‘After Six Months, You Start to Get a Bit Fed up’: A Qualitative Exploration of the Impacts of COVID-19 on the Employment and Mental Health of Four Adults on the Autism Spectrum

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Abstract

The COVID-19 pandemic has led to major economic, social, and psychological consequences. Marginalized groups, such as adults on the autism spectrum, may be even more vulnerable to the effects of the pandemic, especially in the areas of employment and mental health. An analysis of lived experience among this population within both areas is needed to gain a better understanding of the impacts of the pandemic. Although emerging research suggests that COVID-19 has negatively impacted the employment, job supports and mental health of adults on the autism spectrum, many studies were conducted in the months following the initial outbreak, used survey methods and assessed several areas (e.g., work, school, social life) together. This limits our understanding of the impact to the early stages of the pandemic and may fail to capture the depth of lived experience regarding work and well-being. This follow-up study to Di Francesco et al. (2021) sought to explore the lived experiences of adults on the autism spectrum 20 months into the pandemic, specifically looking at how COVID-19 impacted their (1) employment experience, job satisfaction, and satisfaction of employment support services; (2) mental health; and (3) to identify helpful supports during COVID-19. Using an interpretative phenomenological analysis (IPA) framework, four adult males on the autism spectrum without co-occurring intellectual disability completed two questionnaires and a semi-structured interview. Questionnaire responses obtained in this study were compared to those obtained in the previous study and the difference in responses between both timepoints were integrated in the qualitative analysis, while interviews were analyzed using a six-step IPA approach. Results provide evidence for a prolonged negative impact of the pandemic on employment and mental health, with participants reporting increased isolation and a deterioration in their well-being over time, and continued difficulty with obtaining a stable job, thus exacerbating existing inequalities among this population. Results also indicate that participants' satisfaction with their job and the employment support services received were not impacted by the pandemic and shed light on potential protective factors and coping strategies for this population. Overall, participants' narratives indicate a need for supports and services among this population to improve job success and well-being.

Résumé

La pandémie de COVID-19 a provoqué des conséquences économiques, sociales et psychologiques majeures. Les groupes marginalisés, comme les adultes autistes, pourraient être encore plus vulnérables aux effets de la pandémie, notamment dans les domaines de l'emploi et de la santé mentale. Une analyse de l'expérience vécue par cette population dans ces deux domaines est nécessaire pour mieux comprendre les impacts de la pandémie. Des recherches récentes suggèrent que le COVID-19 a eu un impact négatif sur l'emploi, le soutien au travail et la santé mentale des adultes autistes. Bien que les recherches émergentes suggèrent que le COVID-19 a eu un impact négatif sur l'emploi, le soutien professionnel et la santé mentale des adultes autistes, de nombreuses études ont été menées dans les mois qui ont suivi la vague initiale, ont utilisé des méthodes de sondage et ont évalué plusieurs domaines (par exemple, le travail, l'école, la vie sociale) ensemble. Cela limite notre compréhension de l'impact aux premières phases de la pandémie et peut ne pas rendre compte de la profondeur de l'expérience vécue concernant le travail et le bien-être. Cette étude de suivi de Di Francesco et al. (2021) visait à explorer les expériences vécues par des adultes autistes 20 mois après le début de la pandémie, en analysant spécifiquement la façon dont le COVID-19 a eu un impact sur (1) leur expérience à l’emploi, leur satisfaction au travail et leur satisfaction des services de soutien à l'emploi ; (2) leur santé mentale ; et (3) à identifier les soutiens qui ont été aidants pendant le COVID-19. En utilisant une approche d'analyse phénoménologique interprétative (IPA), quatre hommes autistes sans déficience intellectuelle ont rempli deux questionnaires et ont complété un entrevue semi-structurée. Les réponses aux questionnaires obtenues dans cette étude ont été comparées à celles obtenues dans l'étude précédente et la différence dans les réponses entre les deux points a été intégrées dans l'analyse qualitative, tandis que les entrevues ont été analysées selon une approche IPA en six étapes. Les résultats démontrent un impact négatif prolongé de la pandémie sur l'emploi et la santé mentale, puisque les participants ont indiqué un isolement plus marqué et une détérioration de leur bien-être au fil du temps, ainsi que des difficultés persistantes à obtenir un emploi stable, exacerbant ainsi les inégalités existantes au sein de cette population. Les résultats indiquent également que la satisfaction des participants à l'égard de leur emploi et des services de soutien à l'emploi reçus n'a pas été affectée par la pandémie, et mettre en évidence les facteurs de protection potentiels et les stratégies d'adaptation pour cette population. En conclusion, les réponses des participants indiquent un besoin de soutien et de services pour cette population afin d'améliorer la réussite au travail et le bien-être.

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Contribution of Authors

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Chapter 1

Introduction

The COVID-19 pandemic is an unprecedented global crisis, affecting all aspects of society. Characterized by high rates of infection and morbidity (Yao & Park, 2020), COVID-19 has required countries worldwide to implement mitigation measures, such as a ban on social gatherings, physical distancing, travel restrictions, and closures of non-essential businesses. Although necessary to reduce the spread of the virus (Saez et al., 2020), these measures have been accompanied by substantial economic, social, and psychological consequences. In the general population, millions became unemployed and experienced an increase in loneliness and social isolation (Bu et al., 2020), all of which are associated with a greater likelihood of experiencing mental health issues (Paykel, 2003; Wang et al., 2018).

Marginalized groups, such as adults on the autism spectrum, may be even more vulnerable to the effects of the pandemic (Cassidy et al., 2020; Pellicano & Stears, 2020), given that, under usual conditions, this population struggles to obtain and maintain employment (Zwicker et al., 2017) and is at greater risk of developing co-occurring mental health difficulties relative to the general population (Croen et al., 2015). Indeed, one study conducted in the United States found that adults on the autism spectrum ranked employment as the most impacted area with respect to pandemic-related changes compared to other domains (e.g., school, social life; Bal et al., 2021), while another survey in the United States found that 93% of 636 adults on the autism spectrum reported a negative effect on their mental health (Chung, 2020). These findings suggest that the pandemic had a profound negative impact among this population with respect to employment and mental health.

However, these studies and many others examining the impact of COVID-19 on the employment and mental health of this population were conducted during the very early phases of the pandemic and collected data mainly through survey responses, providing only a superficial understanding of lived experience. Although valuable for understanding the initial impacts, further research is needed to examine the longer-term effects taking place among this population, especially given the long-lasting nature of the pandemic. Further, a qualitative exploration of lived experience among this population is needed, as it can enable a deeper understanding of human experience and uncover themes, understandings and insights that may not come to light through statistical analyses (Tewksbury, 2009). A more refined analysis into their experiences will provide a more comprehensive understanding of the enduring impact of COVID-19 on the employment and mental health of adults on the autism spectrum.

The purpose of the current study was to expand on prior research by exploring how COVID-19 impacted adults on the autism spectrum in the long-term, specifically 20 months into the pandemic, through their perspectives. The main objectives were to explore how COVID-19 impacted their (1) employment experience, job satisfaction, and satisfaction of employment support services; (2) mental health; and (3) to identify any supports that were available and deemed helpful to participants during the pandemic. Using an interpretative phenomenological analysis (IPA) approach, participants completed a semi-structured interview and two questionnaires. The knowledge gained from this study will enlighten employment agencies, policymakers and professionals who work with this population (e.g., counsellors) about how the longer-term impact of COVID-19 is being experienced, and may inform ways in which supports and services can be tailored to meet the needs of adults on the autism spectrum and promote job success and well-being in various contexts including and beyond the COVID-19 pandemic.

Chapter 2

Literature Review

The following literature review will focus on two key areas affected by the COVID-19 pandemic: employment and mental health. First, this review will explain the challenges that adults on the autism spectrum encounter in both areas under usual conditions. Second, the impact of COVID-19 on the employment and mental health among the general population will be discussed. Third, emerging research examining the impact of COVID-19 on adults on the autism spectrum in employment and mental health will be presented.

Autism Spectrum

Autism is a lifelong neurodevelopmental condition that presents in early childhood and is characteristic of difficulties with social interaction and communication as well as the presence of restricted and repetitive behaviors or interests (American Psychiatric Association, 2013). Individuals on the autism spectrum often experience high levels of social rejection and isolation from peers (Underhill et al., 2019), low levels of independence (Whitehouse et al., 2009), and tend to experience many challenges in adulthood (Steinhausen et al., 2016), particularly in the areas of employment and mental health (Lugo-Marin et al., 2019; Solomon, 2020).

Autism Spectrum and Employment Challenges

Obtaining and maintaining employment promotes social integration, independence, a sense of purpose, and increased self-esteem among individuals on the autism spectrum (Dudley et al., 2015). The benefits of employment also extend to their families, the community, and the economy (Hedley et al., 2017b). Most individuals on the autism spectrum want to work (Dillenburger & McKerr, 2011), however, despite this, employment has long remained a challenge for this population. Rates of employment have remained significantly lower for this group relative to those without disabilities and any other disability group (Zwicker et al., 2017), as highlighted internationally (Sweden: Järbrink et al., 2007; Ireland: McGlinchey et al., 2013; United States: Nord et al., 2016; UK: Rose et al., 2005). The Canadian Survey on Disability conducted in 2017 shed light on these poor outcomes among this population; the employment rate of individuals aged 20-64 years on the autism spectrum was 33%, less than half the rate of those without disabilities (79%) and lower than any other disability group between 25-64 years (59% [excluding other developmental disabilities]; Public Health Agency of Canada, 2020). These findings echo those of the 2012 Canadian Survey on Disability, in which an employment rate of 14% for individuals on the autism spectrum aged 15-64 was reported, less than a third of the rate for those without disabilities (74%), and lower than any other disability group (63%; Zwicker et al., 2017), demonstrating that little has changed since then.

Autism Spectrum and Mental Health Challenges

Individuals on the autism spectrum are also at greater risk of developing co-occurring mental health conditions that negatively impact their health and quality of life relative to the general population (Croen et al., 2015; Mason et al., 2019a). Critically, rates of co-occurrence increase in adulthood (Joshi et al., 2013) and may have an even greater impact on well-being than core traits of autism (Smith et al., 2019). Common mental health problems experienced by this population include anxiety, depression, suicidal ideation and suicide attempts (Cassidy et al., 2014; Croen et al., 2015). One meta-analysis combined data from 68 studies and 169,829 participants on the autism spectrum and found pooled prevalence estimates of 20% for anxiety disorders and 11% for depressive disorders across the lifespan (Lai et al., 2019). These rates are notably higher than those reported in meta-analyses of the general population (pooled prevalence of 12.9% and 5.4% for anxiety and mood disorders respectively across the lifespan; Steel et al., 2014). Additionally, one study reported that adults on the autism spectrum were significantly more likely to report lifetime experience of suicidal ideation (prevalence rate of 66%) and suicide plans or attempts (prevalence rate of 35%) than were individuals from a general UK population sample (Cassidy et al., 2014). Those who experience discrimination (Botha & Frost, 2020), loneliness (Schiltz et al., 2021), greater social communication difficulties (Rai et al., 2018), and lack meaningful social relationships (Petrina et al., 2014) are also more likely to experience mental health problems, which are of significant public health concern, given the growing research documenting the impact these difficulties can have on quality of life above and beyond what is associated with their autism characteristics (Smith et al., 2019).

Coronavirus disease 2019 (COVID-19)

The COVID-19 pandemic has caused widespread disruption across a multitude of life domains. To combat the virus and mitigate infection, countries worldwide implemented significant public health measures, including the closure of public places, restrictions on gatherings and instructions to stay at home and maintain social distance. Indeed, these measures were accompanied by substantial economic, social, and psychological consequences.

Impact of COVID-19 on Employment in the General Population

Among the general population, the closure of non-essential businesses had dire consequences for individuals in the labor force during this time. For many, this resulted in a temporary or permanent loss of employment (Mimoun et al., 2020), a decrease in hours of work and a decline in labor force participation rates (Béland et al., 2020). Canadian labor force data from the general population showed a sharp increase in the unemployment rate following the onset of the pandemic, reaching a record high of 13.7% (Statistics Canada, 2020b). The number of Canadians on temporary layoff rose from 99,000 in February 2020 to a record 1.2 million in April 2020 (Statistics Canada, 2020b). In Québec specifically, the unemployment rate in April 2020 soared to 17% (from 4.5% in February 2020), the highest rate since 1976 and the highest in the country (Statistics Canada, 2020b). During that time, the number of people on temporary layoff was also highest in Québec and more than one third (36.7%) of the potential labor force did not work or worked less than half of their usual hours (Statistics Canada, 2020b).

Although fewer losses occurred for jobs that could be done remotely or were in essential industries (Montenovo et al., 2020), these workers were still in a potentially vulnerable position (Roberts et al., 2020; Toscano & Zappalà, 2020). Those who remained employed within essential businesses (e.g., health care and grocery store workers) were less likely to face job displacement, however this group was at an increased risk for exposure to COVID-19 due to interaction with the public and colleagues (Baker, 2020). These workers had to therefore remain constantly vigilant of preventative measures, which may have increased the risk of psychological overload and distress (da Silva et al., 2021). Additionally, these individuals may have faced increased levels of job stress due to an intense demand for work (Ramaci et al., 2021). As a consequence, these workers may have been under pressure to make a decision between continuing to work despite the risks or quitting with no safety net, which could have been a particularly challenging decision given the potential adverse effects associated with either choice (Baker, 2020; Forbes & Krueger, 2019).

Fortunately, those with jobs that were deemed non-essential but for whom employment was not terminated were mostly able to transition to remote work. However, the change in work environment can make it difficult to maintain boundaries between work and home time and tends to induce longer working hours (Eurofound and the International Labour Office, 2017). Additionally, working from home may limit the psychosocial benefits of the workplace; research has shown that people view their workplace as a community and as a source of social contact and psychological support (Pratt & Ashforth, 2003).

Taken together, these findings suggest that the different employment scenarios evoked by the COVID-19 pandemic may have significantly impacted the employment and financial security of individuals in the general population. However, although it has been suggested that it may take years for jobs to become available again (Berman, 2020), data in Canada show a substantial improvement in labor market conditions. As of October 2021, Canada’s labor force participation rate and number of people on temporary layoff and Québec’s unemployment rate were close to their pre-pandemic levels (Statistics Canada, 2021b; Statistics Canada, 2021c), demonstrating an exceptional recovery among the general population.

Impact of COVID-19 on Mental Health in the General Population

Given the significant changes associated with the COVID-19 pandemic, there were concerns that some individuals around the world may be particularly vulnerable to the impact of the pandemic (World Health Organization, 2020; Yao et al., 2020). However, the current findings are mixed; although many studies reported a decline in mental health following the onset of COVID-19 (e.g., Xiong et al., 2020), others are reporting stable rates of mental health symptoms (e.g., Al Dhaheri et al., 2021), suggesting that the psychological impact of the pandemic may not be uniformly negative.

For studies reporting a negative impact on mental health, two major contributing factors to these difficulties are the consequences associated with the mitigation measures (e.g., quarantine, social distancing) and the pandemic's subsequent impact on employment. Public health restrictions and social isolation during the pandemic have been associated with symptoms of post-traumatic stress and adjustment disorder and feelings of frustration and uncertainty (Rossi et al., 2020; Serafini et al., 2020). Additionally, individuals experiencing quarantine or isolation during the pandemic were at heightened risk of depression, anxiety, stress-related disorders and anger (Henssler et al., 2021). Three systematic reviews and two meta-analyses including studies conducted across many countries have reported elevated rates of mental health conditions among the general population (e.g., anxiety, depression, psychological distress, insomnia; Arora et al., 2022; Salari et al., 2020; Xiong et al., 2020) compared to prevalence rates prior to the pandemic (Huang et al., 2019), demonstrating the potentially harmful effect of the pandemic on mental health. Additionally, two systematic reviews and meta-analyses consisting of 66 (Wu et al., 2021) and 16 (Necho et al., 2021) studies found that mental health problems were common among different populations, including the general population, quarantined individuals, and COVID-19 patients, and that the levels of depression, anxiety, distress, and insomnia exceeded usual levels. Additionally, denial, anger, fear, confusion, and physical and social inactivity have been identified as major mental health manifestations of the pandemic (Ammar et al., 2021; Brooks et al., 2020; Roy et al., 2021).

Changes in employment because of COVID-19 have also contributed to increased rates of mental health conditions among the general population (e.g., Santabárbara et al., 2021). This is not surprising, given that abrupt changes in employment status, job insecurity, and sudden involuntary unemployment are risk factors for depression and anxiety (Howe et al., 2012; Meltzer et al., 2010; Yoo et al., 2016). Mousteri and colleagues (2020) found that transitioning from full-time employment to underemployment (defined as part-time workers wanting to work more hours) during the pandemic predicted elevated distress levels, comparable to that of becoming unemployed (Paul & Moser, 2009), and the psychological effects of unemployment appear to be substantial and long-lasting (Daly and Delaney, 2013). Unemployment has been found to be independently associated with greater psychological distress among young adults, with increased financial strain contributing to this distress (Achdut & Refaeli, 2020). Many other studies have also reported an increased likelihood of experiencing mental health problems following unemployment during the pandemic (Mazza et al., 2020; Mimoun et al., 2020; Solomou & Constantinidou, 2020; Wang et al., 2020). Even among those who remained employed, job insecurity due to COVID-19 and financial concern were associated with greater depressive and anxiety symptoms, with financial concern partly mediating the relation between job insecurity and anxiety symptoms (Wilson et al., 2020). There is also increased vulnerability to mental health challenges for those who transitioned to remote work, given the difficulty associated with making this transition (Alzueta et al., 2020). For example, working from home for longer hours has been associated with depressive symptoms during the pandemic (Sato et al., 2021).

As mentioned above, there are also studies reporting no changes in mental health throughout the pandemic. This makes sense given that responses to potentially traumatic experiences show substantial variation (Bonanno & Mancini, 2012). Although many may experience persistent and debilitating symptoms (Mancini, 2020), others may experience few mental health symptoms and a stable pattern of adaptive functioning or resilience (Bonanno, 2004). Mounting evidence also suggests that a subset of people exposed to adverse experiences, such as the pandemic, show improved psychological functioning from before to after exposure (Mancini, 2019), consistent with anecdotal reports (Bradley, 2020; Gold, 2020) and empirical evidence (Ahrens et al., 2021) suggesting reduced symptoms of anxiety, depression and stress among individuals during the pandemic, which might be due to reduced stressors (e.g., social pressures) and more time spent with loved ones (Santini et al., 2021; Thompson, 2020). In line with this notion, results from several longitudinal studies among young adults, a vulnerable population during the pandemic (Zhai & Du, 2020), have demonstrated moderate and stable levels of depressive and anxiety symptoms before and during COVID-19 (van den Berg et al., 2021; van Zyl et al., 2021; Watkins-Martin et al., 2021), and even an improvement among those with pre-existing mental health conditions (Hamza et al., 2021). One systematic review and meta-analysis found that there was a significant but statistically small increase in mental health symptoms during the initial phase of the outbreak, however rates decreased and became comparable to those of pre-pandemic levels by mid-2020 (Robinson et al., 2021). This supports other studies indicating an increase in mental health challenges during the onset of COVID-19 followed by a marked decrease over the following months, returning to rates observed prior to the pandemic as early as May 2020 among the general population (Bendau et al., 2021; Gagné et al., 2020; O’Connor et al., 2021) including among those with pre-existing mental health conditions (Daly & Robinson, 2021). One review and meta-analysis found that the impact of lockdowns on mental health symptoms were small in magnitude, but given the substantial variability in their data, concluded that the psychological effects of the pandemic varied across different social groups, contexts and countries (Prati & Mancini, 2021).

Among Canadians specifically, mental health improved over time; 61% of individuals across all age groups reported having excellent or very good mental health in June 2021, up from 48% in May 2020 and close to pre-pandemic levels in 2019 (68%; Statistics Canada, 2021a). This suggests that with time, people were able to adapt and potentially benefit from resilience factors, such as social support and psychological flexibility (Gloster et al., 2020).

Impact of COVID-19 on the Employment of Adults on the Autism Spectrum

As demonstrated among the general population, COVID-19 had an abrupt and significant impact on the labour market. Importantly, the impact may likely have a disproportionate effect on adults on the autism spectrum (Cassidy et al., 2020), a population that prior to the pandemic, already had very low rates of employment (Berrigan et al., 2020). Thus, it is likely the case that many were already in financially vulnerable positions prior to the onset of COVID-19. Research has also shown that in previous economic crises, those with disabilities are at a significantly greater risk of involuntarily losing their job (Kaye, 2010) in a wide range of occupations (Mitra & Kruse, 2016), experiencing longer unemployed periods, and dropping out of the labor force completely (Fogg et al., 2010). As such, it is reasonable to believe that the economic fallout associated with COVID-19 may exacerbate unemployment rates and job loss among individuals on the autism spectrum (Pellicano & Stears, 2020), and its impact will likely be felt beyond the duration of the pandemic (Brooks, 2020; den Houting, 2020).

During the first three months of lockdown in the UK, those with a disability were more likely to be working reduced hours (especially hours reduced by more than 50%), and experience greater levels of financial stress (e.g., behind on bill payments and making use of a foodbank) compared to working-age adults without disabilities (Emerson et al., 2021). A report conducted in Israel in fall 2020 saw the unemployment rate among those with disabilities rise to 62% in October 2020, up from 41% in February 2020, and found that since March 2020, two-thirds of those with disabilities lost their job or were furloughed, a rate almost four times higher than that of the general population (Adler, 2020). The United States Bureau of Labor Statistics reported that in 2020 and 2021, across all age and educational attainment groups, unemployment rates for individuals with a disability were higher than for those without (U.S. Bureau of Labor Statistics, 2021; U.S. Bureau of Labor Statistics, 2022). Similarly, in a survey conducted between June 23 – July 6 2020, in Canada, among individuals with a disability who were employed before the onset of COVID-19, over one-third (36%) reported experiencing a temporary or permanent job loss or reduced hours since March 2020 and over half of the respondents had difficulty meeting at least one financial obligation or essential need (Statistics Canada, 2020a). In Ottawa, one of the few cities in Canada that have published data comparing individuals with disabilities to those without, findings from a survey conducted in June 2020 showed that compared to people without disabilities, those with disabilities were more impacted by income loss since mid-March (25% versus 38%) and had greater difficulty paying for basic needs (14% vs 43%; Ottawa Public Health, 2020). Thus, findings during the pandemic seem to be consistent with research during previous economic crises reporting a disproportionate effect of unemployment among people with disabilities.

Preliminary research in the United States examining the impact of the early stages of the pandemic on different areas of life (e.g., school, social life) among 263 adults on the autism spectrum found that employment was the most impacted area with respect to pandemic-related changes, especially for those who were laid-off, furloughed without pay, or working reduced hours (Bal et al., 2021). Another survey conducted in the United States by the Simons Foundation Powering Autism Research for Knowledge (SPARK) between March 30, 2020 – April 10, 2020 revealed that employment for 89% of 636 adults on the autism spectrum had been negatively impacted by COVID-19, with 95% of respondents reporting their financial security was negatively affected (Chung, 2020). Hedley and colleagues (2021) also found that the pandemic severely impacted Australian adults on the autism spectrum when unemployment, employment uncertainty and reduced employment were experienced. In two studies with a sample size of 263 (United States; Bal et al., 2021) and 23 (Israel; Goldfarb et al., 2021) adults on the autism spectrum, slightly over 30% of the participants who were employed prior to the pandemic lost their job soon after the onset of COVID-19. Similarly, Taylor and colleagues (2021) in the United States reported that of 144 young adults on the autism spectrum, over one-third (37.5%) reported a change in their employment during the first two months of the pandemic, with most of these changes reflecting job loss or reduction in hours or pay. It may not be surprising then, that adults on the autism spectrum reported greater work-related worries (e.g., job loss concerns) relative to their neurotypical peers, even when they believed their job was safe (Oomen et al., 2021).

Adults on the autism spectrum were also able to transition to remote work, however results are mixed for this subset of people. Goldfarb et al. (2021) found that for 5 participants who started working from home, 3 reported that it was their preferred arrangement and spoke about advantages such as reduced commuting, increased work-life balance, autonomy and comfort, and lower risk of a COVID-19 infection. However, along with their positive remarks were negative experiences regarding their mental health (e.g., depressive episodes) and the increased isolation they experienced while working from home. The two other participants in this study who did not state that this was their preferred arrangement spoke of additional disadvantages regarding remote work, such as difficulty defining and limiting work hours and emotionally separating work from home, interruptions and distractions, and lack of communication with colleagues. Mixed responses regarding remote work among this population were also found in another study conducted by Maljaars and colleagues (2022); of 110 adults on the autism spectrum, most of those working from home reported positive experiences and benefits (e.g., less stressful, satisfying for sensory preferences), however, others also discussed the disadvantages and challenges they experienced (e.g., difficulty with concentration and motivation, lack of interactions). Note that the number of people working remotely was not provided in this study, making it hard to compare the proportion of positive and negative responses. In another study conducted by Hedley and colleagues (2021), one of the reasons 16 adults on the autism spectrum reported a positive impact of the pandemic on their mental health was being able to work from home and its association with reduced stress. For example, one participant in this study noted that working from home helped improve his productivity and well-being. However, it is important to note that research in this area is limited.

Interestingly, Goldfard and colleagues (2021) also found, among adults on the autism spectrum, that remaining employed and having to physically report to work served as a protective factor from the negative aspects of the pandemic; these participants were not worried about the consequences of the pandemic given their ability to maintain a steady job. However, in the same study, those who transitioned to remote work were also able to maintain employment but were still at increased odds of experiencing mental health challenges, perhaps pointing to the importance of structure among this population and the workplace as a source of social support, especially for those with disabilities, who tend to have small social networks (Oomen et al., 2021; van Asselt-Goverts et al., 2013). Again, however, research in the area of remote work and essential employment among adults on the autism spectrum is limited.

The restrictions associated with COVID-19 may have also impacted job search and on-the-job training and support that individuals with developmental disabilities would often receive (i.e., job coach services; Sheppard-Jones et al., 2021). In Goldfarb et al. (2021), 43% of 23 adults on the autism spectrum were receiving some form of support from a vocational worker at timepoint 1 (September 2019 – January 2020), whereas only 23% were receiving this support at timepoint 2 (i.e., at follow-up assessing the initial impact of the COVID-19 lockdown on employment; April 2020 – May 2020), which might have been due to the mitigation measures that ultimately prevented vocational workers from being able to provide on-site support. This may have been a sensitive time to lose access to job coach supports given the new rules that were being implemented in the workplace and the increase in job demand and stress (Ramaci et al., 2021), and may have had a negative effect on people's jobs (Sherppard-Jones et al., 2021). Indeed, results from the Pandemic Canadian Autism Needs Survey revealed that members of the autism community believed employment services were problematic during the pandemic and believed this type of support would be useful for them during the COVID-19 crisis (Salt & Soliman, 2020). This complements another finding in their survey, in which members of the autism community reported their search for employment became more challenging than before the pandemic.

Impact of COVID-19 on the Mental Health of Adults on the Autism Spectrum

The pandemic may also have particularly detrimental effects on the mental health of adults on the autism spectrum, as the public health restrictions and the pandemic's impact on employment may exacerbate mental health challenges that were already common in this group (Frankova, 2020; Hollocks et al., 2019; Pellicano & Stears, 2020). Many studies have noted that individuals with pre-existing mental health conditions are at increased risk of being psychologically affected by the pandemic (Blix et al., 2021; Kwong et al., 2021; Na et al., 2021; Özdin & Özdin, 2020). However, there are also studies showing improved functioning or stable rates of mental health among people with pre-existing vulnerabilities during the pandemic (Daly & Robinson, 2021), echoing the mixed results that were also demonstrated in studies among the general population. Not surprisingly then, studies examining mental health in adults on the autism spectrum are also reporting mixed results, suggesting that the negative psychological impact of the pandemic may not be equally distributed across this group.

Many studies reported that the pandemic negatively affected the mental health of adults on the autism spectrum. In a survey conducted by the Simons Foundation Powering Autism Research for Knowledge (SPARK) in the United States between March 30, 2020 – April 10, 2020, 93% of 636 adults on the autism spectrum reported that the pandemic negatively impacted their mental health (Chung, 2020). Another study conducted in the United States found that among 275 adults on the autism spectrum, nearly two-thirds (65.9%) endorsed some form of COVID-related distress, and that those who reported difficulty coping with COVID-related changes and whose mental health was negatively impacted by the pandemic were more likely to experience increased depressive and anxiety symptoms in the early stages of COVID-19 (Adams et al., 2021). Similarly, a study examining the psychological impact of COVID-19 and the containment measures across three European countries (Belgium, the Netherlands, and the UK) found a greater increase in depressive and anxiety symptoms for adults on the autism spectrum (n = 613) compared to their neurotypical peers (n = 431), and the impact of these symptoms on everyday life was greater for the autism spectrum group (Oomen et al., 2021). This study also reported that adults on the autism spectrum worried significantly more about their own safety and security and getting basic needs and felt more stressed about the changes to their daily routines that were caused by the pandemic. Additionally, the neurotypical adults and those on the autism spectrum reported that the loss of social contact throughout the pandemic was very difficult. For adults on the autism spectrum, who are already more likely to experience loneliness and social isolation relative to the general population and those with other disabilities (e.g., learning disability; Ee et al., 2019; Orsmond et al., 2013) and generally have a strong preference for sameness and adherence to routines (American Psychiatric Association, 2013), these stressors may have affected their mental health. These findings compliment another study that found significantly higher rates of stress, anxiety, depression, and PTSD-related symptoms among 45 adults on the autism spectrum relative to 45 gender- and age-matched neurotypical adults during the initial lockdown in Italy (Nisticò et al., 2022). However, in this study, adults on the autism spectrum also reported feeling significantly less tired after a day of work during that time and more comfortable with social distancing measures. A study conducted in the UK found, among 133 adults on the autism spectrum, that factors contributing to negative changes in their mental health included adjusting to changes in everyday routines, living with uncertainty, and barriers to fulfilling basic needs (Bundy et al., 2021). Adults on the autism spectrum also expressed amplified feelings of social detachment due to heightened uncertainty, anxiety and fears of having a meltdown, and experienced greater discrimination throughout the pandemic, which may have also affected their mental health (Botha & Frost, 2020; Mosquera et al., 2021).

The pandemic's subsequent impact on employment may also contribute to worsened mental health among adults on the autism spectrum. Among adults with disabilities, economic insecurity following COVID-19 was associated with increased anxiety, stress and despair (Pettinicchio et al., 2021), suggesting that adults on the autism spectrum may be at particular risk. Goldfarb and colleagues (2021) reported that among adults on the autism spectrum who lost their job during COVID-19, emotional distress significantly increased, in line with previous research demonstrating the psychological effects of unstable employment among individuals on the autism spectrum (Müller et al., 2003). Similarly, employment changes during the pandemic, specifically job loss or a reduction in hours or pay, predicted depressive symptoms among young adults on the autism spectrum 10 weeks later (May 2020; Taylor et al., 2021). Financial and employment uncertainty also contributed to distress among this population (Bundy et al., 2021). In Taylor et al. (2021) however, adults who reported employment changes such as getting a new job, working remotely, an increase in the number of hours worked, and changes in duties overwhelmingly perceived these changes to be positive. In other studies, some adults among the autism spectrum showed negative mental health effects following the transition to remote work (Goldfarb et al., 2021; Maljaars et al., 2022).

On the other hand, while studies have found evidence of negative effects on mental health, others suggest that the COVID-19 mitigation measures had a positive impact on some individuals. The removal of societal obligations to interact with others and camouflage to conform to social expectations due to movement restrictions associated with the lockdown positively impacted the mental health of some adults on the autism spectrum in Spain (Mosquera et al., 2021). In another study also conducted in Spain, adults on the autism spectrum reported a significant improvement in mental health symptoms and sleep quality and a decrease in their self-perceived stress level during the lockdown (Lugo-Marin et al., 2021). Interestingly, in this study, when divided by age, young adults (between 18 and 30 years) showed greater improvement in mental health symptoms, whereas older adults (30 years and above) reported benefiting more from the social distancing measures. Another study that collected data from 196 adults on the autism spectrum and 228 neurotypical individuals from Belgium, the Netherlands and the UK found that the former reported a significantly more positive impact of the pandemic on their social life (Maljaars et al., 2022). Adults on the autism spectrum in this study reported having fewer social demands and more time for leisure activities and family. The positive impact of the pandemic on the mental health of this population was also reflected in another study through the flexibility, space, and time the lockdown allowed for, which in turn reduced stress, increased relaxation and bonding with family and pets (Pellicano et al., 2020). The mixed findings regarding mental health among adults on the autism spectrum echo those found among the general population. The variability of findings both between and within studies make it difficult to note certain trends across countries and demographics. For example, studies conducted within the same region (e.g., Europe) have reported different results and many studies have also found mixed responses within their sample. Further research with adults on the autism spectrum across different geographical regions is needed to be able to assess trends in these important psychosocial outcomes and identify potential risk and protective factors that might be influencing such outcomes.

The Current Study

Taken together, results suggest that COVID-19 has impacted the employment and mental health of adults on the autism spectrum. However, most emerging research focuses on the early stages of the pandemic, thus limiting our understanding of the impact to only the first few months following the onset of COVID-19. While understanding the initial impact of the pandemic is important, several researchers have called for studies examining the longer-term effects among this population (Oomen et al., 2021; Taylor et al., 2021). It is crucial that our understanding of the lived experience of this vulnerable population expands beyond the initial wave of COVID-19, especially given the duration of this pandemic and the multiple waves that have occurred since the initial outbreak. Longer-term data in the general population are reporting improvements in employment and mental health, but it is also important to examine the changes that are taking place among adults on the autism spectrum. Additionally, many studies use survey methods and assess several domains (e.g., school, social life, work) superficially. However, doing so may fail to capture the depth of lived experiences of adults on the autism spectrum, as we are only getting a glimpse into their experiences when conducting survey studies. Using a qualitative approach and focusing specifically on employment and mental health will allow for an informative and detailed analysis, and in turn, understanding, of lived experience and may shed light on influences and factors that were omitted in previous survey studies. This refined analysis will therefore provide much-needed clarity on the effects of the ongoing pandemic, which could be used to inform the supports and services required to assist adults on the autism spectrum in achieving job success and good mental health in various contexts, including and beyond COVID-19.

Objectives

To address this gap in the literature and build on the available short-term data, the purpose of the current study was to explore how COVID-19 impacted the employment and mental health of adults on the autism spectrum in the long-term, specifically 20 months into the pandemic. The main objectives were to explore how the pandemic impacted this population (1) in their employment experience, job satisfaction, and satisfaction of employment support services; (2) in their mental health; and (3) to identify any supports that were available and deemed helpful to participants during the pandemic. Using an interpretative phenomenological analysis (IPA) framework, participants completed a semi-structured interview and two questionnaires. The information gained from this study will shed light on the negative and/or positive aspects of the pandemic through the perspectives of adults on the autism spectrum in the contexts of employment and mental health. This knowledge will be beneficial for employment agencies, policymakers, professionals who work with this population (e.g., counsellors), and stakeholders in the community (e.g., families, caregivers, disability advocates), as the information gained can be used to tailor supports and services in a way that meets the needs of this population throughout and beyond the pandemic.

Chapter 3

Method

Qualitative Research Approach

This project took place during December 2021 and was a follow-up to a recent study (November 2018 – January 2020) that examined the value of employment support services among adults on the autism spectrum and/or with intellectual disabilities (Di Francesco et al., 2021). Using a subsample that was drawn from the previous work, this study took a qualitative approach to analyze the impact of COVID-19 on the employment and mental health of adults on the autism spectrum, and to identify helpful supports. The primary strength of qualitative research is the ability to explore perceptions, feelings, underlying meanings, and the imprint of context on individual experience (Creswell, 2013). Thus, employing a qualitative approach best represented the subjective experiences of the participants in this study. Additionally, participants were administered two questionnaires that they also completed in the previous study assessing their job satisfaction and satisfaction with the employment support services received. The responses obtained in this study were analyzed descriptively and compared to those obtained in the prior study (November 2018 – January 2020) to explore the potential impact of the pandemic on participants' satisfaction with their job and employment support services received during COVID-19.

Interpretative Phenomenological Analysis

This qualitative approach uses an interpretative phenomenological analysis (IPA) framework. IPA is an inductive qualitative research approach that is widely used in the field of psychology (Smith et al., 2009). IPA was best suited for the current study as it is committed to gaining a deep and rich understanding of how a specific phenomenon was experienced from the perspective of certain people in a particular context (Smith et al., 2009), and is being increasingly used as an effective tool in illuminating the experiences of individuals on the autism spectrum (Howard et al., 2019). IPA views participants as the experts of their own personal and social worlds and allows the researcher to acknowledge that the same experience can have different effects on participants (Howard et al., 2019). Additionally, IPA is especially useful when the topic of study is complex, sensitive, and emotionally laden (Smith & Osborn, 2015), such as the one being explored in the current study. Further, IPA studies typically use small samples given the aim is to conduct a detailed, nuanced examination of personal lived experience (Smith, 2004). As such, it is recommended that studies using IPA include four to ten participants (Smith et al., 2009). Consistent with this recommendation, four participants completed the current study.

IPA is rooted within three primary theoretical axes: phenomenology, hermeneutics, and ideography (Smith et al., 2009). IPA is phenomenological in that it is concerned with individuals' personal experiences and perceptions as opposed to formulating objective reports (Smith et al., 1999). In other words, IPA focuses on arriving at the meanings participants draw from their experiences (Smith et al., 2009). IPA recognizes that this is an interpretative endeavor and is therefore informed by hermeneutics, how one interprets and makes sense of individual experiences (Smith, 1996). In IPA, a dual interpretation takes place where the participant makes sense of a phenomenon in their own terms by explaining and interpreting their own experience, while the researcher then interprets and explains the meaning of the participant's account (Smith & Osborn, 2003). Smith and Osborn (2003) coined this process a "double hermeneutic" to emphasize the two interpretations; the first is the participant's meaning-making (interpreting their own experience) and the second is the researcher's sense-making (interpreting the participant's account; Smith et al., 2009). This illustrates the dual role of the researcher; the aim of IPA is to explore the participants' views of the world and to adopt an 'insider's perspective' of the phenomenon under study (Conrad, 1987). At the same time, IPA also recognizes that the research exercise is a dynamic process (Smith, 1996). While the researcher attempts to get close to the participant's world, they cannot do this directly or entirely; the researcher's own conceptions and beliefs are required to make sense of the personal experiences being studied through IPA (Smith, 1996; Chapman & Smith, 2002), highlighting the researcher's integral role in the interpretative aspect of IPA (Smith, 2004). Lastly, IPA is idiographic in its commitment to analyze each case in detail before moving on to more general claims (Smith et al., 2009). Thus, the analytical process of IPA consists of an inductive analysis of each participant's account at a personal level (Hamill et al., 2010), before moving on to a cross-case analysis to compare the commonalities and differences of how individuals experienced the phenomena under investigation (Smith, 2004). In this way, general claims and more specific statements about the experience of individuals can be made (Smith & Osborn, 2008).

Timeframe

This qualitative project was a follow-up to a study originally conducted between November 2018 – January 2020 (i.e., prior to the pandemic). Following the COVID-19 outbreak, an optional follow-up study was developed and seven of the nine participants in the prior study who gave consent to be recontacted for future studies were invited to participate. Four individuals agreed to participate in the current study, which took place in December 2021, 20 months into the COVID-19 pandemic.

Participants

Reflective of IPA methodology (Smith et al., 2009), this study employed a purposeful sample of four adults on the autism spectrum. Participants were recruited from the prior study and had given consent to be recontacted for future research. Participants from that study were recruited from Action main d'oeuvre (AMO), a community organization located in Montreal, Canada providing individualized job coaching services for individuals on the autism spectrum or with intellectual disability, and their employers. Participants were all male and between 33 and 44 years of age, with an average age of 38 years. All participants were francophone and diagnosed as being on the autism spectrum without co-occurring intellectual disability (note that it is mandatory to provide a diagnostic assessment report upon enrollment to AMO). Of the four participants, one possessed a high school equivalency diploma, two completed a Cegep diploma (i.e., Quebec post-secondary education taking place after the eleventh year of schooling), and one held a university degree. To be eligible for the current study, participants had to have access to a mobile device allowing for a phone interview and completion of questionnaires. During the time of this study, participants held positions in retail, healthcare, and public sectors and were all receiving services from AMO. All participants worked in-person during the pandemic, however at the time of this study, two were on sick leave due to a minor foot injury and substance use problem. Two participants were living alone, one with his partner and the other with a roommate. Table 1 provides additional employment information about the participants in March 2020, during the beginning of COVID-19 (obtained through retrospective report), and at the time of this study in December 2021.

Context

At the time of data collection (December 2021), many COVID-related changes were taking place amid the emergence of the Omicron variant and explosion of positive cases in Quebec. Three interviews took place when all non-essential businesses (e.g., restaurants, bars, gyms) were opened, however cases were rapidly increasing. One interview took place at the end of December when some non-essential businesses had been shut down (gyms, bars, theatres), however restaurants were able to operate at 50% capacity and gatherings of 10 people were permitted. The last interview took place the day before stricter measures were implemented provincewide (i.e., curfew, closure of restaurants and a ban on gatherings), illustrating the severity of the situation during the time of this study, although it was 20 months since the pandemic was declared in March 2020.

Table 1. Participants' employment situations at the beginning of COVID-19 and at the time of this study

Participant	Age	Education	Context when COVID-19 began (March 2020)	Context in December 2021	Type of employment (December 2021)
1	33	University degree	Lost job during onset of the pandemic.	Participant recently obtained a full-time, permanent position.	Retail sector
2	41	Cegep diploma	Working two seasonal jobs.	Working one seasonal job due to personal preference.	Public sector
3	44	High school equivalency diploma	Obtained a temporary job during early months of the pandemic.	Participant recently obtained a full-time, permanent position.	Public sector
4	35	Cegep diploma	Paid internship ended but was unrelated to the pandemic.	Participant obtained a full-time, permanent position.	Legal sector

Measures

Demographics Form

Participants completed a brief demographics questionnaire via Microsoft Forms assessing age, gender (options included man, woman, gender-fluid, non-binary, two-spirit), level of education completed and area of study, whether they identified as a member of a visible minority (options included yes, no, prefer not to answer), and additional mental or physical conditions (short-answer filled in by the participant).

Job Satisfaction Questionnaire

In the original study (November 2018 – January 2020), all participants were administered a questionnaire assessing their job satisfaction. Given all participants were employed during this study, the questionnaire was completed again via Microsoft Forms. The measure consisted of 14 items covering job appreciation, work conditions and work relationships (e.g., "My job is interesting"; "I am grateful for my job"; "I have a good relationship with my supervisor"), and each item was rated on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree; see Appendix B for the English version of the questionnaire). The questionnaire was developed based on knowledge gained from previous evaluations of successful support programs (Hillier et al., 2007) and used in a previous evaluation of services (Martin & Lanovaz, 2021).

Satisfaction of Employment Support Services Questionnaire

During the previous study (November 2018 – January 2020), participants were also administered a questionnaire assessing their overall satisfaction with the job coach support they received from Action main d'oeuvre (AMO). Given that all participants were still receiving services from AMO during the current study (either for job search, assistance in maintaining their job or COVID-related support), they completed this questionnaire again through Microsoft Forms. Participants at both timepoints were asked to rate their level of satisfaction on four items related to their overall satisfaction with the job coach support received (e.g., "I am satisfied with AMO in general"), using a 5-point scale ranging from 1 (very dissatisfied) to 5 (very satisfied; see Appendix C for the English version of the questionnaire). Participants were also asked whether they would recommend these services to other individuals on the autism spectrum using a scale of 1 (not at all) to 5 (absolutely). The questionnaire was developed based on knowledge gained from previous evaluations of successful support programs (Hillier et al., 2007) and used in a previous evaluation of services (Martin & Lanovaz, 2021).

Semi-Structured Interview

Following the administration of both questionnaires, the researcher conducted a semi-structured interview with the participant. Semi-structured interviews are the preferred modality for qualitative research, specifically IPA (Creswell, 2013; Reid et al., 2005). Smith and Osborn (2009) note that semi-structured interviews provide flexibility in questioning, allow for new and unanticipated ideas, and truly reflect the participants' personal stories and concerns, giving a much-needed voice to individuals on the autism spectrum (Humphrey & Lewis, 2008). Additionally, semi-structured interviews facilitate rapport-building and empathy between the researcher and participant (Cridland et al., 2015) and are suitable for the exploration of respondents' perceptions, feelings, and opinions regarding complex and sensitive issues (Barriball & While, 2004).

Due to in-person research restrictions related to COVID-19, semi-structured interviews were conducted via telephone. Telephone interviews have been shown to generate data of comparable quality to face-to-face interviews (Cachia & Millward, 2011) and have been successfully used in previous qualitative research involving adults with intellectual and developmental disabilities (e.g., Tassé et al., 2020). The interview protocol consisted of seven open-ended questions designed to gain insight into participants' employment experience (e.g., changes in job position and within the workplace), mental health, and helpful supports during

COVID-19 (See Appendix D for the English version of the interview protocol). The protocol was verified and approved by two experts in autism research. Interviews were conducted by the researcher in French, the first language of all participants, and were audio-recorded using Audacity voice recording software on the researcher’s laptop. All files were then stored on a secured institutional network server at McGill University; recordings were transcribed orthographically using Microsoft Stream (Mercurio, 2018) and were then imported into Microsoft Word documents and were checked by the researcher to ensure that all information had been accurately captured in the transcripts. While listening to the recordings, the researcher also included notes about stances such as pauses, hesitations and changes in tone of voice, which were marked by brackets as these could be important during the interpretation process (Smith et al., 2009). Interview transcripts were analyzed in their original language and only quotes included in this thesis were translated to English by the researcher. Finally, identifying information (e.g., names, places of employment) was removed from transcripts to ensure confidentiality of the participants.

Procedure

After receiving approval from the McGill University Research Ethics Board, participants from the prior study who had given their consent to be contacted for future studies were called by the researcher, who followed a recruitment script. The researcher informed the participants that the study would consist of a one-hour appointment where they would complete an interview and potentially two questionnaires, depending on their situation during the pandemic (i.e., if they were employed and receiving employment services). Of the seven who were called, four agreed to participate in the follow-up study. Since many individuals did not have access to the technology necessary to complete interviews via video conferencing, to increase accessibility, interviews and questionnaires were conducted via telephone. Upon agreeing to participate, the researcher and participant scheduled a study appointment and participants were asked to take the call and complete the study in a quiet location to limit interruptions. Two days before the study appointment, participants were sent a consent form via email to ensure that they had enough time to read through it and prepare any questions for the researcher.

At the time of the appointment, the researcher called the participant, introduced herself, built rapport through conversation, went through the consent form, and answered any questions that were asked by the participant. Verbal informed consent was obtained from all participants, which was audio-recorded by the researcher using Audacity voice recording software. The participants then completed three questionnaires via Microsoft Forms. First, the researcher sent the participant a link to a demographics form via text message and went through each question with the participant as they filled it out. Following this, the researcher explained the second questionnaire (i.e., Job satisfaction), how to complete it, and then sent a link to the participant via text message. Upon completion of the second questionnaire, the researcher repeated the same process for the third questionnaire (i.e., Satisfaction with employment support services). While completing both questionnaires, the researcher remained on the phone to answer any questions the participant might have. After completing both questionnaires, participants were asked if they wanted to take a break before beginning the interview, however, they were all ready to proceed. Interviews lasted between 36 to 55 minutes and were audio-recorded using Audacity voice recording software and transcribed orthographically. Participants received a $25 gift card via email as a token of appreciation for their participation.

Data Analysis

Questionnaire responses obtained in the prior study (November 2018 – January 2020) and 20 months into COVID-19 assessing job satisfaction and satisfaction of employment support services were analyzed descriptively. Both questionnaires consisted of a 5-point Likert scale. For each participant, composite scores were calculated for each questionnaire at both timepoints by averaging all item scores, with higher scores indicating greater satisfaction. The analysis of both questionnaires, specifically the difference in responses between both timepoints, were integrated with the qualitative analyses, specifically with respect to results for the first research objective addressing the pandemic's impact on employment.

Interview transcripts were analyzed using IPA. Smith and colleagues (2009) outlined a six-step approach that guided the analysis of transcripts in the current study. The first four were idiographic steps related to within-case analysis and the final two steps related to cross-case analysis. The steps are as follows: (1) reading and re-reading; (2) initial noting; (3) developing emergent themes; (4) searching for connections across emergent themes; (5) moving to the next case; and (6) looking for patterns across cases. Each step, as they were applied to the current study, are described in greater detail below.

Reading and Re-reading

The idiographic nature of IPA required that transcripts be analyzed case-by-case. The researcher followed the suggestion made by Smith and colleagues (2009) and began the analysis with the "most detailed, complex and engaging" interview (p. 82). For each participant, the researcher listened carefully to the audio recording of the interview while simultaneously reading the transcript. The researcher re-read the transcript multiple times after that, allowing herself to gain familiarity with the content. This process was meant to slow down the automatic interpretations of the researcher and fully engage with the data as they were. During the repeated readings, the researcher made notes about her initial observations and interpretations to acknowledge them and set them aside to ensure her focus remained with the data.

Initial Noting

As the researcher became immersed in the text through repeated readings, initial observations were noted line-by-line. During this stage, the researcher noted anything of interest related to the research questions as well as other experiences that were important to the participant. This step allowed the researcher to deeply engage with the data, go beyond a superficial reading of the text, and generate a comprehensive and detailed set of notes and comments. These observations took the form of descriptive comments, which focused on the content of the participant's statements; linguistic comments, which focused on the participant's use of language (e.g., pauses, hesitancy, tone) allowing the researcher to understand how the content was shared; and conceptual comments, which were more interpretative and allowed the researcher to actively make sense of the participant's meaning making of the topic through a "dialogue between [the researcher's] own pre-understandings, and [the researcher's] newly emerging understandings of the participant's world" (Smith et al., 2009, p. 89), which contributed to emergent and overarching themes in the later steps of the analysis.

Developing Emergent Themes

During this step, the researcher reduced the amount of detail in the notes from preceding steps while trying to maintain the complexity of what was said by organizing the initial coding into emergent themes. To do this, the researcher sought patterns of convergence and divergence in both the transcript and initial notes, which were then developed into more specific themes (i.e., concise phrases that captured and reflected the essence of the participant's experiences).

Themes were reflective of the participant’s original words and thoughts and the researcher’s interpretation, highlighting the double hermeneutic process. Themes were extracted and listed chronologically as they appeared in the transcripts (Smith et al., 2009).

Searching for Connections Across Emergent Themes

The fourth step involved reviewing the emergent themes that had been identified and clustering them into groups based on their commonalities. During this step, some themes were omitted due to lack of fit with the research questions. This process allowed the researcher to then develop super-ordinate themes for each cluster that captured the essence of the participant’s experiences. Here, the researcher’s goal was to develop a structure that illustrated the important aspects of the participant’s transcript. During this process, several strategies suggested by Smith and colleagues (2009) were employed. The process of abstraction was used to form groups between similar emergent themes and develop super-ordinate themes. Subsumption was used in taking an emergent theme and developing it into a super-ordinate theme due to its wide scope. Lastly, the strategy of polarization involved identifying differences between themes rather than similarities; this process allowed the researcher to acknowledge that there were different themes that existed regarding a subject matter (e.g., positive and negative accounts).

Moving to the Next Case

As mentioned above, the idiographic nature of IPA required that transcripts be undertaken one at a time. The fifth step involved repeating steps one through four with each of the remaining three transcripts. When moving onto the next transcript, the researcher attempted to bracket (i.e., set aside) previous ideas and themes that had emerged while coding and analyzing previous transcripts. This process allowed the researcher to remain open to new themes that emerged from each transcript and ensured that each participant's experience was represented in a way that was not influenced by the experiences of others.

Looking for Patterns Across Cases

The sixth and final step involved searching for patterns across the cases. The researcher examined the super-ordinate themes and sub-themes across cases to identify similarities and whether themes in one case helped clarify themes in another. This led to the formation of new super-ordinate themes and the reconfiguring and relabelling of some sub-themes, as encouraged by Smith et al. (2009). The result of this process was a series of super-ordinate themes and nested sub-themes. Final themes and excerpts illustrating each theme are presented and discussed in the Results section.

Quality and Validity

The validity of a study allows the researcher to establish whether the findings are trustworthy and useful (Creswell, 2013; Noble & Smith, 2015; Yardley, 2017). Validity in qualitative studies emphasize the research process (Creswell, 2013) and must be assessed using strategies that are appropriate and specific to the approach being used (Smith et al., 2009). Thus, given the subjective nature of the chosen qualitative approach, efforts were made throughout the research process to ensure validity. Following the recommendation of Smith et al. (2009), the current study employed criteria outlined by Yardley (2000) to assess the quality of research.

Yardley (2000) presented four broad principles: (1) sensitivity to context; (2) commitment and rigour; (3) transparency and coherence; and (4) impact and importance. Sensitivity to context was ensured by situating participants within their specific context and closely engaging with each individual's lived experience, demonstrating empathy, and explicitly stating to participants that their experiences and feelings were important and valuable.

Commitment and rigour were demonstrated through the researcher’s commitment of being attentive with the participants and actively listening to their stories, ensuring they were comfortable with the process, and undertaking a detailed and in-depth analysis, illustrating each theme with quotes from participants. Transparency and coherence were fulfilled by clearly describing the research process (from recruitment through analysis) during the write-up of this study, and ensuring that the reader would be convinced that the study was conducted according to the principles of IPA (i.e., the three theoretical axes: phenomenology, hermeneutics, ideography), and would understand how the interpretation was derived from the data. Lastly, impact and importance refer to the requirement that the study generates knowledge that is useful, in terms of its practical utility, interesting, or important for the population it was intended for, which was the purpose of this study (i.e., expanding on short-term survey data with an in-depth analysis of lived experience among four adults on the autism spectrum to understand the longer-term effects taking place during the pandemic).

Member checking, the process of sharing and confirming findings with the participants (Creswell & Miller, 2000), was not completed in this study. Member checking is debated and suggested to be used with caution (Houghton et al., 2013), as this process may invalidate the interpretative work of the researcher by resulting with a level of analysis that is inappropriately close to the data and at a descriptive level (Morse et al., 2002). Additionally, the practice of member checking is incongruent with phenomenology, as there is no way to know when the ‘right’ interpretation has resulted, given an interpretation can alter depending on the context in which it was analyzed (McConnell-Henry et al., 2011).

Reflexivity

The nature of IPA requires the researcher to reflect upon their role in the interpretative process (Larkin & Thompson, 2012; Reid et al., 2005). This means describing how the researcher's previous experiences and underlying biases intersected with the phenomena under investigation (Creswell, 2013). Doing so provides a way for attaining greater transparency and quality in the product of the research process (Finlay & Gough, 2008). This study centered around adults on the autism spectrum, their employment and mental health, and supports that have assisted them during the pandemic. I hold an undergraduate degree with a major in Psychology and I am currently enrolled in an Educational Psychology master's program with a concentration in Human Development. I have been conducting research in the field of autism for over four years and have been specifically involved with research focusing broadly on social inclusion (e.g., employment) for almost three years. Since then, I have also worked for community programs at various organizations that aim to prepare and assist adults on the autism spectrum to obtain and maintain employment. Thus, I have gained a lot of experience working with adults on the autism spectrum and have frequently observed firsthand the barriers and challenges this population encounters when seeking employment. Working with this population has also exposed me to the mental health challenges these individuals often struggle with.

The knowledge I have obtained through my experiences facilitated rapport building with participants during the interviews. This in turn facilitated the participants' comfort to express themselves in detail, thereby allowing me to gain greater insight into their lived experience (Smith & Osborn, 2008). However, this also meant that I came into this study already aware of the difficulties adults on the autism spectrum encounter regarding employment, mental health and accessing supports and services. I was interested in examining how the pandemic affected adults on the autism spectrum in these areas and acknowledged that the experiences of participants could have varied greatly. The previous experience and beliefs I possessed required me to continuously reflect throughout the process to avoid having those ideas and knowledge influence my interactions with the participants and therefore the interpretation and results of the analysis (Smith, 1995).

However, my previous experience and knowledge also inevitably led to the formation of preconceptions before the start of data collection. Based on emerging research and my previous experiences with this population, I expected that participants would report challenges with obtaining or maintaining employment during COVID-19 and with their mental health (e.g., due to loneliness and loss of routines), even 20 months into the pandemic. Consistent with my preconceptions, difficulties with employment and mental health were reflected upon by participants during the interviews. Even with these preconceptions however, it was still disheartening to learn of how long participants were experiencing these challenges for. Contrary to what I expected, supports and services for employment and mental health remained consistently available and accessible to participants during the pandemic, despite the constant changes that were taking place and the nature of the crisis.

Chapter 4

Results

This chapter presents the results from interviews conducted with four adults on the autism spectrum. The interviews ranged from 36 to 55 minutes and were audio recorded and transcribed orthographically yielding 42 pages of text. The analysis yielded 4 super-ordinate themes and 11 sub-themes shown in Table 2. The results describe the themes in greater detail and include quotes from the participants supporting the themes (Smith et al., 2009). The quotes were translated from French to English by the researcher.

Table 2. Summary of super-ordinate and sub-themes

Super-ordinate themes	**Sub-themes**
Emerging from precarity of employment	Employment precarity
	Employment support
	Job satisfaction
Deterioration of mental health	Social isolation
	Sense of hopelessness
	Emotional distress
Adopting a positive outlook	Permanent employment
	Positive thinking
Community engagement and recreation	Social support
	Engagement in hobbies
	Mental health services

Emerging from Precarity of Employment

All participants reported changes in their employment situation and challenges that arose due to the pandemic, demonstrating that COVID-19 had an impact on participants' employment in this study. Despite all four participants being employed 20 months into the pandemic, three of them were in unstable employment situations from the beginning of COVID-19 to the time of this study. Thus, it was only recently that most participants obtained stable employment. Since participants struggled with obtaining a regular position, many discussed the uncertainty they were faced with throughout the pandemic and their trajectory to finally obtaining stable employment. Further, participants discussed the employment support services they received from AMO, their satisfaction with the job they currently held, as well as with their co-workers, and their perceived safety of entering the workplace. Therefore, the first super-ordinate theme that emerged in this study captures the participants' engagement in precarious work situations throughout most of the pandemic, the employment support they were receiving, and their satisfaction at their current job. As such, the three sub-themes discussed are Employment precarity, Employment support, and Job satisfaction.

Employment Precarity

This sub-theme was evident in the participants' stories as they explained the difficulties in obtaining permanent employment during the pandemic. One participant lost their job at the onset of COVID-19, obtained another job and lost that one (unrelated to the pandemic), and was then hired in the retail sector. This participant only obtained his current position in October 2021, slightly over a year and a half since the pandemic began. Although he was happy to finally obtain a stable job, especially after going through two difficult job losses, he was longing for the job he had at the onset of COVID-19. His previous employer expressed interest in rehiring him when the pandemic ended, thus he explained that he is only holding his current position for the meantime.

> I was supposed to be laid off temporarily, but the pandemic wasn't ending. So, they told me to find a job in the meantime, but I was still hopeful that the pandemic would end soon. But then we had to wait for vaccines and there are so many COVID waves. […] For me, this job is just something I'm doing for now, like while I wait […] because my previous employer recontacted me this past summer [2021] to tell me that they were going to soon bring us back in the office… and I will be taking that job back for sure. In an ideal world, I would be at my old job.

Given events surrounding the pandemic were unknown and constantly evolving, the information the participant was receiving about a potential return to his previous employer was continuously changing, highlighting the unpredictable impact of COVID-19 on employment. He first received news about a potential return in Summer 2021, but this was then pushed to the end of the year, and at the time of this study, the timing of such a return was unknown, highlighting the uncertain and temporary nature of his current employment situation.

Another participant also spoke of the lengthy process to obtain a permanent job. His internship ended at the beginning of COVID-19, and he only obtained a permanent position in December 2021, almost two years since the onset of the pandemic. Despite constantly searching for a permanent position, this participant held two jobs during that time, working as a replacement for another employee on sick leave, and another temporary job.

> When I was hired, I was there as a replacement for another employee who was on sick leave for an undetermined amount of time. So, they told me they had a job available for me but it's a replacement position and we don't know when the employee will be coming

> back. So, at the beginning, they needed help, but they didn't know for how long exactly. […] Then I received another temporary job [at the same company].

This participant expressed frustration with the process, as temporary jobs meant constantly worrying about the future due to financial and job insecurities. His experience therefore demonstrated the precarious nature of his employment situation throughout the duration of the pandemic.

A third participant also described a similar trajectory during the pandemic regarding his employment situation. Although unemployed at the onset of COVID-19, he obtained a job during the early months of the pandemic. However, his job was temporary, obtained through a program that opened in Quebec specifically to help healthcare and other staff workers manage the initial wave of COVID-19. During his time at this job, he transitioned from being a full-time employee to on-call, at times only working two days a week. The temporary nature of his job and sudden change in his schedule evoked feelings of stress and anxiety.

> I was lucky, the first four months, around May, June, July, August, those months there, I worked from Monday to Friday, so the first [COVID] wave, it was good for me because I was accumulating a lot of hours and experience. And with that I was gaining seniority as I went along. But after that, they put me on-call. Because my position was temporary, they had the right to move me from one establishment to another. So, they put me on-call and moved me to another location. […] There were weeks I was working 2 days and some where I was working 5.

Across the three participants, feelings of stress and frustration were evident as they described their employment experience during the pandemic. They all dealt with precarious work situations as they went through temporary positions with vague timelines and varied schedules, that in turn affected them financially and emotionally. In the absence of other job opportunities, participants accepted precarious employment to gain more work experience and lessen their financial burden.

Employment Support

The pandemic's massive disruption to employment and the subsequent challenges that arose drove participants to seek support from job coaches at AMO. Thus, this sub-theme was evident in most of the participants' stories as they described AMO as instrumental in overcoming several difficulties and barriers throughout the pandemic. Although participants described AMO's support at the beginning of the pandemic as slightly disorganized, they expressed that with time to adjust to the unexpected changes, they became more structured, and their support was very helpful.

Three participants described requiring employment support that ranged from job searching, preparing for interviews, and on-site visits to help the participant integrate into their workplace. Two participants were specifically struggling with finding a job and began to lack motivation as time went on, therefore AMO was very helpful in providing them with additional support.

> AMO was helping me find a job and they pointed me to certain key words [to use when searching for jobs online]. So, I was searching for a job, I was doing one hour per day. It doesn't seem like a lot, but it's still a lot in the context of the pandemic. After that, I started looking two hours a day with their help. But I was feeling really frustrated with the job sites. And then… and then AMO found me a job and that was a really good find.

Despite the frustration this participant felt while searching for a job, he persisted with the support of AMO, and was very happy with the job AMO found him. Unfortunately, he lost this job for reasons unrelated to the pandemic, but was recently hired for another position, which again was found with the assistance of AMO.

Another participant also described the important role AMO played in helping him with the process of obtaining employment during the pandemic.

> AMO was helping me find internships… bringing my application to these programs, but these internships were competitive at the federal and provincial level. There was a lot of paperwork to fill out and my job coach helped me fill those out because I'm not that good with that. I had questions… about what the steps were and all that and my job coach helped me. I moved on to the next step for the federal internship, and there were interviews to evaluate you and AMO helped me prepare for those. […] About a month later, I didn't receive a response from those interviews. So then, one of the things AMO showed me was creating a profile on LinkedIn because I didn't have one. They showed me how to create one and gave me tips and tricks on how to network [on LinkedIn]. And by adding contacts on that platform, I added a supervisor from a previous internship, and it was her that wrote to me about a position she had available for me.

For two participants, job coaches also visited the workplace. There were restrictions with the number of times they could visit, however participants noted that AMO still met their needs. Three participants also explained that AMO maintained constant communication through check-ins either via telephone or in-person, depending on the COVID restrictions at a given time. AMO also adapted the number of check-ins with each participant according to their needs. Participants met with their job coach at least once bi-weekly, however, if necessary, the pair met more frequently. Outside of meetings, they kept each other informed of any updates via email or phone call. This was a seemingly smooth process for participants, as one noted “It was enough, really enough. We had a good rhythm going.”

Throughout the pandemic, many participants were going through other challenges unrelated to employment. The support provided by AMO also addressed these other challenges, thus going beyond employment-related services. One participant was transitioning between two seasonal jobs throughout the pandemic, which significantly affected him given the constant change in his routine and schedule. This participant was also struggling with significant mental health problems due to the pandemic (described in later themes), which impacted his work performance. AMO was instrumental in helping him access the services he needed and in acting as an intermediate between the participant and the health care workers that were helping him.

> AMO helped me a lot. They helped me make a schedule, they convinced me to ask for help, to be followed by a social worker from a health clinic. They called my employer to explain my situation. […] It’s AMO that helped me ask for support, who contacted the health clinic. And it was them that was talking with my social worker at the beginning to explain my situation […] to help them and to direct them.

When the participant required other mental health services, AMO facilitated this process as well and again acted as an intermediate between the participant and health care workers. AMO was in constant communication with them and explained the participant’s situation and needs, which the participant explained was crucial in getting the appropriate services.

Three participants described their experience with AMO and the supports they received as very satisfying given the context in which they were working (e.g., the constant change in COVID-related restrictions). When comparing participants’ satisfaction with AMO before and 20 months into COVID-19, there was little change for these three participants on the satisfaction with AMO questionnaire. Composite scores were calculated by averaging all item scores rated on a 5-point scale, with higher scores indicative of greater satisfaction, as shown in Table 3. Satisfaction with AMO slightly increased for one participant, remained the same for another, and slightly decreased for the third participant. The little or no change in scores reflect the positive views participants had about their support from AMO throughout the pandemic. For example, one participant said, “I was very satisfied with their services, it was enough in the context [of the pandemic],” while another said, “I was satisfied, it went well.”

However, participant 4 was not satisfied with AMO, as demonstrated in Table 3. His satisfaction with AMO decreased from before to during COVID-19. This decrease reflects his negative account of the organization and the lack of support and resources they provided him with. He described AMO as being absent for most of the time between the beginning of the pandemic and the time of the study.

> It's mainly that I didn’t feel supported by AMO in what I was experiencing […] They didn’t do anything. Still to this day, I haven’t heard from them.

Therefore, AMO’s services did not meet the needs of this participant. However, it is worth noting that this participant was already struggling with AMO before COVID-19. He explained that conflicts were already present with his job coach prior to the pandemic, due to differences in what they wanted for the participant. This conflict is also reflected in the participant’s low satisfaction score before COVID-19 (2.67 on a 5-point scale). Thus, the participant and his job coach were not on good terms when the pandemic began and between then and 20 months into the pandemic, communication was minimal, and feelings remained unchanged.

Table 3. Participant satisfaction with AMO before and during COVID-19

	Participant	Before COVID-19	20 months into COVID-19
		November 2018 – January 2020	December 2021
Satisfaction of employment support services (AMO)	1	4	4.67
	2	4.67	4.67
	3	4.33	3.33
	4	2.67	1

Although AMO's services may not have met all the participants' needs, as demonstrated by most of the participants, their support throughout the pandemic exceeded employment-related services and played a large role in their journey. Many believed that without AMO, overcoming their obstacles would not have been possible.

Job Satisfaction

Despite the challenges participants encountered when trying to obtain employment, they all expressed being satisfied with their job, co-workers, and supervisor. When comparing the participants' job satisfaction before and 20 months into the pandemic through the questionnaire they completed, there was little change in all the participants' ratings. Composite scores were calculated by averaging all item scores rated on a 5-point scale, with higher scores indicating greater satisfaction. As demonstrated in Table 4, participant job satisfaction increased for two participants and decreased for another two participants. Despite the decrease in ratings for two participants, scores remained high for all participants. Their high scores reflect the statements participants made about their job and the environment in which they worked. One participant described his workplace as very inclusive, encouraging, and supportive.

> I have a good job […] I definitely have a good employer. I always have help and get my questions answered.

Other participants also described a pleasant workplace and positive feelings toward their job. For example, one participant noted, “I am happy [with the job]. I get along well with everyone,” while another participant stated, “Things are going well at my job…my coworkers and supervisor, I get along with very well.”

A sense of security going into the workplace also contributed to participants’ satisfaction, as it decreased their stress and the fear of a COVID-19 infection that they were overwhelmed with during the earlier stages of the pandemic. Participants were working in-person and despite some being very anxious at the beginning, many expressed having adapted to working with COVID-19. One participant described his experience working in the healthcare sector almost two years since the start of the pandemic.

> I’m becoming less and less stressed with time because it’s more than a year and a half and I got my third vaccine last week.

However, during the early stages of the pandemic, he described himself as incredibly anxious due to his place of work and the high risk of infection. This echoes statements from other participants who were fearful before being fully vaccinated and when a lot of uncertainty was still surrounding the nature of the virus.

Table 4. Participant job satisfaction before and during COVID-19

	Participant	Before COVID-19	20 months into COVID-19
		November 2018 – January 2020	December 2021
Job satisfaction	1	3.86	4.43
	2	4.71	3.79
	3	4.93	4.14
	4	2.57	3.79

Deterioration of Mental Health

The second super-ordinate theme centres specifically on how the mental health of participants was impacted by the pandemic over time. Despite it being almost two years since COVID-19 began, all participants reported mental health challenges. The challenges expressed by participants stemmed from a combination of the recent uptick in COVID-19 infections, the ongoing COVID-related restrictions, the seemingly never-ending nature of the pandemic, and difficulties with employment. Although there was hope about a return to normalcy following the administration of vaccines, the new variant and reimplementation of harsh restrictions made participants feel dispirited, as it meant prolonging the loneliness they were experiencing and continuing to struggle with other mental health challenges that arose because of such measures. Through discouraged tones, participants described a roller coaster of emotions throughout the pandemic and at this time they were struggling to see the light at the end of the tunnel. The three sub-themes reflect the types of mental health struggles participants were experiencing: Social isolation, Sense of hopelessness, and Emotional distress.

Social Isolation

The most pronounced shared experience among participants was the lack of social connections throughout the pandemic. Despite only two participants living alone during

COVID-19, all of them reported feeling especially isolated and lonely, and for some, this was the greatest challenge they were dealing with since the beginning of the pandemic. When restrictions were first implemented during the onset of COVID-19, all participants were no longer having in-person gatherings with family and friends and were refraining from unnecessary outings. However, participants explained that at the time of this study, these restrictions remained in place; although in the summer they gathered with others in-person and planned outdoor outings, the worsening COVID-19 situation in December 2021 and reimplementation of mitigation measures continued to restrict their in-person social interactions. One participant described how the restrictions impacted his workplace and in turn his interactions.

> It [the restrictions at work] stressed me out because it was the only place where I had interpersonal relationships, so it cut off those interpersonal relationships. It made me feel even more isolated. So yeah… I felt lonely. My social interactions still haven't come back, it's something I need to work on […] I just lost the habit.

The workplace for this participant was the only place where he socialized with others and given that restrictions remained in place for so long, navigating social interactions within this context was a constant challenge for him. His situation also highlights the unique difficulties for those who lived alone throughout the pandemic. Another participant who lived alone spoke about how the measures impacted his social interactions and how he coped.

> It [the restrictions] cut my socializing for the day […] It's the thing that affected me most. It's for that reason that I bought a collection of stuffed animals. I talk with my stuffed animals. It's a way to break the loneliness.

A third participant who described himself as someone very family-oriented and keen on social outings and gatherings simply said, “You have no quality of life outside of work,” while a fourth noted, “In the long run… I was feeling a little too isolated […] I need socialization and that’s what’s a little hard right now.”

Some participants connected with others via telephone and on Zoom, however feelings about this method of communication were mixed. For example, one participant noted, “We do Zoom calls together and you know, we have a tradition, one day we would talk about our favorite childhood memories, our favorite Christmas, our best Halloween souvenirs, things like that, and it made me feel good, it allowed me to socialize, even if at a distance,” while another participant stated, “[phone calls] are the minimum, but it doesn’t do the job.”

The considerable overlap in responses regarding the profound isolation and loneliness felt throughout the pandemic underscore the importance of human connection for mental health and well-being. Participants’ stories highlighted the loss of social contact as a major contributing factor to the maintenance of poor mental health over time.

Sense of Hopelessness

Participants expressed disbelief in the unexpected length and severity of the outbreak. The multiple waves of the virus and constant public health restrictions from March 2020 to December 2021 in Quebec intensified feelings of helplessness and hopelessness among participants. The longer this situation continued, the harder it was for participants to be hopeful about a return to normalcy and as such, their sense of hopelessness became more prevalent. One participant explained that his ability to function deteriorated with time and was recently “having a hard time taking care of myself. I was having a hard time showing up to work on time, I was sleeping a lot, I wasn't productive." This deterioration was a manifestation of the participant's hopelessness.

Participants also described a low morale and sense of discouragement, which got progressively worse with time, especially amid the Omicron variant and spike in COVID-19 cases in late fall 2021. One participant explained the difference in his ability to cope with the restrictions between the onset of the pandemic and now and explained his frustration with the back-and-forth nature of the pandemic.

> I experienced the [initial] lockdown well […] it was fine but it's true that my morale is a little less good now […] With the vaccine passport, you could've gone to the restaurant and see people, do activities. And now, we're going backwards regarding that. So, I certainly find it a little depressing. But I don't think this will last three months either because normally, we'll reach a peak [in cases] and it will go down again and it will finish by improving soon, until the next time it goes up again.

This participant's words also reflect the assumption that as soon as the situation improves, it will eventually get worse again, shedding light on the continued ups and downs of the pandemic and the impact that had on attitude and hope.

Another participant also expressed a low morale among himself and his co-workers noting, "It's that our morale… everyone at work, they've had it up to here because of the measures," also echoing a sense that society is feeling hopeless amid the new variant. He also expressed frustration with the government regarding their decisions about restrictions, which contributed to his low morale.

The despair and sense of hopelessness expressed by participants at the current situation clearly indicated how the length of the pandemic impacted their ability to remain hopeful about a return to pre-COVID times.

Emotional Distress

Participants reported a deterioration in their mental health over time related to the multitude of challenges brought on by the pandemic and carrying the weight of that burden for almost two years,. This sub-theme reflects participants' various manifestations of distress, such as feelings of sadness, anxiety, frustration, and agitation. Participants' stories demonstrated that distress was often triggered by the long-term consequences of the pandemic, such as limited or no social interactions, prolonged feelings of isolation and loneliness, feelings of hopelessness, and difficulties with employment. The uncertainty surrounding the longevity of the pandemic and the restrictions also contributed to the distress experienced by participants.

One participant described a particularly distressing experience during COVID-19; he developed a substance use problem shortly into the pandemic that progressively got worse. At the time of this study, he had recently checked into a rehabilitation center and was on sick leave from work due to the severity of his condition. He explained that the complete loss of social interactions in and out of the workplace, increased isolation and heightened anxiety pushed him to consume alcohol and drugs, and as the pandemic went on, his mental health continued to deteriorate.

> It [substance use] took up all the space in my life… [His mental health] only got worse. […] I was almost no longer functional, so I had to stop using, it was too much.

Showing great insight and strength, this participant was able to reach out for support, however his story portrays a struggle during the pandemic that stemmed from ongoing restrictions and their associated consequences (e.g., loss of social interactions). Another participant echoed this increasing struggle, stating that at the beginning of COVID-19, “it was going well,” but as the pandemic continued, “it was harder [to manage], I was getting fed up… my happiness went down.”

Another participant stated that his mental health was comparable to the beginning of the pandemic, a time during which he described himself as “frustrated” and “ripping out the walls.” The new wave of COVID-19 cases and reimplementation of mitigation measures were restricting him from spending the Christmas holiday with family, which evoked feelings of sadness and irritability that he had experienced early on as well. His story also sheds light on the cyclical nature of the COVID-19 pandemic and its reoccurring impact on mental health.

In addition to the restrictions, participants’ emotional distress also stemmed from employment-related challenges throughout the pandemic and subsequent financial concerns. The participants who experienced significant difficulties with obtaining employment hinted to the ways in which these prolonged difficulties affected their mental health over time. For example, one participant who lost two jobs during the pandemic described the distressing aftermath following the second job loss.

> Well, psychologically, in the months following my dismissal from [the company], I was feeling a bit down. So, I wasn’t doing much… I was moping around alone playing [video] games. I was trying to escape from this world. It took me a long time to find a job [after that]. It took me really like, it took me a good six months I think to find a job. It affected me a lot, but I’m someone who hides my emotions often.

This participant also spoke about the frustration he felt about having to find a new job noting, “I know what I want to do [for work] but I can’t do it.” In this case, the participant was referring to the first job he lost due to COVID-19, highlighting the frustration and discouragement he continued to experience.

Another participant’s distress also stemmed in part due to his precarious employment situation and the subsequent financial implications. In addition to working a temporary job, his employment status suddenly changed from full-time to on-call. His schedule and hours worked therefore varied every week, to which he said, “Financially, it was definitely stressful.”

Adopting a Positive Outlook

Despite the burden of the pandemic weighing heavily on participants, some also described certain behaviors and activities that were helpful in improving their mental health during these circumstances. Specifically, participants believed that holding permanent employment during such uncertain and lonely times and trying their best to maintain a positive mindset about the pandemic and the future, were somewhat helpful in boosting their mental and emotional well-being. Participants’ thoughts highlighted the fundamental role employment plays in one’s life and the benefits in thinking positively during a difficult time. As such, the two sub-themes discussed are Permanent employment and Positive thinking.

Permanent Employment

Participants reported that eventually being able to obtain a permanent job throughout the pandemic contributed to improved mental health. As discussed above, three of the four participants included in this study encountered several challenges and barriers when searching for a stable job during the pandemic. Through persistence and determination, these participants had recently achieved their goal of obtaining a permanent job. Participants described the relief and joy holding a permanent position evoked, and the positive impact it had on many other areas of their life. Their stories highlighted the integral role employment plays in one's life, especially of adults on the autism spectrum, who repeatedly encounter difficulties when trying to obtain and maintain employment. One participant, who finally obtained a permanent position almost 2 years into the pandemic, described how the benefits of his job transferred to other areas of his life.

> I'm not just talking about the fact that it [his job] is permanent but… it's also just finding a job and getting back to work in general, it's being able to move around, seeing people, so it [obtaining a permanent job] definitely helped my mental health, because I was feeling really isolated and I felt alone. The fact that I get to be around people helps me to socialize and sometimes it's good to see other people… it's just about actually doing something because after more than a year of being stuck at home, at some point, you start looking for something to do- you feel more productive by having a job.

The obvious benefits of job and financial security were also reflected in this participant's thoughts about having a permanent job.

> The fact that it's permanent, I don't have to worry about whether I'm going to continue my job because it's temporary and it's a replacement job. Well then, you never know when it's going to end, so at least it's permanent, so that's reassuring.

Another participant lost two jobs during the pandemic and felt completely discouraged to start searching for a third one. However, he stated that it was the social benefits of employment that motivated him to begin job searching, specifically because a job would "get me out of the house and doing something." His thoughts echo those of the previous participant who also noted, "If I didn't have this permanent job, I would still be isolated and maybe then, the discouragement would last even longer."

A third participant described the positive impact obtaining permanent employment had on himself. He explained that being able to hold a stable position changed his personality as it boosted his self-esteem and made him proud of himself.

Therefore, holding permanent employment improved the mental health of participants, as it reduced the magnitude of isolation and loneliness they felt during the pandemic, as well as reducing their level of stress stemming from employment uncertainty and financial instability, and improved their self-concept.

Positive Thinking

Participants tried to build resilience through engaging in positive thinking in the face of difficulty, specifically as the pandemic worsened amid the new variant. This included trying to view the positive side of difficult situations (e.g., the high number of positive cases and the necessity of restrictions), thinking positive thoughts, and letting go of what could not be controlled. The use of positive thinking in this context was meant to reduce participants' level of negative affect and promote resilience. One participant described his perspective regarding the uptick of COVID-19 cases, shed light on the positive side of having been vaccinated, and spoke of the importance in letting go of what we cannot control.

> Basically, I don't know how to say it but… even if the cases go up, there is a limit in what we can control so, I'm kind of just letting go of it, you know. I'll be careful on my side but […] we even have the vaccines now, so I told myself… well it's for sure not 100% effective and there's always a risk but at least there is less of a chance that it is really bad. […] Having to deal with the yoyo of everything [increase and decrease of COVID-19 cases and restrictions] sucks but I'm quite resigned, so it for sure sucks but, it's out of our control. I'm trying to see the positive.

Another participant explained that while concerns about the longevity of the pandemic persisted, since the start of the initial lockdown, he has tried to look at the positive side.

> I'm like my grandfathers, I try to look at everything positively. They take everything on the positive side. So, I'm a bit like those two people.

Speaking about recent progress regarding his ability to see a few friends again, this same participant notes, "I interact [with friends] a bit more now […] I have regained a little bit of my life with time, it's nothing transcendent, but it's still better than nothing."

Engaging in these thoughts helped reduce the negative affect and distress participants continued to struggle with almost two years into the pandemic. Thinking positively also helped participants feel less overwhelmed about the uncertainty surrounding the nature of the virus.

Community Engagement and Recreation

The range of challenges triggered by the pandemic drove most participants to seek support through different means, depending on their needs. Participants also engaged in hobbies to help cope with the burden of the pandemic. Only one participant did not require external supports or engage in any pastimes throughout the pandemic. Importantly, all supports and coping strategies discussed by participants were health-promoting and deemed helpful by participants. The three sub-themes, reflective of the supports sought during the later stages of the pandemic, are the following: Social support, Engagement in hobbies, and Mental health services.

Social Support

Some participants described the important role of social support throughout the pandemic, particularly from family. They explained that having family available for support was important to help them deal with the difficulties they were struggling with. One participant described the instrumental role his partner played in helping him move beyond the significant mental health challenges he was experiencing at the beginning of the pandemic. He explained that she also helped him obtain employment, constantly checked in on him and was always available to answer any questions he had regarding work, all of which empowered him.

> You know without my partner, all these steps I had to take [to get better] … I would not have advanced […] Look at everything I was able to do with someone supporting me the way she did.

Through the stories of two other participants, it was evident that their parents provided them support throughout the pandemic and were always there for the participants to turn to. These two participants were living alone and explicitly noted the arrangements their parents made to reduce the loneliness and anxiety they were experiencing, for which the participants expressed gratitude. Therefore, support and understanding from loved ones during COVID-19 helped participants manage the long-term physical and mental toll the pandemic was taking on them.

Engagement in Hobbies

One participant described engaging in his hobbies as a way of coping throughout the pandemic. He perceived the initial lockdown in March 2020 as a vacation and compared it to the summer break students have when enrolled in school. However, as time went on, his mental health deteriorated. To help him cope with the loneliness and other mental health challenges he was struggling with, he began pursuing different hobbies. At the time of this study, the participant remained engaged with such hobbies and described his engagement as a way to remain stimulated and focused. He noted, “I started writing a lot… I got into another passion of mine, languages.” He also completed mandalas, designs that are divided into sections with numbers that correspond to a specific color, to relieve stress. Thus, engaging with hobbies was one way in which this participant coped with the long-lasting impact of the pandemic.

Mental Health Services

The measures implemented to reduce the spread of the virus led to an increase in mental health challenges among the participants. For one participant specifically, their mental health continued to deteriorate over time and eventually, he developed a substance use problem (as was discussed in a previous theme). Given his condition was worsening, AMO helped him reach out for support from a health clinic, specifically requesting that he be followed by a social worker. Having the support of AMO streamlined the process of receiving services, allowing the participant to begin meeting with the social worker three to four weeks after submitting the request. The participant visited his social worker in-person once every week and was able to call at any time.

Despite the support from the social worker at the health clinic, the participant's condition continued to worsen. Therefore, AMO helped him reach out for a more appropriate service, specifically from a rehabilitation center. During this time, the participant went on sick leave to prioritize his mental health and started seeing a second social worker from the rehabilitation center.

The participant appreciated the ability to simultaneously receive services from the health clinic and rehabilitation center, all while being supported by his job coach at AMO.

> It was AMO that helped me ask for support […] The three of them together [health clinic, rehabilitation center and job coach] … they are helping me get back to a healthy lifestyle, they helped me make a schedule I can respect… it's helping me a lot, I have more support now.

Thus, the participant reported a positive experience with the mental health services sought, which worked best when receiving them simultaneously, and emphasized that accessibility to such services was facilitated by the continuous support of AMO.

Chapter 5

Discussion

The current study seems to be the first in the literature to explore the ongoing effects of COVID-19 on the employment and mental health of adults on the autism spectrum, specifically 20 months into the pandemic, through their perspectives. This study used an interpretative phenomenological analysis (IPA) approach to explore among adults on the autism spectrum how the pandemic impacted their (1) employment experience, job support (i.e., job coach services), and job satisfaction; (2) mental health; and (3) to identify supports that were available and deemed helpful throughout the pandemic. Participants completed two questionnaires assessing their satisfaction with their current job and the employment support services they received during the pandemic, and a semi-structured interview.

Emerging from Precarity of Employment

Employment Precarity

During the pandemic, three of the four participants in the current study reported challenges with obtaining a permanent job. During the time between the initial wave of COVID-19 and the time in which they were finally hired for stable positions, they were in precarious employment situations. These findings build on prior research that was conducted during the earlier stages of the pandemic examining its impact on employment. During the first few months following the initial lockdown in March 2020, adults on the autism spectrum across several countries (e.g., Australia, Israel, United States) reported many negative employment-related changes (e.g., job loss, reduced work hours; Bal et al., 2021; Goldfarb et al., 2021; Taylor et al., 2021). Adults on the autism spectrum ranked employment as the most impacted area with respect to pandemic-related changes compared to other domains (Bal et al., 2021) and expressed uncertainty surrounding employment and their financial security (Maljaars et al., 2022), which negatively impacted their personal life (Hedley et al., 2021). Findings from the current study demonstrate that similar experiences were still taking place 20 months into the pandemic, as difficulties with the labour market and feelings of insecurity surrounding employment and financial income continued to persist, going way beyond the initial stage of the pandemic.

In Québec, Canada, the unemployment rate among the general population reached 17% in April 2020, reflecting the profound impact the pandemic had on employment (Statistics Canada, 2020b). However, this rate steadily dropped, reaching pre-pandemic levels (4.5%) in November 2021 (Statistics Canada, 2021d). Thus, participants in this study might have been among those who struggled significantly in securing stable employment, as their obtaining of a stable job was in line with the timing of the return to pre-pandemic employment rates. The participants' difficulties in obtaining a stable job throughout the pandemic echo what adults on the autism spectrum were already experiencing prior to COVID-19 with regard to obtaining employment (Chen et al., 2015; see Nicholas et al., 2019 for discussion). Young adults on the autism spectrum spend significantly more time searching for a paid job (average of 14 months) relative to those with other conditions (e.g., emotional disturbances, learning disabilities, speech/language impairments; Wei et al., 2018) and experience greater difficulties with obtaining a job, as reflected in employment rates demonstrating a wide gap between adults on the autism spectrum (33%), the general population (79%) and other disability groups (59%; Public Health Agency of Canada, 2020), irrespective of educational attainment (Hedley et al., 2017a), which have remained consistent over the years (Zwicker et al., 2017). Therefore, the current results confirm concerns expressed by researchers (e.g., Pellicano & Stears, 2020) about the particularly detrimental effect of COVID-19 on the employment of individuals on the autism spectrum, as findings provide evidence for long-lasting consequences among this population.

Further, individuals on the autism spectrum often work in precarious employment (Heasman, 2020; Vincent, 2020), as was the case in the current study for three of the four participants, which in turn tend to harm them in other areas of life (e.g., housing; Garratt & Flaherty, 2021). One study found that the main reason young adults on the autism spectrum became unemployed was because their temporary job ended, and that significantly more of these adults compared to those with other conditions (e.g., learning disabilities) reported holding a temporary job (Wei et al., 2018). Precarious work, inclusive of insecure, temporary, and unstable jobs (Famira-Muehlberger, 2014), is shown to be tightly linked to unemployment in that a high rate of unemployment reduces workers' ability to refuse poor employment and working conditions, thus increasing the precariousness of employment (Vives et al., 2015). In line with this, participants' narratives indicated a lack or loss of other opportunities during the pandemic, leaving them with no choice but to accept unstable, temporary positions. Thus, the pandemic seemed to have exacerbated challenges that adults on the autism spectrum were already struggling with pre-pandemic. However, given that COVID-19 government interventions differed across countries, with Canada among those imposing stringent public health measures (Desson et al., 2020), future research in other geographical regions with larger samples should also examine the long-term impact on employment among this population.

Employment Support

Participants in the current study continued to receive employment support services during the pandemic from action main d'oeuvre (AMO), a community organization located in Montreal, Canada providing individualized job coaching services for individuals on the autism spectrum and their employers. When comparing satisfaction rates obtained in the current study with those obtained prior to COVID-19 (November 2018 – January 2020), the three participants who expressed satisfaction during their interviews also showed little change in their questionnaire responses, showing that the pandemic did not impact their satisfaction with the employment support they received. Only one participant was not satisfied, however, he already had issues with his job coach prior to the pandemic, which may have impacted communication, delivery of services and ultimately, satisfaction. Thus, for the most part, employment support services were satisfactory in the context of the pandemic.

Although studies examining the impact of COVID-19 on employment services remain scarce, researchers suggested a potential disruption of services (e.g., job coaches being unable to provide on-site training or support) to individuals with developmental disabilities due to restrictions (Sheppard-Jones et al., 2021). In line with these concerns, family members of individuals with intellectual disabilities, who took part in focus groups conducted in Canada in February 2021, indicated a need for better access to employment supports and job coaches during COVID-19 (Inclusion Canada, 2021). In one study, the number of participants receiving services from a vocational worker before (43%) and during (23%) the first lockdown almost halved, to which the authors suggested might be due to the pandemic-related restrictions preventing support workers from working (Goldfarb et al., 2021). Findings from the current study demonstrate that for the four individuals already in AMO's system, employment services were accessible throughout the pandemic, with job coaches providing services beyond just employment-related supports when needed for participants. However, job coaches in the current study were restricted in the number of times they could visit their clients at the workplace, providing some evidence to the suggestion made by Sheppard-Jones and colleagues (2021) and Goldfarb et al. (2021) earlier on in the pandemic; job coaches were working but in some ways were still prevented from providing specific services in December 2021, specifically in this case, on-site support, highlighting the long-lasting impact public health measures may have had on employment support for this population. Despite this restriction however, participants were satisfied with the amount of support received. It is worth noting that participants in the current study were lucky in that they were already receiving services from AMO prior to COVID-19, therefore facilitating access following the outbreak. The current waitlist for services from organizations such as AMO are a few years long, thus many do not have access to this support.

Other studies conducted during the early stages of the pandemic reported a disruption or lack of available services during the pandemic for individuals on the autism spectrum (Oakley et al., 2021; Spain et al., 2021). Previous research also demonstrates low or neutral satisfaction among parents or caregivers of individuals on the autism spectrum with autism support services during the early phases of COVID-19 (Ferguson et al., 2021). Although the satisfaction, accessibility and range of supports offered by AMO differ from the findings of these other studies, the current study explored these aspects 20 months into the pandemic. Interestingly, some participants did note that AMO and their job coaches were a bit disorganized at the beginning of the pandemic, however, with time, were able to adjust and become more structured. Their comments about the early stages of the pandemic echoed similar concerns that were expressed by respondents of the Pandemic Canadian Autism Needs Survey conducted in May 2020, which revealed that advocates (i.e., adults on the autism spectrum, parents and caregivers) defined employment services as problematic (Salt & Soliman, 2020). However, given the unexpected and abrupt nature of the pandemic, these findings suggest that perhaps, during the initial lockdown, organizations, such as employment agencies, were not prepared to make such significant changes with service provision. However, with time to adjust their services according to public health restrictions, organizations such as AMO were able to adapt and provide more efficient and satisfactory services, better supporting individuals on the autism spectrum. Thus, further research examining the long-term availability of and satisfaction with services and supports in general is warranted.

Job Satisfaction

Despite the challenges most participants in the current study experienced with trying to obtain a permanent job, all four participants reported being satisfied with their current job. When questionnaire responses assessing job satisfaction before (November 2018 – January 2020) and 20 months into COVID-19 were compared, only slight changes were observed. Satisfaction increased for two participants and slightly decreased for two, but remained high nonetheless, given original scores were already high, which complimented the positive remarks made during their interviews, demonstrating that the pandemic did not negatively impact their job satisfaction. It is worth noting that satisfaction in the current study was evaluated almost two years into the pandemic and may have differed if it was evaluated during the earlier stages of the pandemic, given increased uncertainty surrounding the virus. Nonetheless, these findings replicate those from another study conducted between April – May 2020, also finding that the pandemic did not impact the job satisfaction of adults on the autism spectrum (Goldfarb et al., 2021). Our results suggest that workplaces met the needs of participants and provided a welcoming and pleasant work environment during difficult and unprecedented times.

Participants’ sense of security going into the workplace also contributed to their job satisfaction. These findings are like those of Rajabimajd et al. (2021), who found an association between an increased fear of COVID-19 and decreased job satisfaction. Additionally, a study conducted with the general population revealed that 68% of respondents (84 out of 124) with reduced job satisfaction also reported feeling less safe at work (Hussein et al., 2020), showing the extent to which perceived safety can influence satisfaction. In the current study, participants were able to adapt to the situation and attributed their reduced stress to being fully vaccinated and possessing a better understanding of the nature of the virus, thus improving their satisfaction with their job.

Deterioration of Mental Health

Social Isolation

Among the most inevitable consequences of the pandemic was its profound impact on loneliness and social isolation. Although loneliness tends to be higher among adults with disabilities living alone (Emerson et al., 2021), only two participants in this study lived alone, suggesting that during the pandemic, this arrangement had less of an impact.

For some, the social isolation experienced throughout the pandemic was the greatest challenge they continued to struggle with. While one participant noted that virtual interactions (e.g., Zoom) helped a bit, the other participants disagreed and stated that they were not enough, highlighting the importance of in-person social connections. This finding replicates two other studies conducted during the initial lockdown, which found that one of the greatest difficulties for adults on the autism spectrum was the loss of social contact (Maljaars et al., 2022; Oomen et al., 2021). These results are also in line with other studies that were conducted during summer 2020 among individuals with intellectual and developmental conditions (e.g., on the autism spectrum), parents, and caregivers showing a profound need for social contact during the pandemic and mixed reactions regarding online interactions (Lake et al., 2021; Pellicano et al., 2021). While Lake and colleagues (2021) reported mixed feelings among adults with intellectual and developmental conditions regarding their preferred type of interaction (online, in-person), many individuals on the autism spectrum in Pellicano et al.’s (2021) study expressed dissatisfaction with virtual interactions, highlighting the varying preferences of different populations.

Interestingly, although this study is the first, to my knowledge, to assess the longer-term effects of COVID-19 among adults on the autism spectrum, these results echo findings from another study examining the longer-term impact of COVID-19 on the loneliness of 160 adults with disabilities (e.g., visual impairment, learning difficulties, mental health conditions; Heinze et al., 2021). In that study, researchers found that loneliness was significantly higher for those with disabilities than for those without during April – May 2020 and March 2021. The qualitative accounts in this study are seemingly consistent with the quantitative findings reported by Heinze and colleagues (2021), in that loneliness had a profound impact on participants with disabilities over time. Thus, results from the current study extend on previous findings from the autism and broader disability literature by showing that a marked negative impact on social isolation was still being experienced by participants in December 2021, almost two years into the pandemic, and for some, was the most difficult challenge to grapple with.

Importantly, these results oppose the notion of individuals on the autism spectrum being “natural quarantiners” (Cassidy et al., 2020, pp. 110) or less impacted by physical distancing (Bundy et al., 2021) and theoretical accounts claiming reduced social motivation in autism (Chevallier et al., 2012), lending further evidence to arguments against this assumption (Jaswal & Akhtar, 2019). Participants’ narratives indicated heightened social motivation and point to the need for effective social supports and strategies designed to enhance social connectedness among this population throughout and beyond COVID-19. One participant noted that he was doing well during the initial lockdown and that online interactions sufficed at the time, however, starting in the fall of 2020, started feeling the effects of social isolation, which gradually became worse. This is important, as it suggests that as the pandemic went on, it may have had greater adverse effects even among those who were not previously affected. Another participant also shared that the loss of social contact and isolation was among the main reasons he developed a substance use problem during the pandemic. Participants' narratives therefore support claims that long-lasting social isolation can have deleterious effects on physical and mental health (Banerjee & Rai, 2020). One study conducted during the pandemic on adults with disabilities underscored these negative consequences; social isolation was the strongest predictor of depression and anxiety (Wang et al., in press), highlighting the urgency of addressing these concerns among this population, who are already at greater risk of experiencing mental health problems (Mason et al., 2019a).

Sense of Hopelessness

In the context of the long-lasting nature of the pandemic and implementation of measures, hopelessness became a core emotion experienced by participants. Hopelessness, referred to as the belief that one lacks control over outcomes and holds negative expectations for the future (Everson et al., 1996), emerged later in the pandemic and was especially prevalent during the time of this study, amid the Omicron variant and significant rise in cases.

The participants' feelings of hopelessness and despair are consistent with a survey that was conducted between October and December 2021 among Canadians (Statistics Canada, 2022), very close to the timing of the current study. This survey revealed that individuals aged 15 and older who reported having a disability, difficulty or long-term condition were less likely to report a strong sense of meaning and purpose; slightly under half of these individuals reported having a strong sense of meaning and purpose (49%) compared to two-thirds (67%) of those without a disability, difficulty, or long-term condition. Together, these studies suggest that over time, people with different conditions, such as adults on the autism spectrum, felt more hopeless and discouraged about the situation and meaning of life. Another study conducted during June 2020 found that Canadian adults with disabilities and chronic health conditions who experienced increased loneliness and decreased belonging during the pandemic were among those showing the highest rates of despair (Pettinicchio et al., 2021). Participants in the current study continued to experience those feelings in the long-term (i.e., high levels of loneliness and reduced belonging), which may have contributed to their feelings of hopelessness, potentially indicating loneliness and lack of connectedness as additional risk factors throughout the short- and long-term of the pandemic for feelings of hopelessness.

Critically, a high level of hopelessness has been shown to be a significant predictor of suicide (Gidron, 2013), which is particularly concerning for adults on the autism spectrum, who are three times more likely to attempt and complete suicide relative to the general population (Kõlves et al., 2021). Thus, similar to the findings regarding social isolation, these findings, too, call attention to the importance of addressing these issues among this population throughout and beyond COVID-19.

Emotional Distress

Through the several challenges encountered during the pandemic and a growing sense of hopelessness over time, all participants experienced a deterioration in their mental health in the long-term. Participants’ distress stemmed from two distinct challenges: the ongoing mitigation measures and employment-related difficulties.

The public health restrictions implemented since the beginning of the pandemic led to prolonged social isolation and increased feelings of hopelessness among participants in the current study. These experiences may in part explain the increased emotional distress participants experienced in the long-term. Both social isolation and hopelessness have been shown to be associated with distress among the general population during the pandemic (Kim & Jung, 2021; Yu et al., 2021), suggesting that individuals on the autism spectrum are at risk as well. Further, even prior to the pandemic, adults on the autism spectrum were at risk of experiencing higher levels of psychological distress; compared to the general population, studies have found greater levels of emotional distress among adults on the autism spectrum (McGillivray & Evert, 2018; Worley & Matson, 2011). Thus, the pandemic and the restrictions added an additional layer of risk for participants, an already vulnerable population.

These findings extend on previous research conducted during the earlier stages of the pandemic showing a negative impact of COVID-19 on the mental health of adults on the autism spectrum (e.g., distress, anxiety; Adam et al., 2021; Chung, 2020). Findings from this study suggest that feelings reflective of distress were still being experienced among this population 20 months into the pandemic, potentially at higher rates than during the beginning of COVID-19, given that challenges (e.g., consequences associated with the restrictions) were now being experienced for almost two years by participants. Future research should examine the impact of the pandemic on distress longitudinally to observe whether these results hold in larger, quantitative studies. Nonetheless, findings support Bal and colleagues' (2021) cautioning against the assumption that adults on the autism spectrum may be less affected by the public health restrictions, specifically physical distancing.

Participants' emotional distress was also triggered by the employment challenges they dealt with during the pandemic, namely obtaining a permanent job, and the ensuing financial insecurity. Even though participants were able to obtain temporary positions during the pandemic, a negative impact on their mental health was observed nonetheless, supporting research among the general population showing an association between job insecurity and financial concern due to COVID-19 and greater depressive and anxiety symptoms, even among those who remained employed (Wilson et al., 2020). Participants' narratives are also consistent with the literature showing a significant correlation between subjective job insecurity and negative mental health among general (Klug, 2020) and clinical (Llosa et al., 2018) populations. Participants' distress due to their employment precarity in the long-term supports previous research showing the negative psychological impact unstable employment can have among individuals on the autism spectrum (Müller et al., 2003). The current findings corroborate earlier studies that were conducted during the pandemic showing negative mental health effects among this population following employment and financial insecurity (Bundy et al., 2021; Goldfarb et al., 2021).

Adopting a Positive Outlook

Permanent Employment

Participants described that holding a permanent job protected them from the negative mental health effects of the pandemic, underscoring the pivotal role employment plays in the lives of adults on the autism spectrum (Lysaght et al., 2012) and supports a well-established association between employment and improved mental health (i.e., greater sense of autonomy, improved subjective well-being, reduced depressive and anxiety symptoms, enhanced social status) among the general population (see Modini et al., 2016 for review).

Although there is a paucity of research examining the mental health benefits of employment among adults on the autism spectrum, it has been suggested that holding a job may lead to increased financial independence, a sense of purpose, social integration, and self-esteem among this population (Dudley et al., 2015). In line with those ideas, a qualitative study that included adults on the autism spectrum and their parents found that the advantages of work included social engagement and improved self-esteem (Anderson et al., 2021), while another qualitative study including nine adults on the autism spectrum reported positive outcomes following a transition to supported employment, including improvements in self-esteem, mood, social relationships, opportunities to socialize, a sense of purpose, and financial independence (Hedley et al., 2018). Thus, these results lend further support to findings in previous studies demonstrating the benefits of employment among this population.

Interestingly, these results replicate those reported in another study conducted during the early stages of the pandemic, which found that for adults on the autism spectrum who physically attended work, maintaining employment acted as a protective factor from the negative effects of the pandemic (Goldfarb et al., 2021). In that study, participants emphasized the importance of holding a job and being able to provide for themselves during uncertain times, highlighting, again, the important role of employment for this population, particularly during the pandemic. Although it is not possible to say whether physically attending work contributed to the protective nature of employment in this study, participants' improved mental health could be attributed to holding a stable job in general. Participants' accounts therefore point to the importance of developing programs and interventions aimed at increasing successful employment outcomes among this population, which may have important implications for mental health as well.

Positive Thinking

To buffer against the negative effects of mental health evoked the pandemic, some participants engaged in positive thinking, especially during December 2021 due to the surge in cases at the time. Positive thinking is a cognitive process that creates optimistic ideas and a positive outlook on life, acknowledging both the negative and positive aspects of a situation and steering toward a positive interpretation (Bekhet & Zauszniewski, 2013). In this context, positive thinking mostly consisted of letting go of circumstances that participants had no control over and explicitly trying to think of positive thoughts.

Positive thinking has been shown to be among the most beneficial strategies to engage with for mental health during the pandemic among healthcare professionals (Laurent et al., 2021) and the general population (Budimir et al., 2021). Consistent with these findings, a survey study revealed that support workers recognized positive thinking as the most frequent source of resilience among their clients with intellectual disabilities during COVID-19 (Scheffers et al., 2021). Only one study has shown the use of positive thinking among adults on the autism spectrum as a strategy to reduce stress, specifically during the pandemic (Maljaars et al., 2022), which is consistent with the current findings.

Although much of the research on positive thinking in autism research has focused on the benefits it can have for parents and caregivers (e.g., improved psychological well-being; Bekhet et al., 2012), the results in the current study and that of Maljaars et al., 2022 suggest that benefits may also extend to individuals on the autism spectrum, at least during periods of uncertainty and in the face of adversity. However, more research is needed to understand whether strategies used to promote resilience, such as positive thinking, can also be effective if applied to people on the autism spectrum.

Community Engagement and Recreation

Social Support

Several participants explained that social support, particularly from their family, was very helpful for them in coping with the struggles they encountered during the pandemic. Previously, research has shown that higher levels of social support are associated with higher levels of quality of life among adults on the autism spectrum, suggesting a beneficial effect of social support (Bishop-Fitzpatrick, 2018). It is particularly important during negative life events (Kaniasty, 2012), as it can offer positive experiences and resources throughout stressful times (Panayiotou & Karekla, 2013), such as COVID-19. Indeed, during the pandemic, research has demonstrated a positive effect of social support on the mental health of vulnerable populations, such as healthcare workers (Labrague, 2021), pregnant women (Khoury et al., 2021), and COVID-19 patients (Yang et al., 2020). Among adults on the autism spectrum, one study showed that they sought social support to cope with the negative effects of the pandemic (Maljaars et al., 2022), while for adults with intellectual and developmental disabilities, social support predicted life satisfaction during COVID-19 and partially mediated the relationship between individuals' stress levels and satisfaction with life, highlighting its crucial role in mediating psychosocial outcomes among this population (Fisher et al., 2022).

Consistent with these findings, the current results also show the positive impact that perceived social support can have among this population during a prolonged stressful life event. Perceived social support has been shown to be helpful when people believe their families or friends are available to support them (Helgeson, 1993). In the current study, findings shed light on family, specifically parents and one's partner, as a particularly important source of social support during the pandemic. This is valuable information for clinicians and other stakeholders, such as parents or caregivers, as it suggests family is a core consideration when building supportive social connections among this population. This also suggests that support from family may be driving the mediation between stress and life satisfaction more than other types of support, such as friends or professionals, during the pandemic (Fisher et al., 2022), however further research is needed to examine this among larger samples.

Interestingly, the current findings, which point to the importance of social support interventions among adults on the autism spectrum, provide further support to a study conducted in the UK examining priority concerns for people with intellectual and developmental disabilities during COVID-19 (Tromans et al., 2020); in that study, key individuals (e.g., senior representatives) within organizations and groups providing care to people with intellectual disabilities and/or those on the autism spectrum listed access to social support services as the top priority concern (out of five total) related to the domain 'social circumstances and support.' Thus, even with other supports remaining accessible during COVID-19, such as employment- and mental health-related services, social support was still an important resource to cope with the challenges evoked by the pandemic, suggesting it may be a priority for this population moving forward.

Engagement in Hobbies

To cope with the loneliness and other challenges throughout the pandemic, one participant explained that engaging in his favorite hobbies was helpful. Although this coping mechanism was only expressed by one participant, keeping busy with hobbies has been a coping strategy for others as well, including youth (Lindsay et al., 2021) and adults (Burton et al., 2021) in the general population, and was found to be associated with improved well-being during the initial lockdown (Bu et al., 2021). This finding is also consistent with other studies that found that adults on the autism spectrum reported having more time to engage in their hobbies and meaningful activities throughout the early stages of the pandemic (Bundy et al., 2021; Maljaars et al., 2022; Spain et al., 2021).

The current finding suggests that engaging with hobbies was still being used as a coping strategy in the long-term. However, the participant's hobbies were of a solitary nature and did not require any social engagement. There are studies reporting limited opportunities for specific leisure activities among adults on the autism spectrum and those with intellectual disabilities (Kim et al., 2021; Maljaars et al., 2022) due to required outings in the community, which were difficult during the pandemic. Solitary activities that could take place within the individual's household made it possible for the participant to engage in such activities without any barriers. Given the potential positive benefits of engaging in meaningful hobbies however, results from the current study and others point to the possibility of making group leisure activities available in other formats throughout the pandemic, to offer a wider range of activities to a greater number of people and the opportunity to cope with the pandemic. Overall, however, this finding shows the importance of engaging adults on the autism spectrum in meaningful hobbies, as they may have important implications for their health and well-being. Future research should analyze the association between engagement in meaningful activities and well-being among this population to gain more clarity and observe whether the trend among this population is consistent with others (e.g., general population; Bu et al., 2021).

Mental Health Services

One participant and his job coach reached out to a health clinic and rehabilitation center during the pandemic. The participant was satisfied with the services he was receiving, and the speed with which he accessed such supports. The participant's positive remarks with the supports received are consistent with another study among adults with intellectual and developmental disabilities, which revealed that all participants who accessed virtual mental health support during COVID-19 benefited from them (Lake et al., 2021). However, also in that study, participants wanted more mental health supports available, such as visits with mental health care providers. Several participants in that study also expressed negative experiences with health care professionals and often felt misunderstood, dismissed, or treated unfairly. In the current study, the participant also expressed feeling misunderstood when he first started seeing both social workers. However, he described his job coach as instrumental throughout this process; his job coach provided him with assistance in seeking mental health supports and acted as an intermediate between the participant and healthcare workers. The presence of the job coach then, allowed the healthcare workers to obtain a better understanding of the client and tailor their services to match the specific needs of the participant. Thus, the current findings suggest that job coaches may play a fundamental role in facilitating access to mental health supports and minimizing misunderstandings between the client and healthcare worker, which could in turn lead to a more individualized approach and support. The findings also provide further evidence for the value of job coaches, as they go beyond simply providing employment support and become involved in other areas of the client’s life as well.

These findings differ from other studies reporting challenges with accessing mental health care throughout the pandemic among individuals on the autism spectrum (Bundy et al., 2021; Mosquera et al., 2021; Pellicano et al., 2021). However, all of these studies were conducted during the very early stages of the pandemic. It may be that the abrupt nature of the pandemic hindered service providers’ ability to deliver appropriate support, however with time, they were able to adapt and modify their services accordingly. Future research should examine the long-term availability of different types of provision across regions with larger samples to understand whether this theory holds up. Assessing the availability of services is very important given that prior to the pandemic, individuals on the autism spectrum were more likely to experience challenges with accessing effective healthcare (Mason et al., 2019b), and during the pandemic, may have greater mental health needs (Bal et al., 2021).

Chapter 6

Summary

Implications

This study contributes to the growing body of literature examining the impact of COVID-19 among adults on the autism spectrum by furthering our understanding of its impact on employment and mental health through their perspectives 20 months into the pandemic. Specifically, findings provide evidence for a prolonged negative impact on employment, such that participants continued to struggle with obtaining a permanent job almost two years into the pandemic, and were mostly in precarious employment situations, thus reflective of challenges frequently experienced by this population pre-pandemic. Critically, even with job coach support remaining accessible throughout the pandemic, participants continued to experience several challenges. Results therefore underscore the importance of understanding and addressing the specific needs of this population during difficult times to ensure they are not forgotten and receive the same opportunities as others. Results also speak to the importance of working closely with government and policymakers to develop workplace programs, supports and policies aimed at increasing successful employment outcomes among this population, especially during financial crises, when employment inequalities seem to be exacerbated among vulnerable populations. Participants' narratives also underscore the importance of having employment-related support accessible during these times; perhaps without the support of a job coach, participants' struggles would have been intensified. Regarding the actual workplace of individuals, the findings suggest that providing an inclusive, accommodating, and safe environment can increase job satisfaction among this population.

Importantly, the results also demonstrate a continuation of findings found early in the pandemic regarding mental health challenges among this population. In the long-term, adults on the autism spectrum continued to experience high rates of social isolation, hopelessness, and emotional distress, which gradually deteriorated with time. Interestingly, findings also suggest that while some may have been feeling fine during the initial stages of COVID-19, as the pandemic went on, it had greater deleterious effects, potentially even among those not previously affected. These results are especially important in the context of autism, given that this is a population that is already at risk of experiencing mental health conditions. Thus, the pandemic and its associated consequences added an additional layer of risk for adults on the autism spectrum, exacerbating pre-existing challenges. These findings call attention to the importance of developing autism-specific mental health interventions and supports targeting isolation, hopelessness, and distress. The findings also suggest that it may be important to continuously check-in with individuals throughout the pandemic, even if they seemed to be doing well earlier on. This is therefore valuable information for clinicians, counsellors and other professionals such as job coaches, who work directly with this population and can work to tailor their supports and services in a way that meets the specific mental health needs of this population throughout and beyond COVID-19.

This study also sheds light on potential protective factors, effective coping strategies and supports for this population throughout the pandemic and possibly other negative life events. Although research examining the association between employment and mental health among adults on the autism spectrum is scarce, the current findings provide evidence for the integral role employment plays in this population and the buffering effects it can have during challenging times. The potential mental health implications also provide further support and purpose for developing employment programs aimed at increasing positive outcomes among this population. Results also highlight the potentially protective role positive thinking may play among adults on the autism spectrum. This strategy can potentially be combined with mental health efforts to build resilience and reduce negative affect among this population. Additionally, the findings provide evidence for the effectiveness of social support and engagement with hobbies. This knowledge is important for stakeholders within the autism community, as it suggests that family may be central when developing and expanding social connections among this population and that spending time engaged in meaningful activities may serve as an active way of coping and improving well-being, especially during prolonged periods of stress and uncertainty. Findings also underscore the importance of having mental health supports available and accessible for adults on the autism spectrum and tailoring services to match the specific needs of the individual. Further, the results shed light on the diversified role job coaches may play when working with individuals on the autism spectrum, specifically in facilitating access to supports beyond employment-related and working as an intermediate between the client and service providers. Although it does not have to be a job coach specifically, findings suggest that having a point person assist people on the autism spectrum and potentially those with other conditions seek support and explain their needs would greatly benefit their experience and outcomes.

Limitations and Future Directions

Although this study provides a unique contribution to the literature on the longer-term effects of the pandemic among adults on the autism spectrum, certain limitations should be considered when interpreting the results. First, the small sample size recommended for interpretative phenomenological analysis (IPA) studies limit the application and generalization of findings, as the idiographic nature of IPA studies purposefully focus on the sense-making of a small number of cases (Smith et al., 2009). Second, transferability to other contexts or settings with similar populations is limited given COVID-19 government interventions different across countries. Experiences regarding employment and mental health may be different for those living in countries that took a more stringent or lenient approach. The current study was only preliminary in nature, thus future research in other geographical regions with larger samples is also needed to examine the longer-term impact of the pandemic among this population. Further, IPA acknowledges that there are limitations inherent in the double hermeneutic process; the researcher can never fully understand the inner world of another person and thus brings their own conceptions and beliefs to the process of interpretation (Smith, 1996; Chapman & Smith, 2002). This means that the same data analyzed by a different researcher with a different set of experiences and beliefs may have yielded a different analysis. Although bracketing was conducted by the researcher, there might still be bias present in the final analysis (Cronin-Davis et al., 2009). Additionally, the present study only included males, a common issue in autism research (Sohn, 2019), however it would be important for future studies to recruit a greater proportion of females, as there is research in the general population suggesting a distinct and potentially more severe impact of the pandemic among women (Lowe et al., 2022), and it would be important to examine whether the same trend is taking place among women on the autism spectrum. Lastly, reliability and validity testing were not performed on the two measures used in this study (i.e., the job satisfaction and satisfaction of employment support services questionnaires).

Despite these limitations, the study’s objective was to contribute to the growing body of knowledge about the impact of the pandemic on the employment and mental health of adults on the autism spectrum through a unique longer-term, first-person perspective. It is also important to note that although the sample size limits the generalizability of the study, this research is not designed to generalize to a large population and is rather focused on understanding the individual experiences of a small number of people and developing a body of research that is useful and meaningful in the eyes of the participants (Lincoln et al., 2011).

Conclusion

This study addresses calls for research on the longer-term effects of the pandemic among adults on the autism spectrum (Oomen et al., 2021; Taylor et al., 2021) and support concerns expressed by researchers regarding the vulnerability of this population during COVID-19 (Cassidy et al., 2020; den houting, 2020; Pellicano & Stears, 2020), particularly in the long-term. Taken together, the findings provide evidence for the long-lasting negative consequences of the pandemic on employment and mental health, with participants reporting a deterioration in well-being over time, and continued difficulty with obtaining a stable job, thus exacerbating existing inequalities among this population. However, results also shed light on resources, supports and coping strategies that can protect mental health and help adults on the autism spectrum overcome barriers during challenging and uncertain times. The findings outlined in this thesis mark an important contribution to the field, as it is the first to examine the longer-term impact of COVID-19 among adults on the autism spectrum through their perspectives and underscores the importance of developing specific supports and services to improve job success and well-being throughout the recovery of COVID-19 and beyond.

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Appendix A

Consent Form

School of
Communication Sciences
and Disorders

École des
sciences de la
communication humaine

SCSD

Formulaire d'information et de consentement

« Soutien d'un conseiller en emploi pour les personnes employées autistes ou présentant une déficience intellectuelle »

Visite de suivi virtuelle

Chercheuse principale
Aparna Nadig, PhD, professeure associée, École des sciences de la communication humaine, Université McGill

1. Introduction

La plupart des adultes souhaitent travailler pour avoir un revenu, rencontrer de nouvelles personnes ou apprendre de nouvelles choses.

Les adultes autistes ou ayant une déficience intellectuelle ont de la difficulté à trouver des emplois et à les garder. Seulement 1 sur 3 d'entre eux a un emploi ou s'en cherche un.

La pandémie risque de rendre les choses encore plus difficiles, car elle a considérablement affecté l'emploi et la santé mentale des adultes autistes et des personnes avec une déficience intellectuelle. Les restrictions ont également limité le soutien disponible, comme les conseillers en emploi, qui aident les personnes à trouver et à garder un emploi.

Vous avez déjà participé à une recherche avec nous et Action main-d'œuvre. Nous effectuons maintenant une visite de suivi optionnelle pour mieux connaître les expériences des adultes autistes et des personnes avec une déficience intellectuelle pendant la pandémie.

Nous voulons comprendre comment COVID-19 a affecté les adultes autistes et des personnes avec une déficience intellectuelle et leur santé mentale, et quels soutiens sont nécessaires pour les aider à réussir dans leur emploi et à avoir une meilleure santé mentale.

Ce que nous trouverons aidera les agences d'emploi, le gouvernement et les professionnels d'autres organisations à améliorer les services offerts aux personnes autistes ou aux personnes avec une déficience intellectuelle à travers et au-delà de COVID-19.

2. La recherche

La visite de suivi devrait durer environ une heure. Elle se fera de manière virtuelle (téléphone et Microsoft Forms). Lorsque vous rencontrerez la chercheuse, vous ferez une entrevue, et vous répondrez à 2 questionnaires s'ils s'appliquent à votre situation. L'audio de l'entrevue sera enregistré.

L'entretien concerne votre expérience de travail et votre santé mentale pendant la pandémie. Les deux questionnaires concernent votre satisfaction d'emploi (si vous avez/aviez un emploi) et votre satisfaction à propos des services d'Action main-d'œuvre (si vous recevez/receviez des services) **pendant la pandémie**.

3. Bénéfices

La recherche ne vous aidera pas personnellement. Elle peut aider d'autres personnes à comprendre les expériences des adultes autistes et des personnes avec une déficience intellectuelle pendant la pandémie et leurs besoins.

4. Risques et désavantages

Cette étude prendra environ une heure de votre temps.

Cette recherche pourrait affecter votre perception de votre emploi et votre employeur.

5. Droits du participant et mettre fin à votre participation

Vous pouvez poser toutes les questions que vous voulez avant de décider de participer ou non à la recherche.

Vous avez le choix de participer à la recherche ou de ne pas participer.

Si vous choisissez de participer, vous pouvez changer d'idée et arrêter de participer quand vous voulez. Cela ne changera rien aux services que vous recevez avec Action main-d'œuvre (si vous recevez des services).

Si vous arrêtez de participer, nous vous demanderons si nous pouvons utiliser les informations que vous nous avez données ou si vous voulez qu'on la supprime.

Si vous recevez des services d'Action main-d'œuvre, vous continuerez à recevoir des services si vous dites non à l'étude. Vous continuerez également à recevoir des services d'Action main-d'œuvre si vous dites oui à l'étude.

6. Compensation

Vous recevrez une carte-cadeau de $25 après avoir complété la recherche.

La chercheuse vous enverra la carte cadeau par courriel.

7. Confidentialité

Toutes les informations, l'enregistrement audio et toutes les réponses que vous donnerez au chercheur seront privées et confidentielles.

Votre nom sera remplacé par un numéro pour protéger vos informations. Les chercheurs de notre équipe seront les seuls qui vont connaître vos informations. Vos informations seront gardées 7 ans et détruites par la suite.

Les informations que vous nous données seront conservées dans un classeur verrouillé à l'Université McGill et dans des fichiers protégés sur ordinateur. Notre équipe de recherche aura accès à ces informations.

Les chercheurs partageront les résultats de la recherche dans des conférences et des rapports de recherche. Nous n'utiliserons pas votre nom ou vos informations personnelles. Personne ne sera capable de savoir que vous avez participé à la recherche.

8. Contact

Si vous voulez plus d'information, vous pouvez contacter **Dre. Nadig**:

Dre. Aparna Nadig

Téléphone: 514-398-4141
Courriel: aparna.nadig@mcgill.ca

Si vous avez des questions sur vos droits comme participant, vous pouvez contacter l'administratrice en éthique **Ilde Lepore:**

Mme Ilde Lepore
Comité de révision institutionnel de l'Université McGill
Téléphone: (514) 398-8302
Courriel: ilde.lepore@mcgill.ca

9. Consentement à participer

On m'a expliqué la recherche. Je suis content des réponses à mes questions. On m'a donné une copie électronique de ce formulaire.

J'accepte de participer à la recherche et d'être enregistré pendant l'entrevue. Je ne renonce à aucun de mes droits en signant ce formulaire.

Indiquer mon nom ci-dessous représente ma signature officielle et montre que j'accepte de participer.

Nom du participant ou de la participante: ______________________________

Date:____________________

Nom du chercheur ou de la chercheuse: ______________________________
Date:____________________

10. Consentement à être contacté pour une autre recherche

Dans l'avenir, nous pourrions faire d'autres projets en lien avec celui-ci ou sur d'autres sujets.

☐ Je souhaite être contacté au sujet de recherches de suivi liées au présent projet

☐ Je souhaite être contacté au sujet de recherches futures dans lesquelles je pourrais participer

☐ Je ne souhaite pas être contacté pour des recherches futures ou e suivi

Appendix B

Job Satisfaction Questionnaire

For each item, select the box that corresponds to your answer.

1 (Completely disagree); 3 (Neither agree nor disagree); 5 (Completely agree)

1. My job is satisfying.
2. My job is interesting.
3. My job is enjoyable.
4. My job is useful.
5. My job is challenging.
6. My job is tiring.
7. My job is frustrating.
8. I am happy with my job.
9. I wish I could leave my job.
10. I am grateful for my job.
11. I am satisfied with my salary.
12. I am satisfied with the number of hours I work per week.
13. I have a good relationship with my supervisor.
14. I have a good relationship with most of my colleagues.

Appendix C

Satisfaction of Employment Support Services Questionnaire

For each item, select the box that corresponds to your answer.

1 (Completely dissatisfied); 3 (Neither satisfied nor dissatisfied); 5 (Completely satisfied)

1. During COVID-19, I am satisfied with the support received by the counselor while searching for a job.
2. During COVID-19, I am satisfied with the support received by the counselor after I started my new job.
3. During COVID-19, I am satisfied with Action main d'oeuvre in general.
4. I would recommend the services of Action main d'oeuvre to people on the autism spectrum who are searching for a job.

Appendix D

Follow-up Virtual Interview Protocol

1. Tell me about how you were doing before COVID-19 began. Were you working? How was your job going? How were you feeling?
2. (If applicable) What changes occurred at your workplace during COVID-19 (e.g., closed, transitioned to online format, reduced personnel)?
3. Have there been any changes to your job since the pandemic began (e.g., work hours, employment status)?
4. How did the changes in your workplace and with your job affect your mental health? how did these changes make you feel?
5. How did COVID-19 in general affect your mental health?
6. What were the disadvantages that you experienced from changes in your employment and/or mental health? Were there any advantages that came from these changes?
7. Did you seek any support to help you cope with these changes during the pandemic? What help did you seek and was it beneficial?