society and science should learn and understand about typically developing individuals who present with p-CMS?	MESSAGE TO SCIENTISTS AND SOCIETY	The following section combines the codes which helped to answer the research question three.
	Purposeful vs. purposeless	Explores whether the participants viewed their p-CMS as purposeful or purposeless
	Addictive side of p-CMS	Explores whether the participants viewed their p-CMS as a form of addiction
	Attitude towards research on p-CMS	Explores the participants views of the current research on the subject of p-CMS
	Message to scientists	Explores the participants' explicit messages to scientists

Appendix E: Axial Coding

Table E1

Theme 1: Experiences (Y-axis values)

Code	Participant D	Participant Dj	Participant I	Participant J	Participant Ju	Participant M
Adult view	-4	5	1	-4	-2	3
Changes over time	2	0	5	3	4	3
Creativity and p-CMS	0	0	5	2	5	2
p-CMS and friendships	2	0	0	-3	4	0
p-CMS and romantic relationships	0	0	-1	0	0	0
p-CMS and workplace	-4	0	3	1	2	2
P-CMS in school	-4	1	-3	-1	1	-1
p-CMS in childhood	1	1	-4	4	2	-3
p-CMS and SPED	1	0	0	0	-3	0
Reprimanding experiences	-3	2	1	-4	-3	-1
First time awareness	3	2	-4	-4	-3	-1
Diagnosis	0	0	0	0	1	0
Peer bullying	-1	0	-1	-1	-2	-1
Privatization	1	1	-3	-1	-1	-1
Suppression	-3	3	-3	-3	-4	-2
p-CMS episode	4	5	4	5	5	-2
IIM, vivid imagery	4	3	4	4	5	1
p-CMS for different states	0	0	4	3	1	0
Purpose vs. purposelessness	-4	0	1	1	4	3
Coping	1	0	3	1	3	0

Physical manifestation	4	1	-1	1	-1	1
Triggers	3	4	3	3	3	-2
p-CMS and social activities	3	0	0	-1	0	3
Comorbidities	-4	-2	-3	-4	-3	-1
Growing out	1	0	0	0	4	2
Autism	-1	0	-1	0	0	0
Medication	0	0	0	0	0	0
Y-Axis coordianate (Total sum of values)	2	26	10	2	22	5

Table E2

Theme 2: Perceptions (X-Axis coordinates)

Code	Participant D	Participant Dj	Participant I	Participant J	Participant Ju	Participant M
Personal definition of p-CMS	5	5	1	1	3	3
Perception of p-CMS	2	5	1	-1	0	2
Desire to eliminate p-CMS	3	0	-2	-2	1	2
Safety	0	0	-2	0	-1	-4
Secrecy	0	0	-1	-4	-1	0
Shame	0	0	-3	-4	-2	0
Self-esteem	0	0	-4	-4	5	3
Missing out due to p-CMS	0	0	0	-2	-2	2
X-Axis coordinate	10	10	-10	-16	3	8

Table E3

Final XY Values for the Axial Graph

	Participant D	Participant Dj	Participant I	Participant J	Participant Ju	Participant M
X-Axis Coordinate	10	10	-10	-16	3	8
Y-Axis Coordinate	2	26	10	4	22	5