

**THE LIVED EXPERIENCE OF FETAL ALCOHOL SPECTRUM DISORDER (FASD)
SUPPORT WORKERS THROUGH THE COVID-19 PANDEMIC**

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ABSTRACT

This phenomenological study explores the lived experience of support workers who have worked with clients with Fetal Alcohol Spectrum Disorder (FASD) during the COVID-19 pandemic. Through in-depth interviews with five support workers, the study aims to understand the extent to which working during the pandemic has impacted the support workers' experiences and their relationships with clients. The findings reveal that the pandemic brought numerous challenges, including the need for constant adaptation, limited ability to provide necessary support, and disruptions in routine and resources. Participants identified building rapport and trust as crucial aspects of successful relationships with their clients. The pandemic presented barriers to building trust with new clients, but pre-existing rapport mitigated some of these challenges. Clients with FASD experienced negative impacts on their well-being, including increased substance use, limited access to resources, and difficulties in maintaining self-care. Support workers faced unique challenges in advocating for the FASD population during the pandemic, stemming from limited knowledge and training on FASD, as well as disruptions in service provision and communication. Effective communication strategies and person-centered approaches were identified as essential in supporting clients with FASD. Support workers also faced significant mental health challenges, mirroring those experienced by other healthcare workers during the pandemic. This study contributes to the understanding of the experiences of support workers and clients with FASD during times of societal upheaval. The findings highlight the need for targeted interventions, enhanced training, and support systems to address the unique needs of this population. Practical implications include the importance of day-to-day adaptive strategies, fostering trust and rapport, effective communication, and supporting the mental well-

being of support workers. Further research should explore long-term effects, evaluate interventions, and examine the experiences of clients with FASD themselves.

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Chapter 1: Introduction

The aim of this thesis is to explore the lived experience of support workers who assist clients with Fetal Alcohol Spectrum Disorder (FASD) during the COVID-19 pandemic. The study also investigates the potential impact of the pandemic on the relationships between support workers and their clients.

FASD is characterized by neurodevelopmental impairments resulting from prenatal alcohol exposure, including deficits in adaptive function, executive function, motor function, social cognition, verbal and nonverbal learning, and externalizing behaviours (Lange et al., 2019; Gelb & Rutman, 2011).

FASD is a lifelong disorder with varying degrees of severity, and it represents the leading known cause of preventable developmental disability in Canada (Public Health Agency of Canada, 2017). However, the actual prevalence of FASD remains uncertain due to challenges in diagnosis and under-detection (Public Health Agency of Canada, 2017; Burd, 2016). Estimates suggest a prevalence rate of 4% in the general Canadian population, with higher rates expected in specific groups (Flannigan et al., 2018). The social and economic impacts of FASD on families and the broader community are significant, underscoring the importance of understanding the scope of the issue (Flannigan et al., 2018).

While FASD prevention has received considerable attention in research, there is a notable gap in literature regarding support for adults living with FASD (Vincent et al., 2014). Evidence-based practices for the treatment of FASD in adults are limited, yet some interventions, strategies, and therapies implemented by support workers have shown positive outcomes (Bagley & Badry, 2019). The lack of formal diagnoses and recommended support plans for adults with FASD presents challenges for support workers, who may require specialized knowledge,

experience, and dedicated staff to cater to the unique needs of individuals with FASD (Bagley & Badry, 2019). Furthermore, the availability of resources, supports, and outreach for adults with FASD is already limited and may be further constrained during periods of economic and societal distress.

Statement of Purpose

Given the scarcity of literature exploring the intersection of FASD and support workers during the COVID-19 pandemic, further understanding of how support workers can effectively assist clients with FASD during time of societal upheaval is needed. The primary objective of this phenomenological research study is to illuminate the lived experience of support workers who provide care and support to adults with FASD throughout the COVID-19 pandemic.

Research Questions

This study aims to address the following research questions:

- *What is the lived experience of support workers who have worked with clients with FASD during the COVID-19 pandemic?*
- *To what extent has working during the COVID-19 pandemic affected the experience of support workers and their relationships with their clients?*

Significance/Importance

This study holds significant value as it explores the lived experience of support workers during the COVID-19 pandemic in relation to their clients with FASD. Through the identification and interpretation of common themes derived from participant responses, the study aims to generate knowledge and enhance clarity surrounding the lived experience of support workers during this challenging period. Phenomenological research provides insights in the specific needs of support workers within their organizational contexts, facilitating a better understanding of

appropriate response procedures when advocating for clients with FASD during times of societal distress.

Theoretical Model

Phenomenology, deeply rooted in philosophy, provides the framework for this research study. Phenomenology draws extensively from the works of Edmund Husserl and other philosophers like Heidegger, Sartre, and Merleau-Ponty (Smith, 2013). Central to phenomenology is the exploration of consciousness, the context of conscious experience, and the embodied nature of human beings (Connelly, 2010). It focuses on understanding the lived experience, including judgments, perceptions, and emotions, as it is directly experienced by the individual (Connelly, 2010). Phenomenology recognizes that every act of consciousness contains both object and subjective aspects. In line with the purpose of this study, providing access to the experiential worlds of human beings (McPhail, 1995). Additionally, phenomenology acknowledges the embodiment of human existence, emphasizing that individuals experience life through their physical bodies (Connelly, 2010). Its aim is to delve into the firsthand experience of individuals, capturing not only their reactions but also the essence of lived experience itself (Connelly, 2010).

In line with the study, a phenomenological research methodology will be employed to answer the research questions. Phenomenology involves defining a phenomenon, known as lived experience, and exploring the common meaning of the phenomenon across individuals. Phenomenology focuses on identifying shared themes and patterns across participants and examines phenomena as they are presented in an individual's direct awareness and experience, studying their authentic recall of those experienced (Creswell, 2017). For this research study, the

phenomenon under investigation is the lived experience of support workers assisting clients with FASD during the COVID-19 pandemic.

Specifically, a transcendental phenomenological lens will be applied, characterized by bracketing or setting aside preconceived ideas and beliefs to allow the true meaning of the phenomenon to naturally emerge (Creswell, 2017; Moustakas, 1994). By employing bracketing, I aimed to adopt a non-judgmental perspective that does not impede the participants' perception of the phenomenon.

Data collection in phenomenology commonly involves interviews (Creswell, 2017). In this study, semi-structured interviews were utilized to gather in-depth responses from support workers regarding the impact of the COVID-19 pandemic on their work with clients with FASD. The interview process is seen as a privileged opportunity to engage with participants, gaining profound insights into their experiences. The focus of the interviews will be on understanding the participants' personal meanings and interpretations of their experiences. By conducting detailed, semi-structured interviews, I aimed to elicit clarity, meaning, and deep insights into the lived experience of the participants.

Definition of Research Terms

FASD

According to the Centers for Disease Control (2022), FASD encompasses various issues, including central nervous system (CNS) problems, facial deformities, growth problems, learning difficulties, memory impairments, attention span challenges, communication issues, and sensory impairments. Individuals with FASD may also exhibit intellectual disabilities, behavioural problems, poor academic performance, and difficulties with math, memory, attention, judgment, and impulse control. For this research study, participants are eligible if they work with clients

suspected to have FASD, even if these clients have not received an official diagnosis due to the limitations in diagnostic capacity.

Support Worker

In the context of this research study, a support worker is defined as any professional closely involved in working with clients with FASD. This includes individuals with job titles such as social worker, case worker, mental health worker, crisis response worker, addictions worker, outreach worker, and shelter worker. The term encompasses professionals from various non-profit and outreach organizations who play a crucial role in supporting individual with FASD.

By conducting this research, an understanding of the lived experience of support workers during the COVID-19 pandemic can be achieved. The findings will contribute to knowledge about the challenges, experiences, and needs of support workers in their interactions with clients with FASD. Furthermore, the interpretation of themes emerging from participant responses will offer valuable insights into the support workers' perspectives, aiding in the development of effective strategies and response procedures for supporting clients with FASD during times of societal distress.

In summary, this thesis aims to shed light on the lived experience of support workers who assist adults with FASD during the COVID-19 pandemic. Through a qualitative, phenomenological research methodology, the study seeks to uncover the essence of the support workers' experiences and explore the potential impact of the pandemic on their relationships with clients. By delving into their perceptions and meanings, this research contributes to a deeper understanding of the challenges faced by support workers and provides valuable insights for enhancing support services in times of societal upheaval.

Chapter 2: Literature Review

Individuals with FASD are a marginalized population, and the COVID-19 pandemic has further exacerbated their marginalization. However, limited literature exists to explore the specific relationship between clients with FASD and support workers during times of societal difficulties. Understanding what constitutes a successful relationship between clients with FASD and support workers, and how support workers can better advocate for this population during pandemics and similar future events, is crucial.

The literature examining the detrimental effects of the COVID-19 pandemic on alcohol consumption provides valuable insights into the potential risks faced by individuals with FASD. A study conducted by Finlay and Gilmore (2020) reveals a significant increase in alcohol sales during the pandemic, shedding light on the concerning trend of heightened alcohol consumption. The surge in alcohol use raises concerns about its implications, particularly for vulnerable populations. The authors predict potential rises in domestic violence and an increased number of babies born with FASD as a result of the increased alcohol consumption during the pandemic. Sher (2020) emphasizes the urgent need to address the discussion around FASD prevention and its often permanent effects, which have been largely ignored in the broader context of lowering alcohol consumption. The heightened risk of FASD during the pandemic calls for increased attention and proactive measures to protect individuals from the potential harms associated with alcohol use. Additionally, Ghosh and Sharma (2021) highlight the disruption of screening and intervention for substance use disorders as a result of the pandemic, which further compounds the challenges faced by individuals with FASD seeking help in this regard. The limited access to resources and support during the pandemic poses significant barriers for individuals with FASD in receiving the necessary interventions and assistance for managing substance use disorders.

Understanding the complex interplay between the pandemic, alcohol consumption, and the risks faced by individuals with FASD is crucial for developing targeted strategies, intervention, and support systems to mitigate these risks and provide the necessary support for individuals with FASD during times of societal upheaval.

Support workers often describe their relationships with clients with FASD as a dynamic interplay of challenges and rewards. While they recognize the inherent difficulties in working with individuals with FASD, they also acknowledge the profound satisfaction that comes from making a positive difference in their clients' lives. However, these dedicated professionals face various challenges in effectively advocating for the FASD population. One notable challenge is the limited knowledge of FASD and its exclusion from training, support, and diagnostic contexts, which leaves support workers ill-equipped to fully understand and address the unique needs and complexities of their clients (Bagley & Badry, 2019). This knowledge gap hinders their ability to provide tailored support and appropriate interventions. Despite these challenges, support workers can have a transformative impact on the worker-client relationship by embracing anti-discriminatory and rights-based approaches (Bagley & Badry, 2019). By recognizing the inherent dignity and worth of their clients, support workers can create an inclusive and empowering environment that fosters the development of client independence and self-advocacy (Bagley & Badry, 2019). Moreover, demonstrating genuine concern and a compassionate understanding of their clients' experiences further strengthens the bond and the trust between support workers and individuals with FASD. These responsive and person-centered approaches are shown to have a positive and lasting impact on the worker-client relationship, promoting better outcomes for individuals with FASD and improving their overall well-being.

Effective communication plays a pivotal role in fostering a successful worker-client relationship, particularly when working with individuals with FASD who encounter difficulties in various aspects of communication. Individuals with FASD often struggle with auditory processing, information processing, expressive language, and interpreting social cues (Melrose, 2019). Recognizing these challenges, support workers can employ strategies to facilitate effective communication. Encouraging clients to reiterate the information they have heard in their own words promotes active engagement and comprehension, allowing for clarification and ensuring accurate understanding of important details (Melrose, 2019). Additionally, using simple and concrete language whenever possible can enhance comprehension and reduce confusion for individuals with FASD, who may have difficulty grasping abstract concepts or complex language structures (Melrose, 2019). By implementing these communication strategies, support workers can create a conducive environment for effective information exchange, enabling clients with FASD to express themselves more confidently and fostering a stronger worker-client connection.

The successful relationship between a support worker and a client with FASD hinges on a variety of elements. The worker must demonstrate understanding and acceptance of FASD and its implications, as this fosters trust and respect within the relationship. Their acknowledgement of the client's limitations and unique capabilities without judgment is crucial to this understanding (Green, 2007). Additionally, the support worker must provide consistent and structured assistance. This is because clients with FASD often thrive in environments that offer routine and predictability. The relationship can thus be enhanced through consistent communication, the setting of clear expectations, and the provision of structured support (Stade et al., 2011). Communication is another significant factor to this dynamic. The support worker

should communicate clearly and simply, utilizing visual aids, repetition, and checking for understanding, as clients with FASD can struggle with complex instructions or abstract concepts (Brown et al., 2007).

Patience, Compassion, and Trust

Patience, compassion, and trust are also key, given that clients with FASD may exhibit behaviours that are challenging and unpredictable. The support worker must effectively manage their emotions and reactions while demonstrating understanding and compassion (Denys et al., 2011). According to Denys et al. (2009), this trust becomes pivotal when implementing programs and interventions for clients with FASD. Accumulated feedback from these clients underscores that the success of social and independence programs is intertwined with the security, stability, and trust they experience within the relationship with their worker. This sense of trust extends beyond the mere act of providing support, enabling clients to fully engage and actively participate in these programs. Empowering the client is another important element to this relationship. The support worker can focus on the client's strengths, celebrate small victories, and encourage decision-making within the client's abilities, which can enhance the client's self-esteem and motivation (Kapasi, n.d.). Finally, the relationship should involve collaboration with other individuals such as family members, healthcare professionals, and educators. This helps ensure a comprehensive support system for the client and contributes to the success of the relationship (Fast & Conry, 2009). Thus, the support worker's role is not only to assist the client but to foster an environment where trust becomes the bedrock of the relationship. This is achieved through an understanding and acceptance of FASD and its implications, a consistent and structured approach to support, clear and simplified communication, patience and compassion, and a focus on the empowerment and collaboration with other individuals. By

building trust, clients with FASD are encouraged to engage in programs and interventions effectively, facilitating their journey towards independence and social integration (Denys et al., 2011).

Notably, the COVID-19 pandemic has likely had a significant impact on the well-being of support workers, mirroring the challenges faced by healthcare workers. Extensive research by Tella et al. (2020) and Kim et al. (2021) highlights the increased rates of depression, anxiety, burnout, and mental health issues among healthcare workers during the pandemic. These findings can be generalized to support workers, who often work closely with high-risk COVID-19 clients. The demanding nature of their roles, combined with the uncertainties and heightened stress brought about by the pandemic, have put support workers in an increased risk of experiencing similar psychological challenges. The unique circumstances, such as the need for enhanced infection control measures, increased workload, and emotional strain of supporting vulnerable individuals during a global crisis, have undoubtedly taken a toll on the well-being of support workers. Recognizing and addressing the mental health needs of support workers is crucial for ensuring their resilience, effectiveness, and overall well-being in providing vital support to clients with FASD during times of societal upheaval. Implementing strategies for self-care, access to mental health resources, and organizational support systems can help alleviate the burden and promote the well-being of support workers in the face of these unprecedented challenges.

Furthermore, it is important to recognize that individuals with FASD and their support workers face unique challenges and vulnerabilities during times of societal upheaval, such as the COVID-19 pandemic. Historical evidence indicates that individuals with mental health issues and cognitive impairments have been disproportionately affected by various crises, including

natural disasters, economic collapses, and pandemics (Makwana, 2019). These vulnerable populations often experience increased difficulties accessing necessary resources, support systems, and healthcare services, exacerbating their existing challenges.

Specifically, individuals with FASD, who already face numerous social and cognitive impairments, are at heightened risk during times of societal distress. The COVID-19 pandemic has brought to the forefront the significant impact of homelessness on individuals with FASD, as they are more likely to experience homelessness due to the intersection of various factors, such as limited resources, poor social networks, and difficulties in maintaining stable employment (Badry et al., 2015). Homeless shelters, which are critical in providing temporary refuge and support to individuals experiencing homelessness, have faced substantial challenges in adapting their services to comply with the public health guidelines and ensure the safety of both staff and clients.

Support workers, who play a vital role in advocating for clients with FASD, encounter additional complexities and risks in their efforts to provide assistance during the pandemic. The close proximity and direct contact with high-risk individuals pose potential health risks for support workers themselves, who may face increased exposure to infectious diseases like COVID-19 (Kar et al., 2020). Moreover, the disruption of regular support services, limited availability of resources, and strain on healthcare systems further hinder the ability of support workers to effectively address the unique needs and challenges faced by clients with FASD.

It is crucial to understand these contextual factors and their impact on the worker-client relationship. By examining the experiences of support workers during times of societal upheaval, including the challenges they face and the strategies they employ, valuable insights can be gained into how to better support both the workers and their clients with FASD in such

challenging circumstances. This knowledge can inform the development of targeted interventions, policies, and support systems that promote resilience, enhance advocacy efforts, and foster improved outcomes for individuals with FASD during crises and similar future events.

Synthesis of the Literature

Existing literature discusses the unique relationship between support workers and clients with FASD, particularly focusing on the challenges and rewards inherent to this dynamic. An escalating concern apparent in the literature is the increase in substance use, particularly alcohol, during societal upheavals such as the COVID-19 pandemic. This increase could lead to more cases of FASD among the population. Moreover, there is evidence to suggest a surge in homelessness rates amidst such crises, thereby exacerbating the vulnerability of this population.

However, what the existing body of knowledge conspicuously lacks is a focused exploration into the specific impact of crises like the COVID-19 pandemic on the dynamics between support workers and their clients with FASD. Despite understanding the general pressures the pandemic has exerted on individuals and communities worldwide, we know relatively little about its distinct repercussions on the worker-client relationship within the FASD context. More precisely, we lack understanding of how these external stresses influence support workers' ability to successfully navigate and maintain these relationships and how these relationships in turn affect the well-being and outcomes of individuals with FASD.

This thesis, therefore, sets out to investigate this unexplored domain. It aims to shed light on how the COVID-19 pandemic, as a specific example of societal upheaval, has influenced the relationship between support workers and their clients with FASD.

Summary

In summary, this literature review underscores the urgent need for research that delves into the experiences of the COVID-19 pandemic on support workers and their clients with FASD, as well as the factors that contribute to a successful worker-client relationship during times of societal upheaval. The available evidence highlights the detrimental effects of the pandemic on individuals with FASD, exacerbating their already marginalized status. Increased alcohol consumption during the pandemic raises concerns about potential rises in FASD rates and the need for targeted prevention efforts.

Support workers face unique challenges in advocating for clients with FASD, including limited knowledge and training on FASD, as well as insufficient resources and diagnostic support. However, effective responses such as anti-discriminatory practices and a rights-based approach have been shown to positively impact the worker-clients relationship. Intentional and clear communication strategies are crucial for effective interactions with clients, considering their cognitive impairments and communication difficulties.

Moreover, the pandemic poses additional hardships for support workers, with increased rates of depression, anxiety, burnout, and mental health issues observed among healthcare workers, which can be extrapolated to support workers. The intersecting vulnerabilities of individuals with FASD and homelessness further complicate the support workers role as homeless shelters, an important support avenue, face their own challenges in providing adequate care and protection during the pandemic.

This review emphasizes the pressing need for further research to better understand the specific impacts of the COVID-19 pandemic on support workers and clients with FASD. By investigating the experiences and perspectives of support workers during times of societal

distress, valuable insights can be gained to inform the development of targeted interventions, policies, and support systems. These efforts aim to enhance resilience, strengthen advocacy efforts, and ultimately improve outcomes for individuals with FASD, both during crises and in similar future events. Such knowledge is vital for addressing the unique needs of this marginalized population and ensuring their well-being and inclusion in times of societal upheaval.

Chapter 3: Methodology

Research Design

This research uses a phenomenological approach, which is used in health science research, and emphasizes detailed phenomenological descriptions. The goal of these descriptions is to produce effective imagery as to allow others to share in how a particular phenomenon is experienced (O’Leary, 2021). The intent of the research design is to utilize data collection and analysis of themes to develop a visual experience of the said phenomenon. The proposed research design will incorporate multiple participant perspectives and the classification and interpretation of identified themes. The phenomenological methodology operates on the assumption that participants have unique experiences and opinions, and as a result it becomes my role to collect and classify multiple perspectives into the development of themes and to then in turn interpret those themes (O’Leary, 2021). Moreover, the intent of phenomenology is that the sorting and classification of themes among participant responses is key to the analysis process (O’Leary, 2021). The purpose of this research study is to examine the lived experience of support workers aiding individuals with FASD during the pandemic. As a result, the phenomenology research design is necessary in terms of emphasizing the importance of identifying themes among participant responses regarding the study topic.

According to Moustakas (1994), the phenomenological research design incorporates the following four steps:

Bracketing

Bracketing, a crucial process in phenomenological research, involves identifying and setting aside preconceived beliefs and opinions about the phenomenon under investigation. This

process, crucial for confronting the data in its purest form, was initiated before conducting interviews and involved a four-step approach:

A. Self-Reflection

My journey began with deep self-reflection to identify and become aware of my own preconceptions, biases and experiences related to the phenomenon. This entailed introspection about my background as a support worker at Turning Leaf Services and my experiences during the pandemic, ensuring that my pre-existing knowledge or assumptions were recognized.

B. Acknowledgement and Setting Aside Preconceptions

In this crucial step, I consciously acknowledged and set aside these preconceptions and biases. This required a strong commitment to openness, ensuring receptiveness to the diverse experiences and perspectives of the participants.

C. Maintaining a Phenomenological Attitude

I consistently adopted a phenomenological attitude throughout the study, focusing on the participants' experiences without imposing my interpretations. This approach demanded diligence, particularly in analyzing the transcripts, to capture the true essence of the participants' experiences.

D. Reflexivity and Reflection

Ongoing reflexivity and reflection were integral to critically examining my own assumptions and reactions. This ongoing process was key to ensuring that my biases and perspectives did not unduly influence the findings.

Through these steps, I strived to minimize the impact of my biases, allowing the participants' lived experiences to emerge authentically within the phenomenological inquiry.

The following is an excerpt capturing my personal experience and reflections on the phenomenon being studied:

Throughout the COVID-19 pandemic, working as a community support worker for clients with Fetal Alcohol Spectrum Disorder (FASD) at Turning Leaf Services has been a multifaceted experience that brought both challenges and rewards. The uncertainties and restrictions imposed by the pandemic highlighted the unique difficulties faced by individuals with FASD in adapting to the new circumstances. The sudden disruptions in routines, changes in service provision, and the shift to virtual interactions posed significant barriers for our clients.

As a support worker, witnessing resilience and determination of individuals with FASD in navigating these challenges has been truly inspiring. Despite the upheaval and uncertainty, they demonstrated remarkable strength in finding ways to cope and adjust.

As their support worker, my role extended far beyond the provision of practical assistance. It involved a holistic approach that focused on fostering emotional well-being, promoting self-regulation strategies, and helping them maintain connections in a socially isolated world. This experience underscored the importance of tailored support.

Understanding the specific needs of clients arising from their condition became even more evident. Each interaction deepened my appreciation for the immense strength and resilience exhibited by individuals with FASD in the face of adversity. It emphasized the significance of person-centered care and the need to address the unique challenges they encountered during the pandemic. Being part of their journey during this unprecedented time provided a profound sense of fulfillment as I witnessed their growth, adaptability, and independence. The experiences shared by clients with FASD during the pandemic

served as a constant reminder of the importance of advocating for their rights, providing empathetic support, and working collaboratively to enhance their well-being and quality of life. Overall, the role of a community support worker during the COVID-19 pandemic demanded flexibility, creativity, and a deep understanding of the complex needs of individuals with FASD. The collective resilience demonstrated by both clients and support workers exemplified the strength of human spirit and the power of compassionate care in times of adversity.

Intuiting

After bracketing is complete, I now remain focused on the attributed meaning of the phenomenon (Greening, 2019). Through this process, a shared understanding of a phenomenon is achieved. To ensure the accuracy of this process, I will furnish the participant with their transcript for review. This allows for the opportunity to confirm that all the information has been correctly interpreted and understood.

Analyzing

The process of analyzing consists of coding, where categorizing and making sense of the significant meanings of the phenomenon is created (Greening, 2019). Persistent working with the data leads to the emergence of universal themes (Greening, 2019). Here, I will immerse myself for as long as possible for attaining a thorough description of the phenomenon (Greening, 2019).

Describing

The descriptive process is where comprehension and definition of the phenomenon are done by the researcher (Greening, 2019). This step offers distinctions and critical descriptions in both written and verbal form (Greening, 2019).

Population and Sample

The proposed research study aimed to interview approximately 12 participants employed as frontline workers at Turning Leaf Services, New Directions, and Life's Journey in Winnipeg, Manitoba.

Sampling Method

The sampling method for this study is based on purposive, convenience and criterion sampling. Purposive sampling (also known as judgment or selective sampling) is a sampling technique in which I will rely on his or her own judgment when choosing members of the population to participate in the study (Business Research Methodology, 2010). Purposive sampling is a non-probability sampling method, and it occurs when I hand pick the participants based on his/her own judgment (Business Research Methodology, 2010). Moreover, the sampling method is built upon homogenous sampling, which focuses on one subgroup in which all the sample members are similar (Business Research Methodology, 2010). In the case of this research study, the sample members are similar in occupation and in the clients that they support. Criterion sampling involves the identification of a particular criterion of importance and the articulation of this said criterion. For the proposed study, the two criteria employed is that the participant has worked during the COVID-19 pandemic and that they have supported individuals with FASD during that period. Experiencing work during the pandemic is pivotal because the pandemic has been a unique and significant event impacting lives globally. By focusing on individuals who have worked during this period, participants selected have looked through a specific, impactful experience. This aligns with phenomenology's emphasis on understanding the essence of experiences as they are lived. Moreover, Fetal Alcohol Spectrum Disorders (FASD) present unique challenges and experiences, both for those with the condition and those

supporting them. By selecting participants who have supported individuals with FASD during the pandemic, a specific lived experience is targeted that is rich in emotional, physical, psychological, and practical complexities. This criterion ensures that the study delves into a deep, contextual understanding of these experiences.

Recruitment Strategies

Initially, the population of interest were support workers employed at Turning Leaf Services, New Directions, and Life's Journey. These organizations support and advocate for independent living among their adult clients with mental illness, addiction, and developmental disabilities. I acknowledge that employees at each agency may have different job titles while the essence of their jobs are similar. Recruitment methods consisted of an email addressed to the human resource department of each agency. When the agency was interested in participating in the study, the agency would contact their employees directly. This correspondence described the study and the expectations of the participants. To ensure confidentiality, participants who are interested emailed myself directly. Participants were selected based on their response to the email, if they meet the criteria for selection and on a first-come first-served basis. After two weeks, if the sample size is not met, a second email was sent to prompt the support worker's consideration for the study.

During the recruitment process, I had to modify my approach to successfully engage participants for the study. Initial emails to the agencies went unanswered, which prompted me to call each agency directly. I left a voicemail at each agency, outlining the study's purpose. This procedure was repeated three times with each agency, yet it yielded limited success. Looking for additional opportunities, I extended the search to Avis's Place, located in Brandon, Manitoba. Although the agency responded positively and an interview was scheduled with a staff member,

the individual ultimately decided to withdraw from the study. Additionally, I contacted Touchstone FASD Program, located in Winnipeg, Manitoba. The agency responded positively but I was unable to recruit an individual for the study due to lack of response. Of the five agencies initially contacted, only Turning Leaf Services contributed to the study. Unfortunately, I was unable to establish contact with New Directions or Life's Journey.

The successful recruitment of participants from Turning Leaf Services was achieved through a strategic, multi-tiered communication approach. Initially, the Human Resources department played a pivotal role. They acted as a bridge between my research and the potential participants by directly reaching out to case managers within the organization. This proactive engagement by Human Resources was critical in garnering initial interest.

The case managers, in turn, utilized the organization's internal communication networks to further the reach. They leveraged the convenience and immediacy of WhatsApp group chats, a platform where support workers were already actively engaged. This method proved to be highly effective. The group chat served as an interactive forum, fostering a sense of community and immediacy, which is often missing in traditional email communications.

As participants expressed their interest in the study through these chats, the case managers then guided them to the next step. They provided clear instructions for the interested support workers to contact me directly. This personal touch, coupled with the endorsement from their managers, likely contributed to the higher engagement and trust levels, facilitating a smoother recruitment process.

This layered approach, initiating from the Human Resources department to the case managers, and finally to the support workers through a familiar and accessible platform like WhatsApp, not only enhanced the efficiency of the recruitment process but also ensured a higher

degree of comfort and willingness among the potential participants to be involved in the study. It exemplifies a successful recruitment strategy that aligns with the communication preferences and organizational culture of the participants.

I purchased five Tim Horton's E-gift cards valued at \$10.00 each as an incentive for the participants of the study. The gift cards were sent to the participants via email upon completion of the interviews.

Procedures

Before data collection commenced, I was granted approval by the Health Research Ethics Board (HREB) at the University of Alberta. After ethical approval, Turning Leaf Services, New Directions, Life's Journey, Avis's Place, and Touchstone FASD Program were approached via an introductory email explaining the research study's premise. Agencies willing to participate received a detailed schedule outlining the anticipated timeline for interviews. I strived to complete the interviews within three weeks of the initial request, ensuring flexibility to accommodate participants' work schedules with due permission from management. I was prepared to address any questions or concerns the agencies might have regarding the study, and direct contact information was shared. Upon distributing the information letters to the agencies, the primary inquiry received was regarding the duration and scheduling of the interviews. I clarified that interviews will be individually arranged with each participant and are expected to last approximately 45 minutes to an hour.

The research study required informed verbal consent, given that the interviews were conducted online over Zoom. Before each interview, I ensured to obtain this verbal consent, recorded via Otter.ai software. This approach was deemed most feasible for online interviews or

focus groups (Best Practices for Working Remotely, 2020). Previous qualitative studies also used Otter.ai as a tool for data analysis and transcription assistance (Galarneau, et al. 2021).

Participants were initially contacted via email to determine their eligibility for the research study based on the established criteria. Once eligibility was confirmed, interview dates were scheduled with each potential participant. Various measures were taken to protect their confidentiality, including assigning pseudonyms to each participant, and using those names in all written texts.

Before the interview began, participants were asked for their verbal consent to be audio recorded, and this consent was captured through recording. Furthermore, participants were provided with a transcript of the interview. I conducted 'member checking', which is a procedure where I return to the participants to confirm the credibility of the data and interpretations. This step ensures that the findings accurately reflect the participants' perspectives and experiences (O'Leary, 2021).

Interview questions were focused on how the pandemic played a role in the participants' relationships with their clients. The interviews aimed to explore, clarify, and expand upon the lived experiences of the participants. For example, 'What aspects of your relationship with your client were impacted by the pandemic?'

The interview process commenced by asking participants about their experiences of working during the pandemic. Subsequently, participants were asked if the pandemic had impacted their ability to support clients with FASD, and if so, how. Participants were further queried about their relationships with their clients, identifying aspects they deemed successful, and noting any observed changes in their clients during the pandemic. Additionally, participants were invited to share strategies they employed to mitigate pandemic-related disruptions and were

asked to provide examples of challenges they encountered and how they overcame them. Each interview took place in a comfortable environment for the participant and lasted between 50 minutes to 1.25 hours. I documented with notes during the interview process. My notes focused on highlighting specific words or phrases emphasized by the participant, as well as capturing phrases or quotes that stood out as significant, ensuring these elements were not overlooked in the actual transcription. An empathetic and non-judgmental approach was employed throughout the interviews to gain deeper insights into their experiences of the phenomenon.

Throughout the interview process, I maintained a personal journal to record my own experiences and reflections. These reflections, alongside the interactions with the participants, played a crucial role in deepening the understanding and development of themes.

Interviews were transcribed using Otter.ai software, with myself taking responsibility for reviewing and analyzing the transcription notes from each interview, under my supervisor's direction who also had access to the data. After the interviews were meticulously transcribed, I initiated an in-depth 'member checking' process to fortify the credibility and validity of the research. This critical phase involved reaching out to each participant individually with a copy of their interview transcript. The purpose was twofold: to verify the accuracy of the transcription and to ensure that their conveyed experiences and perspectives were authentically represented. During this phase, participants were encouraged to thoroughly review their transcripts and provide feedback. This feedback could range from confirming the accuracy of the content to offering additional insights or clarifying certain points that might have been misinterpreted or not fully captured during the initial interview. The participants' active involvement in this stage was crucial for maintaining the integrity of the research. To facilitate an open and honest review process, I emphasized the importance of their contributions in refining the data. I assured them

that their feedback would not only enrich the study but also contribute significantly to its authenticity. This collaborative approach allowed the participants to feel more connected to the research and assured that their voices were being accurately and respectfully represented. Once the feedback was collected, I meticulously integrated it into the analysis. This iterative process ensured that the interpretations and conclusions drawn were not solely based on my perspective as a researcher but were deeply rooted in the participants' lived experiences. The participants' inputs during member checking sometimes led to the refinement of themes and even to the identification of new, previously unnoticed aspects of their experiences. Throughout this process, I was careful to maintain confidentiality. Pseudonyms were assigned to each participant, and these pseudonyms were consistently used in all phases of the study - transcription, data analysis, and in the final thesis draft. This practice safeguarded the participants' identities, allowing them to share openly without concern for personal or professional repercussions. The combination of member checking and the use of pseudonyms not only strengthened the reliability of the research findings but also upheld the ethical standards of the study.

The phenomenological framework involved intensive data analysis to identify themes among participants. I closely acquainted themselves with the data, examining interview transcripts, and identifying significant statements. These are sentences or quotes that illuminate the participants' experience of the phenomenon, a process referred to as horizontalization (Moustakas, 1994, as cited in Creswell, 2017). From these statements, thematic clusters were developed, which were then used to describe the participants' experiences, known as textual description (Creswell, 2017). To enhance the analysis, I included personal experiences and the context that shaped them.

Saturation

To ensure the attainment of saturation in this phenomenological research study, a rigorous and systematic approach was employed throughout the data analysis process. Saturation, a crucial aspect of qualitative research, signifies the point at which new data cease to provide additional insights or generate novel themes, indicating that theoretical saturation has been achieved (Guest, et al., 2006).

The initial step in the analysis involved the transcription of the five interviews, ensuring the accurate representation of the participants' narratives. The transcripts were then carefully reviewed and read repeatedly to gain familiarity with the data and to immerse myself in the participants' experiences. This immersion allowed me to grasp the nuances and subtleties embedded within the interviews, enabling a comprehensive analysis.

A phenomenological approach was adopted, emphasizing the exploration of the essential meaning and essence of the support workers' experiences (Creswell, 2013). I engaged in a process of open coding, identifying initial codes and concepts that emerged from the interviews. These codes were then organized into potential themes, capturing the commonalities and variations in the support workers' experiences during the COVID-19 pandemic (University of Illinois Library, n.d.)

As subsequent interviews were conducted and analyzed, I engaged in constant comparison, moving back and forth between the emerging themes and the new data. This iterative process allowed for the refinement and expansion of the initial themes as new insights and perspectives emerged. I actively sought out disconfirming evidence and deviant cases to ensure the comprehensive exploration of the phenomena under investigation.

Through analysis and extensive dialogue, I critically examined the data, challenged my assumptions, and refined the themes and sub-themes. This iterative process of analysis continued until I reached a point of theoretical saturation, where no new significant insights or themes emerged from the data (Guest et al., 2006).

In the fifth interview, I found that the emerging themes and sub-themes exhibited consistency and comprehensiveness with the previous interviews. The data analysis indicated that the themes had reached saturation, providing a comprehensive understanding of the support workers' lived experiences during the COVID-19 pandemic in relation to their work with clients with FASD. Recruiting participants posed challenges; nevertheless, had more participants been available, I would have extended the interviewing process to achieve a more thorough saturation of the data.

The attainment of saturation in this study underscores the richness and depth of the data collected from the interviews. The thorough analysis and exploration of recurring patterns and themes ensured that the research findings accurately represented the support workers' experiences contributing to the validity and the trustworthiness of the study's results.

Data Trustworthiness

In phenomenological research, ensuring data trustworthiness is crucial to establish the credibility and rigor of the study (Finlay, 2009). Data trustworthiness refers to the extent to which the data collected, and the interpretations derived from it accurately represent the participants' lived experiences. It involves employing strategies to enhance credibility, transferability, dependability, and confirmability (Finlay, 2009).

Credibility, as a component of data trustworthiness, emphasizes my efforts to establish the authenticity and plausibility of the findings (Finlay 2009). In this study, credibility was

enhanced through various means. Firstly, one interview was conducted with each participant who had worked with clients with Fetal Alcohol Spectrum Disorder (FASD) during the COVID-19 pandemic. This allowed for a comprehensive exploration of their lived experiences and ensured a diverse range of perspectives. Moreover, participants were given ample time and space to share their stories and perspectives without interruption, fostering an environment of trust and authenticity. I actively listened, clarified, and sought participant validation to ensure the accurate representations of their experiences. Furthermore, direct quotations from the interviews were included in the analysis, adding an additional layer of authenticity and allowing the participants' voices to be heard.

Transferability refers to the extent to which the findings of the study can be applied or generalized to other contexts or populations (Finlay, 2009). While phenomenological research prioritizes the in-depth exploration of individual experiences, efforts were made to provide sufficient contextual information and rich descriptions that allow readers to assess the applicability of the findings to similar populations or settings. By providing detailed descriptions of the research context, the participants, and the phenomenon under investigation, transferability is enhanced.

Dependability focuses on the consistency and stability of the data and the analytical process (Finlay, 2009). To ensure dependability, a systematic and transparent approach was followed throughout the research process. Detailed notes were taken during the interviews, and the process of data analysis was well-documented.

Confirmability refers to the objectivity and neutrality of the findings, minimizing influence of the researcher's biases and preconceptions (Finlay, 2009). To enhance confirmability

reflexivity was employed, as discussed in a previous section, which involved critically examining my own subjectivity and acknowledging any potential biases or assumptions.

In phenomenological research, bracketing stands as a cornerstone, pivotal for ensuring data trustworthiness and enhancing researcher reflexivity. The process of bracketing, as outlined by Finlay (2009), involves the conscientious effort by the researcher to acknowledge and set aside any preconceived notions, biases, and assumptions regarding the phenomenon under study. In this research, I employed bracketing to approach the data collection and analysis with an open and unbiased mindset, focusing on authentically capturing the participants' lived experiences.

Prior to conducting the interviews, I dedicated time to introspective exercises, aimed at identifying and acknowledging my own beliefs and preconceptions, particularly those related to working with clients with FASD during the COVID-19 pandemic at Turning Leaf Services. This self-awareness exercise was crucial in ensuring that I entered the data collection phase with a neutral stance.

Throughout the interview process, I continuously practiced bracketing. This entailed consciously suspending my personal judgments, interpretations, and assumptions to foster a safe and non-judgmental environment for participants. My focus was on listening and capturing their experiences, while being vigilant of any personal biases or notions that might surface. Actively setting aside was essential to maintain the purity of the data collection process.

Following the interviews, the practice of reflexivity was integral in examining my own subjectivity and its potential impact on data interpretation. Regular self-reflection and reflexivity exercises allowed me to critically evaluate any biases or preconceptions that might have influenced the analysis. This step was crucial for ensuring that the interpretations and findings were rooted in the participants' narrative rather than coloured by my own experiences or beliefs.

By diligently implementing bracketing and engaging in ongoing reflexivity throughout the research process, I aimed to enhance the overall trustworthiness and credibility of the study. This meticulous approach ensured that the research findings were a true reflection of the participants' experiences, untainted by my own perspectives, thereby contributing to the integrity and authenticity of the phenomenological exploration.

In conclusion, the data trustworthiness was a priority in this phenomenological study. By addressing credibility, transferability, dependability, and confirmability, efforts were made to ensure the integrity and authenticity of the data and interpretations. Through a combination of strategies, including multiple interviews, participant validation, detailed descriptions, peer debriefing, bracketing, and reflexivity, the study aimed to establish data trustworthiness and contribute to the broader understanding of the lived experiences of support workers who have worked with clients with FASD during the COVID-19 pandemic.

Data Analysis

For data analysis, I followed the approach outlined by Moustakas (1994). I immersed myself in each participant's story by reading and re-reading their transcribed narratives. During this process, I highlighted statements that stood out and made corresponding notes. These notes helped me identify core themes that emerged from the data and enriched the description of the phenomenon under investigation. To fully engage with the participants' words, I utilized handwritten notes.

To ensure comprehensive understanding, I actively conversed with each participant, clarifying doubts, and probing for deeper insights. Each participant received a transcript of their interview. I then initiated contact to confirm the accuracy of the content and ascertain if anything was overlooked or required clarification. Four out of the five participants responded, leading to

scheduled follow-up discussions. During analysis, I consistently cross-referenced with relevant literature, fortifying the context and offering a foundational reference point.

Themes began to crystallize as I reviewed notes, and I identified brief phrases or quotes that captured the most significant aspects. These quotes were loosely clustered together to extract meaning, and each theme was thoroughly reflected upon. Moustakas (1994), refers to this process as horizontalization (Creswell, 2017). The analysis process involved a thoughtful review of the literature, aligning the emerging themes with existing knowledge of the participants' lived experiences. This iterative process continued until a comprehensive list of deeper themes, which encapsulated the participants' lived experiences, was developed. To analyze the data, I adopted a written descriptive narrative approach. As I delved into the transcripts, I discerned significant meaning regarding the impact of COVID-19 on both the workers and the clients. Notably, the participants consistently used the term 'uncertainty' to describe their experiences of working during the pandemic. Building upon this notion, I introduced the concept of 'embodied uncertainty' to capture the participants' description of how this uncertainty took a tangible presence in their lives. Thus, the overarching theme of 'embodied uncertainty' emerged from their collective lived experience. Sub-themes within the major theme of 'embodied uncertainty' were derived from the participants' narratives, which provided rich insights into their firsthand encounters with this embodied uncertainty.

Thematic Analysis

Thematic analysis is a qualitative analytical approach commonly used in phenomenological research studies to identify and interpret themes or patterns within participants' experiences. It involves systematically examining qualitative data, such as interview

transcripts, to extract meaningful themes that represent the essence of the participants' lived experiences (Creswell, 2017).

In the context of this phenomenological research study, thematic analysis aims to uncover the underlying structures, meanings, and essences of the phenomenon under investigation. This study involved a process of coding and categorizing the data to identify recurring patterns, concepts, or ideas that capture the central themes emerging from participants' descriptions.

The process of thematic analysis involved these steps:

Familiarization with the Data

I immersed themselves in the data by repeatedly reading, reviewing, and listening the interviews to gain a deep understanding of the participants' experiences.

Initial Coding

I generated initial codes by systematically labeling and organizing segments of the data that are relevant to the research question. This process involved highlighting specific words, phrases, or concepts that capture key aspects of the participants' experiences.

Theme Development

I identified potential themes by collating related codes and exploring connections between them. Themes represent patterns or concepts that emerge across the dataset and are relevant to the research question.

Reviewing and Refining Themes

I reviewed and refined the identified themes by revisiting the data and considering how well they represent the participants' experiences and their connection to the overarching essence of embodied uncertainty. This process involved comparing themes to original data, considering

alternative interpretations, and ensuring the themes accurately capture the essence of the phenomenon.

Defining and Naming Themes

I provided clear definitions and descriptions for each theme, capturing their meaning and relevance to the research question. I assigned names to the themes to succinctly convey their essence.

Writing the Narrative

I integrated the identified themes into a cohesive narrative that presents a comprehensive and rich description of the participants' lived experiences. This narrative provides a holistic understanding of the phenomenon and effectively conveys the key findings of this study.

Strengths and Weaknesses

The methodology utilized in this study possesses several strengths. Primarily, the use of a phenomenological approach enabled an in-depth understanding of the lived experiences of support workers during the pandemic, lending priority to participants' perspectives, and consequently allowing for the emergence of rich insights. Furthermore, the combination of purposive, convenience, and criterion sampling, supplemented by homogenous sampling, ensured the relevance and expertise of the selected participants, thereby enhancing the quality and validity of the data collected. Ethical rigor is also evident through the acquisition of approval from the Health Research Ethics Board (HREB) and the collection of informed consent from the participants. The inclusion of modern technological tools such as Otter.ai for transcription, Zoom for conducting interviews, and email for member checking is a testament to the efficiency of the data collection and analysis process. Finally, the extensive data analysis procedure involving coding, categorizing, and theme generation likely yielded reliable and insightful results.

Nevertheless, several weaknesses can also be identified. The relatively small sample size (n=5) may limit the robustness and generalizability of the findings, despite its common acceptability in phenomenological studies. The recruitment process presented multiple challenges, including a lack of responses from organizations, which constrained the pool of potential attrition. Lastly, despite the measures implemented to ensure confidentiality, the use of online tools and email for communication and data storage inherently poses a risk for data breaches.

Bracketing, integral to phenomenological research, involves setting aside my preconceived beliefs and biases. This process carries both strengths and challenges.

Bracketing enhances objectivity in qualitative research. By suspending my pre-existing notions, I was able to interpret the data more authentically based on participants' experiences. This process bolstered the credibility and trustworthiness of the research, showcasing a robust approach to minimizing researcher influence and enhancing transparency (Moustakas, 1994).

Achieving complete detachment from one's beliefs and prior knowledge is challenging, often deemed impossible (Ahern, 1999). Given the deep immersion required in phenomenological research, completely bracketing my perceptions was a complex task. Critics argue that our comprehension of phenomena is intrinsically linked to our previous experiences (Tufford & Newman, 2012). Furthermore, bracketing, while promoting objectivity, risks oversimplifying the phenomenon by neglecting valuable insights that the researcher's experiences might offer (LeVasseur, 2003).

While bracketing is critical for research integrity, it requires careful navigation to balance the need for objectivity with the richness that personal insights can bring to data interpretation.

Summary

This section provides an overview of the research methodology employed in this study. It begins with an explanation of the phenomenological approach adopted to explore and understand the phenomenon under investigation. My interpretation of the participants' experiences is then refined, highlighting the iterative nature of the analysis process. This section further elucidates the process of participant selection, detailing the interview procedures and the my utilization of bracketing techniques to maintain objectivity. Additionally, the analysis process is described, emphasizing the careful examination of the collected data. Ethical considerations in the research, including confidentiality and participant well-being, are also explored. Overall, this section provides a thorough account of the research methodology, encompassing the theoretical framework, participant engagement, data analysis, and ethical considerations.

Chapter 4: Results

This research endeavor delved into the nuanced experiences of support workers assisting clients with FASD amidst the challenges of the COVID-19 pandemic. Stemming from comprehensive qualitative interviews with five distinct support workers, the study illuminated critical themes: the intricate process of system navigating and support coordination, the foundational importance of relationship cultivation and trust, the accessibility to and need for vital resources and backing, suggested strategies and insights, the augmented difficulty of supporting clients with FASD, the impact on the dynamics of the worker-client relationship, as well as the overarching sentiment of unpredictability and instability during these unprecedented times.

Rich Descriptions

In order to provide a deeper understanding of the lived experiences the participants, rich descriptions were collected through interviews with individuals in the field. These rich descriptions offer detailed narratives that capture the nuances, challenges, and moments of resilience that emerged in the support worker-client relationship. By delving into the vivid accounts shared by support workers, a more comprehensive picture of their experiences during this extraordinary time is revealed. This section presents a series of rich descriptions that provide an intimate glimpse into the world of support workers and their clients, shedding light on the complexities of navigating the pandemic and offering insights into the strategies, emotions, and coping mechanisms employed by both parties.

Nick

Nick, a dedicated support worker, described his experience during the COVID-19 pandemic as a constant balancing act between adapting to ever-changing guidelines and

maintaining the much-needed support for his clients. He vividly recalled the initial challenges of adjusting to the sudden restrictions, where visits were limited to 15 minutes and longer, meaningful interactions seemed out of reach. Nick expressed a deep sense of frustration, recognizing that the reduced time spent with clients hindered his ability to provide the comprehensive support they needed.

However, amidst these challenges, Nick's unwavering commitment to his clients shone through. He described moments of connection and resilience, where he employed creative strategies to bridge the physical distance imposed by the pandemic. Nick passionately shared anecdotes of organizing virtual sessions, phone calls, and even outdoor meetings while adhering to safety protocols. He emphasized the importance of maintaining the rapport he had built with his clients before the pandemic, as it served as a foundation of trust and facilitated their ongoing communication and support.

Nick's description of the pandemic painted a vivid picture of the impact on his clients' well-being. He expressed deep concern over the increased substance use he observed, as the limitations on recreational activities and the closure of essential support services exacerbated their struggles. Nick's account revealed a profound understanding of the unique coping mechanisms employed by his clients, as they navigated the overwhelming uncertainties of the pandemic. He shared how some turned to art, nature, or virtual communities as sources of solace and connection.

Amidst the difficulties, Nick's determination and adaptability shone through. He demonstrated an unwavering commitment to his clients, going above and beyond to ensure their needs were met despite the limitations. Nick's rich description provided a glimpse into the complexities and challenges faced by support workers, highlighting their resilience and the

invaluable role they played in supporting individuals with FASD during the turbulent times of the pandemic.

Rachel

Rachel, a committed support worker, vividly described her experience working with clients with FASD during the COVID-19 pandemic. In her accounts, she painted a detailed picture of the challenges and triumphs she encountered in her role. She conveyed a sense of deep empathy and commitment towards her clients, emphasizing the importance of building trust and rapport. Rachel narrated instances where she had to adapt and be resourceful in providing support, as face-to-face interactions were limited. Despite the constraints imposed by the pandemic, she demonstrated resilience and creativity, using virtual platforms and phone calls to maintain connections and offer assistance. Her words conveyed a palpable sense of compassion and determination as she strived to be a consistent presence in her clients' lives during a time of immense uncertainty. Rachel's rich description offered a profound insight into the unique struggles faced by support workers and the profound impact they can have in supporting individuals with FASD during times of crisis.

Amy

Amy's interview provided a rich and insightful glimpse into her experiences as a support worker during the COVID-19 pandemic. Throughout the conversation, Amy expressed a deep sense of empathy and dedication towards her clients with FASD. She shared vivid anecdotes that highlighted the challenges and complexities of supporting individuals with FASD during the pandemic. Amy emphasized the importance of building rapport and trust with her clients, recognizing that it formed the foundation for successful outcomes. Her description painted a vivid picture of the struggles faced by her clients in adapting to the constantly changing

circumstances brought about by the pandemic. Amy's account demonstrated her commitment to being a consistent and reliable source of support for her clients, even in the face of limited resources and restrictions. She spoke passionately about the impact of the pandemic on her clients' mental well-being and the increase in substance use as a coping mechanism. Amy's rich description conveyed her unwavering determination to provide the necessary support and advocate for the unique needs of individuals with FASD, highlighting the profound impact that support workers can have in navigating challenging times.

Kristen

Kristen's interview provided a compelling and detailed account of her experiences as a support worker during the COVID-19 pandemic. Throughout the conversation, Kristen's passion for her work and dedication to her clients with FASD shone through. Her rich description painted a vivid picture of the challenges faced by individuals with FASD during the pandemic and the profound impact it had on their lives. Kristen spoke eloquently about the importance of building rapport and trust with her clients, recognizing that it was the cornerstone of a successful support relationship. She shared poignant stories that highlighted the struggles her clients faced in adapting to the changes brought about by the pandemic, including the disruption of routines and limited access to resources. Kristen's deep understanding of the unique needs and vulnerabilities of individuals with FASD was evident in her accounts of the strategies she employed to provide tailored support and promote their well-being. Her description conveyed a sense of empathy and compassion as she navigated the complexities of supporting her clients during this challenging time. Kristen's rich description offered valuable insights into the lived experiences of individuals with FASD and the crucial role of support workers in providing the necessary guidance and support to help them navigate the pandemic with resilience and dignity.

Molly

Molly's interview provided a deeply personal and introspective account of her experiences as a support worker during the COVID-19 pandemic. Her rich description delved into the emotional and psychological aspects of her role, revealing the profound impact it had on her own well-being. Molly spoke candidly about the challenges she faced in maintaining her own mental health while simultaneously supporting her clients with FASD. Her narrative highlighted the emotional strain and burnout she experienced, often feeling overwhelmed by the demands of her job and the added complexities of the pandemic. Despite these challenges, Molly's dedication to her clients was unwavering, and she shared heartfelt stories of the meaningful connections she formed with them. She emphasized the importance of empathy and compassion in her work, recognizing the significance of truly understanding and validating her clients' experiences. Molly's rich description captured the multifaceted nature of being a support worker during a global crisis, offering a glimpse into the internal struggles, triumphs, and personal growth that accompanied her journey. Her introspection and self-reflection underscored the profound impact that the support worker-client relationship can have, not only on the clients themselves but also on the well-being and personal development of the support workers. Molly's rich description illuminated the intricate dynamics of the support worker's role, revealing the interconnectedness of their own experiences and the experiences of their clients with FASD during a time of profound societal upheaval.

Presentation of Themes

In this phenomenological exploration of support workers' experiences during the COVID-19 pandemic, particularly with clients affected by Fetal Alcohol Spectrum Disorder (FASD), a series of interconnected themes emerged, all resonating with the overarching essence of embodied

uncertainty. The first theme, navigating systems and coordinating support, captures the challenges and complexities faced in adapting to the shifting landscape of healthcare and legal systems, illustrating how support workers had to continuously improvise and adapt in response to the unpredictable environment. Access to resources, another critical theme, reflects the struggle to secure essential services and support amidst the limitations and closures, underscoring the tangible impact of uncertainty on resource availability and distribution. Strategies and recommendations represent the innovative and adaptive approaches developed by support workers to navigate these uncharted waters, showcasing their resilience in the face of continuous change. The theme of uncertainty and instability captures the constant flux and unpredictability that became a hallmark of the pandemic experience, directly impacting the work and well-being of support workers and their clients. This leads to the increased difficulty in supporting clients with FASD, a theme that emphasizes the additional challenges brought on by the pandemic, exacerbating existing difficulties due to the unique needs of individuals with FASD. Finally, the impact on relationships with clients echoes throughout, as the pandemic significantly altered the ways in which support workers interacted with and supported their clients, adding layers of complexity to their roles. Collectively, these themes paint a vivid picture of a workforce navigating an environment rife with uncertainty, continuously adapting and innovating to meet the needs of their clients while also grappling with the profound impacts of the pandemic on their professional and personal lives.

1. Navigating Systems and Coordinating Support

This theme revolves around the challenges faced by support workers in navigating various systems and coordinating support for individuals with FASD during the pandemic. It encompasses the difficulties encountered in adapting to virtual court proceedings, the limitations

imposed by pandemic protocols on in-person support, and the logistical barriers in accessing necessary resources and services. The theme highlights the need for innovative solutions to overcome these challenges and ensure effective coordination of support within a complex and rapidly changing environment. Furthermore, this theme is intrinsically tied to the essence of embodied uncertainty. The constantly changing protocols and new challenges introduce a tangible sense of unpredictability. This uncertainty manifests in the daily work of support workers as they adapt to virtual court proceedings and navigate logistical barriers, constantly adjusting to the evolving situation.

Nick discussed the challenges of virtual court proceedings and logistical issues, such as limited contact in offices and difficulty in hosting virtual appointments.

Nick: “I really felt a feeling that a lot of these systems that we deal with, regularly weren’t coordinated in a way that was in the best interest of the individuals that we were supporting... A lot of the systems that we deal with, regularly weren’t coordinated in a way that was in the best interest of the individuals that we were supporting... The role of FASD in the action is relevant... navigating the system and afterwards, brought about challenges that really didn’t lend itself to the success of the individuals living with FASD.”

Amy talked about the challenges of adjusting and adapting to the changing pandemic situation, which often hindered the ability to provide proper support.

Amy: “There was a lot of adjustments and adapting that needed to happen. It was changing every single day.”

Kristen discussed the challenges caused by frequent changes and the confusion during the pandemic, affecting the support provided to participants.

Kristen: “A lot of confusion within the pandemic, a lot of things changing frequently... It created a lot of instability and frustration, and confusion for the participants.”

Molly described the difficulties in navigating the pandemic’s changing rules and limitations, which impacted support for clients.

Molly: “Navigating visits with participants during the pandemic was different... a lot of things that we weren’t allowed to do that normally, we used to be able to do.”

Rachel discusses the complexity and challenges faced in navigating systems, especially for clients with FASD. She notes how the pandemic added another level of difficulty in connecting with these individuals who already have challenges in understanding day-to-day structures.

Rachel: “FASD adds another level of difficulty on a regular day, right. They don’t remember appointments; they don’t know what day it is or what time it is. They rely on us staff a lot and this proved more difficult during this time.”

Adapting to Virtual Court Proceedings

Support workers face challenges in adapting to virtual court proceedings, including technical difficulties, limited non-verbal cues, and the need for additional advocacy efforts to ensure individuals with FASD receive fair and appropriate treatment within the legal system.

Nick described this difficulty below:

Nick: “One of the major changes was that often court was done virtually, there were a lot of logistical challenges with that, including access to a phone or a computer... Our ability to support them in attending virtually was limited because the office was limiting its contacts and people coming in and out. I often would do a court appointment with a client in my car in the dead of winter with them in the backseat and both of us wearing masks... It was as struggle.”

Limitations of In-Person Support

The pandemic protocols, such as social distancing and restricted access, limit the ability of support workers to provide in-person support, hindering the development of trusting relationships and effective communication with individuals with FASD.

Nick describes his difficulties in dealing with limited in-person support:

Nick: “When a client found out that they were diagnosed with COVID, or even suspected that they were diagnosed with COVID, they didn't have the ability to isolate. And, you know, even if they did have the ability to isolate, ensuring that their basic needs were met, because they didn't have friends and family that would be able to support them was so difficult.”

Molly also discussed the detriments of limited in-person support:

Molly: "It affected your rapport building with participants. We weren't allowed to stay in someone's place for longer than 10 minutes, which really affects your relationship with them. A lot of participants really want face-to-face interaction, and also transportation."

Logistical Barriers in Accessing Resources and Services

Support workers encounter logistical barriers, such as limited transportation options and reduced availability of resources and services, which necessitate creative solutions and effective coordination to ensure individuals with FASD receive the support they need.

Molly explains her experience:

Molly: “We couldn’t transport people, shelters were full, food hampers were scarce... So, it made things a lot more difficult, we had to do our best with what we were given.”

2. Access to Resources and Support

This theme delves into the impact of the pandemic on individuals with FASD in accessing essential resources and support services. It encompasses challenges such as limited access to food centres, reduced support during medical visits, the need to develop independent living skills, reduced in-person support, and dependency on support workers. The theme highlights the importance of finding alternative solutions, such as building bussing abilities, to ensure individuals can access necessary resources and support despite the constraints imposed by the pandemic. Furthermore, this theme highlights the physical and tangible aspects of embodied uncertainty. The restrictions on movement and closures of services not only create logistical barriers but also add to the sense of instability and unpredictability in meeting the basic needs of clients with FASD.

Nick described the impact of the pandemic on accessing resources, like good resource centres and medical care.

Nick: “Things like good resource centres... would make people wait outside... and so that’s a deterrent.”

Amy discussed the difficulties in accessing resources during the pandemic, such as the closure of services and the challenges in obtaining essential items.

Amy: “The resource piece for sure was affected because a lot of them closed, or they weren’t, you know, they didn’t have the drop-in services.”

Kristen mentioned the impact on accessing resources, with changes in services and limitations affecting clients.

Kristen: “When it comes to resources... the style of resource that was provided changes... reaching out to resources definitely lessened over time during the course of the pandemic.”

Molly mentioned the impact on clients’ ability to access resources, such as food and shelter, during the pandemic.

Molly: “A lot of resources that we would take clients to, we often just did it for them, because we didn’t want to risk them going into the community and getting sick. So, we did a lot more for the clients during this period. There was a time where we didn’t really drive anyone. So, I think it made them rely more on staff to get them resources.”

The impact of the pandemic on accessing resources is evident in Rachel’s account. She mentions the difficulty in accessing food banks, shelters, and the change in services, which were particularly challenging for clients who already struggle with such tasks.

Rachel: “Resource centres, the doors used to just be unlocked, you walked in, there was no capacity, there were no ratios, you went in and did what you needed to do... Now, everything is so systemized and overwhelming, not only for us but for our clients.”

Limited Access to Food Centres

The pandemic restricts access to food centres, which negatively affects individuals with FASD who rely on these resources. Support workers explore alternative solutions, such as meal delivery services or assistance with grocery shopping, to ensure individuals have access to nutritious food.

Rachel describes her experience:

Rachel: “Most places where I had gotten hampers in the past no longer had stock and you could have to wait a week or more to get a hamper by putting your name on a list. There

was no more just come and get what you need. This was ridiculous because our people needed food right away, not a week from now... I had to start budgeting with my people more seriously to ensure that they had good throughout the week.”

Molly describes her experience:

Molly: “I did most of the grocery shopping for my clients... I had clients that had a hard time moving around on their own because they used a walker or were in a wheelchair, for those cases I had to set up a meal-delivery service for them.”

Reduced Support During Medical Visits

The pandemic protocols and limited availability of healthcare professionals result in reduced support during medical visits for individuals with FASD. Support workers play a crucial role in advocating for comprehensive care, facilitating communication between healthcare providers and individuals with FASD, and ensuring their medical needs are addressed.

Rachel describes her experience:

Rachel: “I had a person who was in the hospital, and I couldn’t go and see them because of the restrictions. This was very hard for that person because they already had past trauma from interactions with the medical system... In a less serious case, I had another person who I couldn’t attend a routine doctor’s appointment with. That person relied on me to advocate for them in a medical environment, but I could not go with them.”

Developing Independent Living Skills

With limited external support, individuals with FASD face challenges in developing independent living skills. Support workers implement strategies to enhance self-sufficiency, including providing structured routines, teaching life skills, and promoting self-advocacy.

Molly explains her experience:

Molly: “I tried my best to instill a routine that my clients could follow without me being there, due to restrictions... I had to think of simple things they good do every day without me there... Like, making sure you eat breakfast, taking a shower... These are simple things for you and I but it was a lot to ask of my clients when I wasn’t there to assist them in sticking to a routine.”

Changes in Visits and Restrictions

Participants mentioned that the pandemic brought about significant changes in their interactions with clients. Rules and restrictions limited the duration of visits and prohibited certain activities that were previously allowed, affecting the support workers’ ability to establish rapport and build relationships with their clients. Furthermore, face-to-face interaction, which was crucial for many clients, was limited or replaced by remote communication. Transportation services were restricted to essential needs only, limiting the support workers’ ability to accompany clients to important appointments or social outings.

Kristen notes that visits were the most important part of client interaction:

Kristen: "In person interactions was a lot of participants rely on that. So that was a huge part about part of what was missing.”

Nick explains that phone conversations did not have the same effect as in-person visists:

Nick: “I tried my best to engage with people over the phone, but it was difficult. I think that they thought that if I couldn’t see them or assist them in person, that they didn’t need me or want to reach out for support... I can understand how they were feeling... It was difficult.”

Importance of Rapport Building

Building rapport with clients was deemed essential for successful support. Support workers highlighted that a strong relationship facilitated communication, trust, and clients' willingness to disclose important information.

Amanda explains her experience:

Amanda: "I already had a strong relationship with some of my clients before the pandemic, so the pandemic didn't impact the trust in that way... I found that it was harder to start new relationships with new clients during the pandemic, but the existing relationships I had, they were almost strengthened because we were going through this together."

Dependency on Support Workers

Clients became more dependent on support workers for accessing resources and services. The close of agencies and limited transportation options led to an increased reliance on support workers to meet their needs. This dependency persisted even after the restrictions were lifted, posing challenges in helping clients regain independence.

Molly describes her experience below:

Molly: "A lot of resources that we would take participants to, we often just did it for them... I think it made them rely more on staff to get them resources. And I think this is still happening now, even though there isn't any more restrictions on staff driving clients. We have had to teach clients independence again in this regard."

3. Strategies and Recommendations

The theme of strategies and recommendations focuses on the practical approaches and suggestions employed by support workers to address the unique challenges presented by the

pandemic. It includes strategies such as preparing for future events, incentivization to motivate clients, setting boundaries for self-care, focusing on client-centered solutions, and fostering open communication with colleagues and clients. These strategies aim to prioritize personal wellness, prevent burnout, and manage expectations effectively to maintain the quality of support provided to individuals with FASD. Furthermore, this theme is deeply influenced by the overarching essence of embodied uncertainty. The unpredictability and fluid nature of the pandemic environment necessitated that support workers adopt flexible, creative strategies and continuously reassess their approaches. This need for adaptability and responsiveness to ever-changing circumstances is a direct response to the embodied uncertainty that pervades the support workers' environment, guiding their decision-making and influencing the formulation of new, innovative recommendations to effectively support individuals with FASD during these challenging times.

Nick talked about using incentivization as a strategy to motivate clients and the importance of setting personal boundaries for mental health. Nick also discussed bending protocol, where possible, to garner cooperation from clients.

Nick: "One thing that we do, as you know, is incentivization... And during the pandemic so many of the asks were so much bigger and more daunting."

Nick: "Another strategy, and I'm not sure if this was something that was used, but I know that it was tempting for a lot of people to bend protocol."

Amy mentioned being more assertive in expressing support to clients and taking things day by day as a coping strategy.

Amy: "I just did things a little bit more intensely, making sure they hear me when I say, I'm here for you."

Kristen talked about being creative with support strategies, like making lists of activities clients could do at home.

Kristen: “I had made of list of like 50 things that you can do on your own or at home or like just things to occupy your time. Just along with creating your own resources, and that was like 100% important because of the pandemic’s restrictions affecting so much.”

Molly talked about adapting strategies to support clients, like managing grocery shopping and accessing mental health resources.

Molly: “I think that something like that, grocery shopping for clients, but for people that are like, deathly afraid to leave their house.”

Rachel speaks about adapting her approach during the pandemic, such as keeping her phone on for clients to reach out anytime, indicating a shift towards more direct and immediate support.

She also mentions delivering essentials like food and PPE to clients.

Rachel: “When I used to get home, I would turn my phone off. My day was over at four and I was exhausted. But during the pandemic, my phone never got turned off... I would make sure my clients had the essentials like food and PPE even though I couldn’t visit with them in person.”

Preparing for Future Events

Participants emphasized the need to plan ahead and have contingency measures in place for future crisis. Proactive strategies should be developed in order to better support clients, enhance their quality of life, and address challenges that may arise during similar situations.

Molly describes preparing for future events:

Molly: "Actually, I really like to do like conferences and stuff. I did this Indigenous conference, where we talked about, like, what we could have done differently. And something that I would say would be to like, plan ahead."

Incentivization and Motivation

Support workers employ incentivization strategies, such as rewards and positive reinforcement, to motivate individuals with FASD in accomplishing tasks and achieving personal goals.

Nick describes his use of incentivization:

Nick: "One thing that we do, as you know, is incentivization... And during the pandemic so many of the asks were so much bigger and more daunting. I would incentivize clients with cigarettes or a cup of coffee if they achieved a small goal on to-do on that day."

Setting Boundaries for Self-Care

To prevent burnout and maintain personal well-being, support workers emphasize the importance of setting boundaries, practicing self-care, and seeking support from colleagues and supervisors.

Kristen explains her experience:

Kristen: "I felt closer to my coworkers during this time, we had to rely on each other more to get things done and it worked out where we could all support each other."

Rachel explains her experience:

Rachel: "In between seeing people, I would take some time in my car to play some music and have a smoke... Even this little thing helped me relax and do something for myself during all the chaos."

Focus on Client-Centered Solutions

It was recommended to prioritize clients' well-being and find creative solutions to meet their needs. The emphasis was on developing resources and support systems that prioritize face-to-face interactions, social engagement, and mental health support for clients with FASD. Support workers recognized the need to be more assertive and proactive in expressing their commitment to clients during the pandemic. Support workers made deliberate efforts to ensure clients felt heard, understood, and supported by emphasizing their availability and willingness to help.

Amanda explains her experience:

Amanda: "I was more aggressive with my support and letting my clients know that I was there for them... I would call them more often if they didn't answer and would drive around the areas they were known to be, more frequently... When I saw them, I always had something for them, whether it was an ear to listen or something as simple as a granola bar."

Fostering Open Communication

Support workers prioritize open and transparent communication with both clients and colleagues. This includes regular check-ins, collaborative problem-solving, and seeking feedback to ensure the provision of effective support and adaptability in a changing environment.

Nick explains his experience:

Nick: "Our team had more frequent check-ins that were hosted by our manager. This gave us a chance to talk about anything, personal or work-related, and to update everyone on things going on with our clients."

Kristen explains her experience:

Kristen: “Even when my people didn’t want support, I would still check-in periodically during when our visit would be to see if they changed their mind would like to see me, even just for a bit outside.”

4. Uncertainty and Instability

Support workers identified feelings of uncertainty and instability, and this reflects the challenges and difficulties they faced as they navigated the rapidly changing circumstances and restrictions imposed by the pandemic. The themes of confusion, frequent changes, and resistance to restrictions directly tie into the concept of embodied uncertainty. The support workers and their clients are continually adapting to a shifting landscape, where routines are disrupted and stability is elusive, embodying the very essence of uncertainty in their daily interactions and strategies.

Nick’s comments on constantly changing pandemic protocols and the impact on service provision reflect the theme of uncertainty and instability.

Nick: “Our organization, I think a lot of organizations just align their policies with what the government recommended, public health recommended. And that changed all the time.”

Amy described the constant changes and the need to adapt as significant challenge, reflecting the theme of uncertainty and instability.

Amy: “It was, I think, the bouncing back and forth that was the toughest piece... constantly flip flopping.”

Kristen’s comments reflect the theme of uncertainty and instability due to the changing pandemic protocols.

Kristen: “There was a lot of fighting back, so to speak, against the restrictions... trying to explain the importance or why they’re in place.”

Molly’s comments reflect the theme of uncertainty and instability due to the pandemic’s impact on clients’ routine and mental health.

Molly: “It was really hard... people who are clients that only see staff and don’t really have any outside supports or friends to see during the day to day... I think they suffered the most.”

Rachel talks about the constant changes and difficulties in planning and providing consistent support, which was heightened for clients with FASD. Rachel notes how clients with FASD relied heavily on staff for the latest information.

Rachel: “They didn’t really know what to expect from day to day. And in their position, they couldn’t watch the news. Most of them don’t even have a radio, they don’t know what’s happening in the city or in the world even. So, they really relied on staff to be that information for them. And this was particularly challenging because often we didn’t know the latest information as staff.

Confusion and Frequent Changes

The support workers described a sense of confusion resulting from the constant changes in pandemic-related guidelines and restrictions. They highlighted the difficulty of keeping up with the evolving situation and the impact it had on their ability to provide consistent support to their clients. The clients they worked with also struggled with the constant changes, which added to their frustration and confusion.

Amanda describes her experience:

Amanda: “Oh wow, this was the worst part of it... There was one time where I had a scheduled appointment that I was going to attend with my client and then the restrictions changed, and I could no longer drive them. I had to tell my client that I could no longer take her to the appointment and had to try to figure out how she could get there on her own. This sudden change frustrated her, and she felt discouraged and ended up canceling the appointment.”

Instability and Frustration

The ever-changing circumstances brought about by the pandemic created a sense of instability for both the support workers and their clients. The clients’ routines and the support workers’ work process were disrupted, leading to frustration and feelings of uncertainty. The support workers mentioned the challenges of explaining the reasons behind the changes and managing the clients’ resistance to the imposed restrictions.

Nick describes his experience:

Nick: “It was hard to explain these changes to my clients, especially when I didn’t quite understand the new restrictions myself... I felt like my clients could tell that I didn’t really know why I couldn’t drive them, just that I was told to. I could tell this upset them because they felt like I was disappointing them, even though I had no control in this situation.”

Amanda explains her experience:

Amanda: “I was asked many times by my people to just drive them, even though I wasn’t allowed to, it was hard to say no, and they definitely would push that boundary and even act up disrespectfully towards me if I held my ground.”

Client Resistance to Restrictions

The support workers mentioned that some of the clients they worked with exhibited resistance to the restrictions imposed during the pandemic. This resistance could manifest itself as questioning the necessity of the restrictions or expressing frustration about the changes. The support workers had to navigate these situations and find ways to effectively communicate the importance of the restrictions while maintaining the clients' trust.

Kristen describes her experience:

Kristen: "It definitely created a lot of frustration for the participants. Because as the restrictions changed, certain things that were okay last week were now not okay."

5. Increased Difficulty in Supporting Clients with FASD

The support worker reflected on the challenges they faced in effectively addressing the unique needs of individuals with FASD in the context of the pandemic. The exacerbated challenges faced by individuals with FASD during the pandemic are a direct reflection of embodied uncertainty. The cognitive impairments and difficulties with routine and structure inherent in FASD are intensified in an unpredictable pandemic environment, highlighting how uncertainty becomes a tangible part of their lived experience.

Nick detailed the specific challenges in supporting clients with FASD during the pandemic, like difficulties with virtual court appearances and understanding public health measures.

Nick: "It was difficult, because some of the clients that I supported who were living with FASD, were justice involved... So, it was difficult to find a place to host in, and if we were as support workers attending their residence and helping them attend virtually with our phones, there were still protocols that limited our ability to be with them fully."

Amy talked about the specific changes of supporting clients with FASD, like difficulties in understanding the pandemic protocols and maintain routine.

Amy: “The consistency was lacking, the routine was lacking, which I noticed with participants with FASD.”

Kristen noted the increased difficulty in supporting clients with FASD due to the pandemic’s impact on routine and consistency.

Kristen: “Consistency and routine were out the window during this time... during the pandemic I had to think on my feet to support my clients with FASD.”

Rachel: "I mean, our participants are difficult to engage with and connect with at the best of times. So COVID added another level of difficulty."

Molly noted the increased difficulty in supporting clients with FASD due to limitations on in-person interactions and changes in routine.

Molly: “It was harder to be able to support clients with FASD in particular... We weren’t allowed to stay in someone’s place for longer than 10 minutes for example... I found the disruptions increased the difficulty of supporting clients with FASD.”

Rachel points out the added difficulties in supporting clients with FASD during the pandemic, given their challenges with memory, time perception, and adapting to changes. She also mentions the increase in substance use and mental health challenges among clients.

Rachel: “I did see an increase in drug use a lot. Honestly, they didn’t have people keeping so many tabs on them. Our participants are difficult to engage with and connect with at the best of times. So COVID added another level of difficulty... They thrive during routine, and this routine was destroyed... So, trying to build routine for my clients with FASD during this time felt impossible.”

Heightened Challenges due to FASD Characteristics

Support workers already encounter difficulties in supporting clients with FASD even under normal circumstances. However, the pandemic added another layer of complexity. FASD is characterized by cognitive impairments, memory deficits, and difficulties with time perception. These pre-existing challenges were exacerbated during the pandemic, making it even more challenging to engage, communicate, and provide effective support to clients.

Amy and Rachel describe their experience:

Amy: "Participants with FASD rely on consistency and routine... They had a hard time understanding the changes and restrictions... It was tough for them."

Rachel: "Trying to have those conversations with people that don't necessarily understand a regular day was very difficult."

Staffing Challenges and Limited Support

The pandemic led to staffing issues, with some workers being unable to work due to exposure or isolation requirements. This resulted in limited resources and support available to clients with FASD, further increasing the difficulty in meeting their needs. The lack of consistent and available support staff impacted the continuity and quality of care potentially hindering progress and support outcomes.

Nick describes his experience:

"So many of our staff were sick, we were short staffed every day so some clients would not get staff when they needed them. I think this contributed to their feelings of isolation during this time period."

Adaptation and Flexibility in Support Approaches

Support workers had to adapt their support strategies to accommodate the restrictions and safety protocols imposed by the pandemic. The limitations on face-to-face interactions and reduced access to community resources required creative solutions to maintain support for clients with FASD. Support workers needed to find alternative ways to connect, engage, and aid, while still considering the unique needs and challenges associated with FASD.

Kristen: "I would search the city for free things being handed out, for example I found free art kits offered by the Art Gallery, so I got a bunch of those and handed them out to my clients... It was important as a support worker to be able to know where to look for extras like that."

Navigating Changes in Routine and Structure

Individuals with FASD often rely on routines and structure to navigate daily life successfully. The disruption caused by the pandemic, including changes in schedules, closure of services, and restrictions on activities, significantly impacted their ability to maintain stability and predictability. Support workers had to navigate these changes, helping clients adapt and cope with the sudden disruptions to their established routines.

Amy describes her experience:

Amy: "I would say probably the consistency was lacking, the routine was lacking, which I noticed with my participants with FASD, they really rely on consistency and routine, there was a lot of not being able to understand why we can't visit for longer than 15 minutes, why we have to wear masks all the time, why we can do certain things and go places."

Kristen describes her experience:

Kristen: "The lack of routine affected our clients... They struggled with the changes... It created additional stress and anxiety for them."

Emotional Impact on Clients

Individuals with FASD may have difficulty understanding and expressing their emotions. The uncertainty, fear, and isolation associated with the pandemic likely affected their emotional well-being. Support workers faced the challenge of addressing and managing these emotions, providing reassurance, and helping clients cope with the heightened stress and anxiety caused by the pandemic.

Molly describes her experience:

Molly: "There were more outbursts with my clients during the pandemic. They were fearful and didn't understand what was going on, and then they couldn't see me as often or as long as usual... I found that explaining to them that we were figuring this out together helped them understand that this was a new situation for both of us. I didn't pretend to have all the answers."

Increase in Substance Use

Support workers emphasized an increase in substance use among their clients, such as a shift from methamphetamine to opiates and heroin due to supply change disruptions caused by the pandemic. The support workers expressed concerns about the negative consequences of heightened substance use, including overdose rates and the potential long-term impacts on the mental health and well-being of individuals with FASD.

Amy and Rachel describe their experience:

Amy: "There was an increase in substance use... We lost a lot of people... It was very isolating for them on top of the existing barriers."

Rachel: "On my caseload, I did see an increase of drug use a lot. Honestly, they didn't have people keeping so many tabs on them."

6. Impact on Relationships with Clients

The support workers expressed how the pandemic influenced the dynamics, communication, and overall connection between support workers and clients with FASD. The need for flexibility and an adaptation in support approaches is a response to the embodied uncertainty of the pandemic. The support workers' ability to creatively adjust their methods to continue providing care amidst the changing circumstances is a testament to their resilience in the face of uncertainty.

It emphasizes the significance of establishing strong connections based on consistency, reliability, and predictability. Support workers recognize the impact of past trauma and the associated challenges in differentiating genuine support from exploitative relationships. Furthermore, support workers emphasized an increase in mental health challenges in their clients during the pandemic. Building trust becomes essential in overcoming these barriers and creating an environment where individuals feel safe and supported. Additionally, this theme reflects the embodied uncertainty faced by both support workers and their clients. The limitations on in-person support and the need to differentiate genuine support from exploitative relationships are underscored by the unpredictable and unstable environment, making the establishment of trust even more crucial and challenging.

Nick emphasized the importance of rapport and trust, particularly when dealing with clients who have a history of trauma.

Nick: "Rapport and trust are huge... building trust, through consistency, and through reliability, and predictability, I think was really an important thing."

Amy emphasized the importance of rapport building and trust, particularly when dealing with new participants.

Amy: “I think first and foremost is building a rapport and building trust... if I didn’t trust my staff, I’m not going to want to do anything with them, I’m not going to want to pursue goals. So really making sure rapport building is number one, and building trust and reliability is a big piece.”

Kristen emphasized the importance of trust, routine, and consistency, especially for clients with FASD.

Kristen: “It helps with routine. And just the consistency, especially with FASD, that consistency being important.”

Molly emphasized the importance of rapport building and the challenges it faced due to pandemic restrictions.

Molly: “It was harder to be able to build a relationship with someone over the phone... it’s really hard to build a relationship with someone if you don’t have that personable effect with you seeing them in person.”

Emphasizing the importance of being an active listener and empowering clients to lead their support, Rachel highlights the role of trust and rapport. She notes how the pandemic posed challenges in maintaining these aspects of the relationship due to the lack of face-to-face interactions.

Rachel: “I think being an active listener, I think listening is a huge part of this job, especially when you’re dealing with the demographic of FASD.”

Nick spoke about the difficulties in maintaining relationships due to pandemic restrictions, such as limited visit times.

Nick: “I think it was more difficult to be reliable and consistent and trustworthy, because of some of the protocols... we necessarily limited visit times in-home to a certain length.”

Amy highlighted the difficulties in maintaining relationships due to pandemic restrictions and the challenges in building new relationships.

Amy: “The hardest part was not being able to provide the supports that they needed... It was very isolating for them.”

Kristen highlighted how the changing pandemic restrictions affected relationships with clients, leading to frustration and trust issues.

Kristen: “It definitely created a lot of frustration for the clients... just understanding why things are changing... broke down some trust between us and them.”

Molly highlighted the impact of the pandemic on relationships with clients, including challenges in building rapport and trust.

Molly: “It’s really hard to build a relationship with someone you may not have even met in person due to the pandemic... you are just an empty voice on the other end of the phone, it would be very hard for our clients.”

Rachel notes how the lack of regular, structured interactions and the reliance on staff for information and basic needs affected the dynamics of these relationships.

Rachel: “I probably called the police a lot more during this time, hospitals, and remand. I mean, we do that, you know, weekly or monthly, but at this time, trying just to locate them to make sure they were safe.”

Recognizing the Impact of Past Trauma

Support workers acknowledge the impact of past trauma on individuals with FASD and the subsequent challenges in building trusting relationships. They employ trauma-informed approaches to create safe and supportive environments, emphasizing consistency, reliability, and predictability.

Kristen highlights her experience:

Kristen: “All the individuals I work with who have FASD have significant trauma...

Trauma makes it harder for them to form good relationships and can make it hard for staff to connect with them. The pandemic made this process even more difficult.”

Nick describes his experience:

Nick: “It’s important for me to acknowledge and respect what my clients have been through... And understanding how what they’ve been through affects their behaviour and how they dealt with the pandemic... I did my best to always actively listen and without judgement... That is the crux of relationship building for me.”

Differentiating Genuine Support from Exploitive Relationships

Individuals with FASD may struggle to distinguish between genuine support and exploitive relationships due to their vulnerability. Support workers focus on building trust, providing clear boundaries, and fostering open communication to help individuals discern safe and support relationships.

Nick highlights the difficulty in explaining these differences in relationships to his clients:

Nick: “Rapport and trust are huge. A lot of the are some of the individuals that I work directly with, had a history of trauma. I think that trauma was compounded with their

FASD diagnoses. Building trust, through consistency, and through reliability, and predictability, I think was, was really an important thing, and continues to be."

Mental Health Challenges

The pandemic negatively affected clients' mental health. Isolation, limited social interactions, and fear of going out exacerbated mental health issues such as anxiety, depression, and Obsessive Compulsive Disorder (OCD). Some clients relied on support workers for social contact and engagement, which became more challenging during the pandemic.

Rachel describes the challenges she noted with mental health:

Rachel: "Mental health doesn't take a break. And when you add a pandemic, and fear-based situations to people who already fear every day and are in flight or fight mode all the time. It gets worse."

Limited Interaction and Engagement

The pandemic restrictions and safety protocols often limited face-to-face interactions between support workers and clients. This reduced opportunities for meaningful engagement, socialization, and relationship-building that are crucial for effective support. Support workers had to find alternative ways to connect and maintain contact, such as phone calls, video chats, or outdoor meetings while adhering to safety guidelines.

Nick describes his experience:

Nick: "I remember meeting with my clients, even for 5 minutes, in -30 weather to have a quick smoke with them and to give them a coffee. I could tell this meant a lot to them."

Amanda describes her experience:

Amanda: “I started playing word games over the phone with one of my clients. Since we could only interact on the phone, playing a game together was better than nothing and I think helped the time pass for them.”

Increased Reliance on Support Workers for Information

Clients with FASD often relied on support workers as their primary source of information about the pandemic and its impact. They may have had limited access to news, radio, or technology to stay informed. Therefore, support workers played a vital role in keeping clients updated, explaining changes in protocols, and addressing their concerns or questions related to the pandemic.

Kristen explains her experience:

Kristen: “I would often read the news from my phone or updates on the pandemic to my client while I was on the phone with them. I would let them ask questions and answer them to the best of my ability.”

Heightened Emotional Support

The pandemic brought forth heightened levels of fear, uncertainty, and isolation for many individuals, including those with FASD. Support workers had to provide emotional support, reassurance, and empathy to help clients cope with the emotional impact of the pandemic. They acted as a source of stability, listening ear, and trusted confidant during challenging times.

Amanda explains her experience:

Amanda: “More often than not I would just listen to my clients on the phone, they would vent and sometimes cry but I could tell it was helpful for them.”

Flexibility and Adaptation in Support

The pandemic necessitated flexibility in providing support to clients. Support workers had to adjust their approaches, considering the limitations imposed by the pandemic and tailoring their strategies to meet the unique needs of each client. This flexibility involved finding new ways to deliver services, address changing priorities, and support clients in managing disruptions caused by the pandemic.

Amy describes her experience:

Amy: "One in particular that I was supporting at the time, they really relied on creativity and coloring and crafts, in order to cope with their mental health, that was deemed non-essential for a short period of time. And it was very detrimental to their progress."

Celebration of Milestones and Achievements

Despite the challenges, support workers continued to celebrate milestones, accomplishments, and progress made by clients during the pandemic. Recognizing and acknowledging their achievements, no matter how small, fostered a sense of motivation, self-worth, and resilience. These celebrations served as reminders of the progress made in the face of adversity and maintained a positive and empowering atmosphere within the worker-client relationship.

Rachel describes her experience:

Rachel: "I think some of them gained some voice. I think some of them learned how to navigate some systems because they had to do some things on their own. This was the best outcome I could hope for despite all the struggles, I really think they grew."

Embodied Uncertainty

In this phenomenological study, the overarching theme of ‘embodied uncertainty’ emerges as a central thread connecting the various experiences of support workers during the COVID-19 pandemic. This concept captures the tangible, lived experience of uncertainty, where the unpredictability and fluidity of the pandemic environment are physically and emotionally manifested in the daily lives of both support workers and their clients with FASD. Each identified theme – from the complexities of navigating systems and coordinating support, to the challenges of building trust and relationships, and the struggle to access necessary resources – is permeated by this sense of embodied uncertainty. It is evident in the constant adaptation to changing protocols, the heightened emotional and mental health challenges, and the need for innovative, flexible approaches to support. This uncertainty is not just a background context but actively shapes the experiences and responses of support workers and their clients. It underscores the resilience and adaptability required in these unprecedented times, highlighting how support workers continually navigate an ever-shifting landscape, where stability and predictability are elusive. In essence, embodied uncertainty serves as a lens through which the complex, dynamic experiences of support workers and their clients during the pandemic can be understood, offering a profound insight into the impact of living and working in a world defined by constant change and unpredictability.

Interpretation and Discussion

The purpose of this study was to explore the lived experience of support workers who have worked with clients with Fetal Alcohol Spectrum Disorder (FASD) during the COVID-19 pandemic and to understand the extent to which working during the pandemic has affected the experience of support workers and their relationship with their clients. Through interviews with

support workers and a review of relevant literature, this section discusses and interprets the findings in the context of the research questions and existing knowledge.

Impact on Support Workers and Clients with FASD

The interviews revealed that working during the COVID-19 pandemic presented significant challenges for support workers. The ever-changing nature of the pandemic and the associated restrictions made it difficult for support workers to provide the necessary supports and longer visits to their clients. The lack of consistency and routine, which are crucial for individuals with FASD, resulted in increased confusion and frustration among clients. The closure of recreational facilities and limited access to resources further exacerbated the mental health issues experienced by clients with FASD. The findings align with existing literature on the detrimental effects of the pandemic, particularly on vulnerable populations.

Building Rapport and Trust

Building Rapport and trust emerged as essential factors in establishing a successful relationship between support workers and clients with FASD. The interviews highlighted the importance of support workers developing a strong rapport and trust with their clients, as this facilitated the clients' willingness to engage in goal pursuit and seek support. However, the pandemic presented challenges in building rapport with new clients due to limited face-to-face interactions. Support workers who had already established rapport with their clients before the pandemic found it easier to maintain a sense of trust and continue providing support remotely. These findings align with existing literature emphasizing the significance of trust and rapport in worker-client relationships.

Mental Health Implications

The interviews shed light on the mental health implications of the pandemic on clients with FASD. Participants reported an increase in substance use, particularly the shift from methamphetamine to opiates, as a result of disrupted drug supply chains. This increase in substance use had severe consequences, including a higher number of overdoses and deaths within the FASD population. The limited access to mental health resources, support groups, and in-person interactions further compounded the mental health challenges faced by individuals with FASD during the pandemic. These findings align with the existing literature, which highlights the adverse effects of the pandemic on mental health and the need for targeted interventions and support systems.

Strategies and Adaptations

Support workers demonstrated resilience and adaptability in response to the challenges posed by the pandemic. They adopted strategies such as taking it day by day and intensifying their support to ensure their clients felt heard and supported. The implementation of anti-discriminatory and rights-based approaches, along with effective communication strategies, played a pivotal role in fostering successful worker-client relationships. By recognizing the unique needs and challenges of individuals with FASD, support workers were able to provide tailored support and promote client independence and self-advocacy. These findings align with the existing literature emphasizing the importance of person-centered approaches and effective communication in supporting individuals with FASD.

Well-being of Support Workers

The interview revealed the significant impact of the pandemic on the well-being of support workers. Like healthcare workers, support workers experienced increased rates of

depression, anxiety, burnout, and other mental health issues. The demanding nature of their roles, combined with the uncertainties and heightened stress of supporting vulnerable individuals during global crisis, contributed to their psychological challenges. The well-being of support workers is crucial for ensuring their effectiveness in providing support to clients with FASD during times of societal upheaval. The findings align with existing literature on the mental health implications faced by healthcare workers during the pandemic.

Marginalization and Vulnerabilities

The study also highlighted the marginalization and vulnerabilities faced by individuals with FASD and their support workers during times of societal distress. Individuals with FASD are a marginalized population, and the pandemic has further exacerbated their challenges, such as homelessness and limited access to necessary resources and support systems. Support workers face additional complexities and risks in providing assistance during crises, including increased exposure to infectious diseases and disruptions to regular support services. These findings align with existing literature emphasizing the vulnerability of individuals with mental health issues and cognitive impairments during crises.

In conclusion, this study provides valuable insights into the lived experience of support workers who have worked with clients with FASD during the COVID-19 pandemic. The findings reveal the challenges faced by support workers in providing necessary supports, building rapport, and addressing the mental health needs of their clients. The study also highlights the strategies and adaptations employed by support workers, the impact on their well-being, and the marginalization status and vulnerabilities of individuals with FASD and their support works during times of societal upheaval. The integration of existing literature further strengthens the understanding of these issues and emphasizes the need for targeted interventions,

policies, and support systems to better support individuals with FASD and their support workers during crises and similar future events.

Reflexivity

In phenomenological research, reflexivity is not just a methodological tool but a vital lens through which the entire research process is viewed and understood. This practice, as articulated by Finlay (2002), involves a continuous and critical engagement with one's own subjective experiences, biases, and preconceptions, ensuring they are acknowledged and scrutinized at every stage of the research. My background as a support worker at Turning Leaf Services, closely aligned with the study's population, brought a unique depth to this reflexivity. Throughout this study, my role as both a researcher and a support worker created a dual lens of introspection and understanding. This dual perspective was instrumental in critically examining how my personal experiences, beliefs, and interactions with clients, especially those with Fetal Alcohol Spectrum Disorder (FASD), might color my interpretation of the data. By actively reflecting on these experiences, I sought to minimize their influence on the findings, aiming for a nuanced portrayal of the support workers' lived experiences during the COVID-19 pandemic. My firsthand knowledge as a support worker at Turning Leaf Services allowed me to recognize and set aside preconceived notions about the challenges and dynamics involved in working with FASD clients. This self-awareness was crucial in approaching the data collection and analysis with an open mind, allowing me to be fully receptive to the participants' unique perspectives and insights without the interference of my pre-existing assumptions. Moreover, my background as a support worker enriched the interview process. It facilitated a deeper connection and understanding with the participants, fostering a space of empathy and shared experience. This connection, however, also required careful navigation to ensure that my own emotions and

reactions, borne out of personal experience, did not overshadow the narratives of the participants. Such self-monitoring was a continuous aspect of the reflexive process, enhancing the authenticity of the data interpretation. The reflexive journey was an ongoing process throughout the data analysis and interpretation phases. Regular introspection allowed me to identify and challenge my own biases and assumptions, ensuring that the interpretations remained true to the participants' voices and experiences. This iterative process of reflexivity was not just about self-awareness but also about refining the interpretations to ensure they resonated authentically with the realities of the support workers I was studying.

In conclusion, the integration of my personal experiences as a support worker into the reflexive process has significantly contributed to the rigor and validity of this study. It has allowed for a deeper, more empathetic engagement with the data, ensuring that the collection, analysis, and interpretation phases were approached with an openness and transparency that might not have been possible otherwise. By navigating my dual roles and minimizing the influence of my personal perspectives, the findings presented in this study aim to offer an authentic and nuanced understanding of the participants' experiences. This reflexive journey has enriched the phenomenological exploration of support workers' experiences with FASD clients during the COVID-19 pandemic, adding depth and authenticity to the research findings.

Chapter 5: Discussion

Recapitulation of Findings

Based on the information and insights gathered from the interviews conducted in this study, a recapitulation of findings reveals several key themes and observations related to the lived experience of support workers who worked with clients with FASD during the COVID-19 pandemic. These findings shed light on the challenges faced by support workers, the impact on their relationships with clients, and the strategies employed to navigate these difficulties.

One prominent theme that emerged from the interviews was the increased difficulty in providing support to clients with FASD during the pandemic. Support workers highlighted the challenges of adapting to rapidly changing circumstances, such as shorter visits and limited access to resources and recreational activities. The lack of consistency and routine, which are essential for individuals with FASD, posed significant barriers to their well-being and progress. Additionally, the restrictions on transportation and the closure of essential support services further compounded the challenges faced by both support workers and their clients.

Another significant theme centered on the impact of the pandemic on the relationships between support workers and their clients with FASD. The importance of building rapport and trust emerged as a crucial aspect of successful support worker-client relationships. However, the pandemic presented obstacles in establishing and maintaining trust, particularly for support workers who had limited prior contact with clients. The limitations on in-person interactions and the need for physical distancing disrupted the continuity and depth of the relationships, highlighting the need for innovative approaches to maintain connections and ensure ongoing support.

Interpretation of Findings

The findings from the interviews provided rich insights into the challenges, experiences, and perspectives of support workers in their interactions with clients with FASD during the pandemic. The themes that emerged, such as the increased difficulty in providing support, the impact on relationships, and the strategies employed, offer a comprehensive understanding of the phenomenon being explored.

One of the central themes that emerged was the increased difficulty in supporting clients with FASD during the pandemic. Support workers expressed the challenges they faced in adapting to the rapidly changing circumstances, such as the shortened visits and limited access to resources. These challenges affected the ability to provide consistent and comprehensive support, which is particularly crucial for individuals with FASD who rely on routine and consistency. The interviews shed light on the frustration and limitations experienced by support workers in meeting the diverse needs of their clients while adhering to pandemic restrictions and protocols.

The findings also highlighted the significant impact of the pandemic on the relationships between support workers and their clients with FASD. Building rapport and trust emerged as fundamental aspects of successful support worker-client relationships. However, the pandemic introduced barriers to establishing and maintaining trust, particularly for support workers who had limited prior contact with clients. The disruption of in-person interactions and the need for physical distancing posed challenges to the depth and continuity of these relationships. The interviews revealed the resilience and adaptability of support workers as they found alternative ways to connect and provide support, including through phone calls, messaging, and public meetings while adhering to safety measures.

Moreover, the interviews shed light on the mental well-being of clients with FASD during the pandemic. The increase in substance use, changes in drug preferences, and the subsequent rise in overdose rates underscored the vulnerability of individuals with FASD. Support workers expressed their concern for the limited access to mental health resources and interventions, exacerbating the challenges faced by their clients. The findings emphasize the need for tailored support systems and interventions to address the mental health needs of individuals with FASD during times of societal upheaval.

During the pandemic, the significance of effective communication in the support worker-client relationship was magnified, especially with clients having FASD. The interviews emphasized the unique communication challenges faced by these individuals and highlighted adaptive strategies employed by support workers. Techniques such as using simplified language, encouraging clients to repeat back information, and providing clear, concrete instructions were not just communication aids; they were essential tools for navigating the added complexities brought on by the pandemic. These approaches proved crucial in enhancing comprehension and engagement in a time of heightened uncertainty. More than just promoting effective communication, these strategies played a pivotal role in strengthening the bond and mutual understanding between support workers and their clients with FASD, an aspect particularly crucial in the turbulent times of the pandemic.

As a phenomenological research study, this interpretation emphasizes the subjective experiences and perspectives of support workers. It recognizes the complex interplay of personal, social, and contextual factors that influence their interactions with clients with FASD during the pandemic. The findings highlight the need for a holistic understanding of the phenomenon and

the importance of capturing the nuances and lived experiences of the participants to inform future interventions, policies, and support systems.

Overall, this phenomenological exploration provides valuable insights into the challenges and experiences of support workers who worked with clients with FASD during the COVID-19 pandemic. It deepens our understanding of their lived experiences, the impact on their relationships with clients, and the strategies employed to navigate the difficulties. These findings contribute to the existing knowledge base and provide a foundation for further research, policy development, and the improvement of support systems for individuals with FASD during times of societal difficulties.

Integration with Existing Literature

The integration of existing literature sheds light on the challenges faced by individuals with FASD and support workers during times of societal difficulties, particularly in the context of the COVID-19 pandemic. The literature review reveals several key themes and findings that are relevant to understanding the experiences and needs of this marginalized population and the impact of the pandemic on their well-being.

One significant area of literature that informs this study is the examination of the detrimental effects of the COVID-19 pandemic on alcohol consumption. Finlay and Gilmore (2020) highlight the increase in alcohol sales during the pandemic, which raises concerns about the potential risks faced by individuals with FASD. The heightened alcohol consumption during the pandemic may lead to an increased number of babies born with FASD and exacerbate the challenges faced by this population. Sher (2020) emphasizes the urgent need to address FASD prevention and its often-permanent effects, which have been overlooked in broader discussions about lowering alcohol consumption. This literature underscores the heightened risk of FASD

during the pandemic and calls for proactive measures to protect individuals from the potential harms associated with alcohol use.

Furthermore, Ghosh and Sharma (2021) highlight the disruption of screening and intervention for substance use disorders during the pandemic, which further compounds the challenges faced by individuals with FASD seeking help in this regard. The limited access to resources and support during the pandemic poses significant barriers for individuals with FASD in receiving the necessary interventions and assistance for managing substance use disorders. Understanding the complex interplay between the pandemic, alcohol consumption, and the risks faced by individuals with FASD is crucial for developing targeted strategies, interventions, and support systems to mitigate these risks and provide necessary support during times of societal upheaval.

The literature also addresses the relationship between support workers and clients with FASD. Bagley and Badry (2019) highlight the limited knowledge of FASD and its exclusion from training, support, and diagnostic contexts, which hinders support workers' ability to fully understand and address the unique needs of their clients. This knowledge gap underscores the importance of incorporating FASD education and training into support worker programs to enhance their understanding and effectiveness in providing tailored support and appropriate interventions. Support workers characterized their experience of working with the FASD population as challenging, describing it as a steep learning curve. They noted that adapting to the specific needs of this group was a continuous process, which became even more demanding during the pandemic.

To overcome these challenges, support workers can adopt anti-discriminatory and rights-based approaches that recognize the inherent dignity and worth of their clients (Bagley & Badry,

2019). By demonstrating genuine concern, compassion, and a compassionate understanding of their clients' experiences, support workers can strengthen the bond and trust with individuals with FASD. These person-centered approaches promote better outcomes for individuals with FASD and improve their overall well-being. Participants highlighted the importance of maintaining consistent presence during the pandemic, in various forms, and observed that their relationships with participants notably strengthened during this period.

Effective communication is crucial in fostering a successful worker-client relationship, particularly for individuals with FASD who experience difficulties in various aspects of communication. Melrose (2019) suggests strategies such as encouraging clients to reiterate information in their own words and using simple and concrete language to enhance comprehension and reduce confusion. These communication strategies create a conducive environment for effective information exchange and foster a strong worker-client connection.

The literature also highlights the impact of the COVID-19 pandemic on the well-being of support workers. Research by Tella et al. (2020) and Kim et al. (2021) on healthcare workers reveals increased rates of depression, anxiety, burnout, and mental health issues during the pandemic. These findings can be generalized to support workers who face similar challenges and heightened stress in supporting vulnerable individuals during a global crisis. Recognizing and addressing the mental health needs of support workers is crucial for ensuring their resilience, effectiveness, and overall well-being in providing vital support to clients with FASD during times of societal upheaval.

Moreover, literature emphasizes the unique challenges and vulnerabilities faced by individuals with FASD and their support workers during times of societal distress. Historical evidence suggests that vulnerable populations, including those with mental health issues and

cognitive impairments, are disproportionately affected by crisis. Makwana (2019) highlights the increased difficulties faced by these populations in accessing necessary resources, support systems, and healthcare services during crises. This understanding underscores the need to develop targeted interventions, policies, and support systems that promote resilience, enhance advocacy efforts, and foster improved outcomes for individuals with FASD and their support workers during times of societal upheaval.

By integrating the findings from existing literature, this study contributes to a deeper understanding of the challenges faced by clients with FASD and support workers during the COVID-19 pandemic. The literature review highlights the detrimental effects of the pandemic on alcohol consumption, the importance of FASD education for support workers, the significance of person-centered approaches and effective communication in the worker-client relationship, the impact of the pandemic on the well-being of support workers, and the unique challenges faced by individuals with FASD and their support workers during times of societal distress. This knowledge informs the development of targeted interventions, policies, and support systems that can better support individuals with FASD and their support workers in times of crises and similar future events.

Comparison with Previous Research

In comparing the findings of this study with previous research, it is evident that the experiences of support workers who worked with clients with FASD during the COVID-19 pandemic align with broader themes and trends identified in the existing literature. The literature review highlighted the detrimental effects of the pandemic on alcohol consumption and the potential risks faced by individuals with FASD. This study's findings echoed those concerns,

revealing an increase in substance use, changes in drug preferences, and the subsequent rise in overdose rates among clients with FASD during the pandemic.

Moreover, the literature review emphasized the challenges faced by individuals with FASD in accessing necessary resources and support systems. This study's findings corroborated these challenges, particularly in relation to the limited availability of mental health resources, disrupted access to support groups and interventions, and the closure of essential service providers. The experiences of support workers align with previous research, highlighting the impact of these limitations on the well-being and ability of clients with FASD to access the support they require.

The themes emerging from the interviews, such as the importance of building trust and rapport, the impact of limited routine and consistency, and the challenges in adapting to changing circumstances, resonate strongly with existing literature on working with individuals with FASD. The literature emphasizes the significance of understanding FASD and the necessity for tailored training and support for professionals in this field. Bagley and Badry (2019) highlight the knowledge gap in FASD among support workers, which impacts their ability to offer appropriate support. The study's findings echo these concerns, with support workers detailing the limitations of their training and its effect on their support capabilities. Furthermore, the increased risks associated with the heightened alcohol consumption during the pandemic, as outlined by Finlay and Gilmore (2020), and the disruptions in substance use disorder interventions noted by Ghosh and Sharma (2021), emphasize the exacerbated challenges faced by individuals with FASD and the critical need for informed, empathetic support during such crises. Similarly, the communication strategies identified by Melrose (2019) for individuals with FASD, such as using simplified language and encouraging repetition, align with the findings of this study, indicating

their effectiveness in enhancing understanding and engagement. The overarching theme of fostering a successful worker-client relationship through patience, compassion, trust, and clear communication, as discussed by Green (2007) and State et al. (2011), further corroborates the study's findings. These elements are crucial, especially during times of societal upheaval like the COVID-19 pandemic, where support workers face challenges similar to those experienced by healthcare workers, as indicated by Tell et al. (2020) and Kim et al. (2021). The insights from this study, therefore, not only align with but also add depth to the existing literature, highlighting the ongoing need for comprehensive understanding and support strategies for professionals working with the FASD population, particularly during challenging times like pandemics.

Moreover, effective communication was identified as a key element in the support worker-client relationship, with the strategies observed in this study aligning with prior research recommendations. The adoption of simplified language and encouraging clients to reiterate information, as advocated by Melrose (2019), have been recognized as effective communication strategies for individuals with FASD. The study's findings further reinforce the importance of these approaches in promoting effective communication. Providing clear and concrete instructions, a technique emphasized in this study, aligns with the communication needs of individuals with FASD as highlighted by Brown et al. (2007), who emphasize the importance of straightforward, unambiguous communication. The consistency of these findings with previous literature not only validates the current study's outcomes but also stressed the crucial role of tailored communication strategies in enhancing the support worker-client relationship, particularly for those with FASD. This is especially pertinent given the unique communication challenges faced by this population, such as difficulties with auditory processing and interpreting

social cues, which necessitate adapted and thoughtful communication approaches to foster a stronger, more effective connection between support workers and their clients.

Overall, the comparison with previous research reveals consistency and alignment in the experiences and challenges faced by support workers who worked with clients with FASD during the pandemic. The findings of this study contribute to the existing literature by providing specific insights into the lived experiences and perspectives of support workers, highlighting the unique challenges posed by the pandemic, and underscoring the need for tailored support systems and interventions for individuals with FASD during times of societal upheaval.

The study contributes significantly to the existing body of knowledge by providing detailed insights into the dynamics of the support worker-client relationship, particularly in the context of working with individuals with FASD during the COVID-19 pandemic. It offers a nuanced understanding of the challenges and strategies specific to this period of societal upheaval, which is not extensively covered in the existing literature. The emphasis on effective communication strategies and the unique stressors faced by both support workers and clients with FASD during the pandemic adds a new dimension to our understanding of these relationships. However, the interpretation of these findings must be contextualized within the limitations of this study, including its small sample size and the socio-cultural and geographical setting in which the research was conducted. These factors may limit the generalizability of the results. Future research could enhance our understanding by investigating the experiences of support workers in diverse settings and examining additional variables that impact the support worker-client relationship during challenging times. Such studies would not only validate and expand upon the findings of this study but also enrich the broader discourse on the care and support of individuals with FASD.

Theoretical Insights

In this section, we will explore the theoretical insights that emerge from the phenomenological exploration of support workers' experiences in working with clients with FASD during the COVID-19 pandemic. Phenomenological research allows for a deeper understanding of the subjective experiences and meaning-making processes of individuals, shedding light on the underlying theoretical implications of the study (Finlay, 2009).

Embodiment and Lived Experience

This study emphasizes the deeply embodied nature of the support worker-client relationship, especially in the context of working with individuals with FASD. Support workers highlighted not only the verbal aspects of communication but also the profound impact of non-verbal cues, such as body language, facial expressions, and tone of voice. These non-verbal elements are integral to building rapport, trust, and understanding with clients. The physical presence of the support worker, along with their ability to read and respond to these subtle cues, plays a crucial role in establishing a strong, empathetic connection. This embodied approach to communication goes beyond mere words; it involves a holistic sensory engagement, where gestures, eye contact, and even the physical environment contribute to the effectiveness of interaction.

Furthermore, the study reveals how the pandemic has intensified the sensory and emotional aspects of these relationships. The physical constraints and heightened emotional stress of the pandemic have altered the ways in which support workers and clients interact, making the nuances of embodied communication even more significant. For instance, the increased reliance on virtual communication platforms may have limited some aspects of embodied interaction, necessitating a greater awareness and adaptation to the remaining sensory

cues. The embodied experiences of both support workers and clients during the pandemic – encompassing stress, anxiety, and the need for reassurance – are intricately woven into the dynamics of their interactions. These experiences shape not only the methods of communication but also the overall quality and effectiveness of the support provided.

In essence, the findings of this study accentuate the importance of considering the embodied and sensory dimensions of the support worker-client relationship. Understanding and responding to these dimensions is vital for effective communication and support, particularly in challenging times like the COVID-19 pandemic. The embodied experience of support workers and clients with FASD are pivotal in shaping their interaction, thereby influencing the success and satisfaction of both parties in the relationship.

Social Construction of Reality

The study reveals the impact of social and environmental factors on the experiences of support workers and clients with FASD. The restrictions imposed during the pandemic, such as limited access to resources, closure of essential services, and changes in routine, influenced the well-being and support available to clients. These findings align with the social constructionist perspective, which posits that individuals' experiences are shaped by the socio-cultural context in which they are situated (Berger & Luckmann, 1966). The pandemic acted as a powerful social force, impacting the support worker-client relationship and highlighting the significance of the broader societal context in understanding their experiences.

Intersectionality and Marginalization

The experiences of support workers and clients with FASD during the pandemic emphasize the intersectional nature of their identities and the resulting vulnerabilities and marginalization they face. Individuals with FASD, already a marginalized group, saw their

challenges intensified by the pandemic. This was further compounded by intersecting factors such as substance use, mental health issues, homelessness, and limited access to resources, exacerbating the difficulties faced by this population. Additionally, the pandemic influenced how support workers interacted with their clients, affecting the dynamics of their relationship from support workers' own perspectives as well. This altered interaction highlights the importance of understanding these experiences through an intersectional lens, which is crucial for informing targeted support and interventions tailored to the needs of individuals with FASD and their supports in such challenging times.

Reflexivity and Ethical Considerations

These theoretical insights, including the nuances of reflexivity and ethical considerations, significantly enhance our understanding of the support worker-client relationship within the context of FASD and the COVID-19 pandemic. Reflexivity involves the conscious acknowledgment and examination of the researcher's own biases, perspectives, and influence on the research process (Finlay, 2002). This introspection is critical in understanding how personal experiences and values of both support workers and researchers might shape their interactions with clients and the interpretation of data. By embracing reflexivity, researchers and practitioners can better navigate the complex interplay between their own experiences and those of their clients, leading to more empathetic and effective support strategies.

Ethical considerations, on the other hand, provide a framework for respecting the dignity, rights, and well-being of individuals with FASD. These considerations guide the conduct of research and practice, ensuring that the vulnerabilities of individuals with FASD are safeguarded, especially during challenging times like the pandemic. The inclusion of ethical considerations in research and practice emphasizes the need for informed consent, confidentiality, and the

protection of participants from harm. It also highlights the importance of culturally sensitive approaches that respect the diverse backgrounds and experiences of individuals with FASD.

Together, reflexivity and ethical considerations offer profound insights into the dynamics of the support worker-client relationship. They underline the importance of self-awareness and ethical responsibility in shaping interactions and interventions. By integrating these theoretical insights, along with an understanding of embodied experiences, socio-cultural factors, and intersectionality, future research, policy development, and practice can adopt a more holistic and informed approach. This comprehensive strategy is essential to support individuals with FASD effectively and address their unique needs during times of societal upheaval, ensuring that their care is not only supportive but also respectful and ethically sound.

It is essential to acknowledge that these theoretical insights are based on the specific context and findings of this study. Future research can further explore and expand upon these insights, considering diverse contexts, populations, and theoretical frameworks to deepen our understanding of the support worker-client relationship and its implications for individuals with FASD.

Practical Implications

The findings of this phenomenological research study hold several practical implications for support workers, organizations, and policymakers involved in providing assistance to individuals with FASD during times of societal difficulties, such as the COVID-19 pandemic.

Firstly, the study highlights the critical importance of building and maintaining rapport and trust between support workers and clients with FASD. Support workers should prioritize establishing strong relationships based on mutual respect, understanding, and reliability. This can be achieved by investing time and effort in getting to know the unique needs and preferences of

each individual, as well as actively involving them in decision-making processes. By fostering a sense of trust and security, support workers can enhance their effectiveness in providing support and facilitating positive outcomes for individuals with FASD.

Secondly, it is essential to recognize the impact of the COVID-19 pandemic on the mental health and well-being of support workers themselves. Organizations and policymakers should prioritize the provision of adequate resources and support systems to address the increased risks of burnout, stress, and emotional strain faced by support workers during times of crisis. This includes implementing strategies for self-care, promoting work-life balance, and ensuring access to mental health resources and support networks. By prioritizing the well-being of support workers, organizations can enhance the quality of care provided to individuals with FASD and improve overall outcomes.

Furthermore, the study emphasizes the need for targeted interventions and support systems that address the unique challenges faced by individuals with FASD during times of societal upheaval. This includes ensuring continued access to essential resources, such as mental health services, substance use disorder interventions, and social support networks. Organizations and policymakers should work collaboratively to develop and implement strategies that bridge the gaps in service provision, mitigate the impact of disruptions, and ensure the continuity of care for individuals with FASD.

Additionally, the findings underscore the importance of effective communication strategies when working with individuals with FASD. Support workers should employ clear and concrete language, encourage active engagement, and provide opportunities for clients to clarify and reiterate information. By adapting communication styles to meet the unique needs of

individuals with FASD, support workers can enhance understanding, facilitate meaningful interactions, and strengthen the worker-client relationship.

Lastly, the study highlights the need for ongoing training and education for support workers on FASD awareness, understanding, and interventions. Organizations should prioritize providing comprehensive training programs that equip support workers with the knowledge and skills necessary to effectively support individuals with FASD during times of crisis. This includes training on recognizing and responding to the specific needs and challenges associated with FASD, as well as strategies for crisis management and adaptation during times of societal difficulties.

In summary, the practical implications derived from this phenomenological research study emphasize the importance of building rapport, prioritizing support worker well-being, developing targeted interventions, enhancing communication strategies, and providing ongoing education and training. By implementing these practical recommendations, support workers, organizations, and policymakers can enhance the quality of support and care provided to individuals with FASD during times of societal upheaval, ultimately improving their well-being and outcomes.

Limitations

While this phenomenological research study provides valuable insights into the lived experiences of support workers who have worked with clients with FASD during the COVID-19 pandemic, it is important to acknowledge certain limitations that may have influenced the findings and interpretation of the data.

Firstly, the sample size of this study was relatively small, consisting of five participants. While efforts were made to ensure diversity in terms of age, gender, and experience, the findings

may not fully capture the range of experiences within the broader population of support workers. Therefore, caution should be exercised when generalizing the results to a larger population (Creswell, 2013).

Secondly, the study relied on self-reported data obtained through interviews. It is important to recognize that the subjective nature of individual experiences and perceptions may introduce bias or recall inaccuracies. Participants' recollection of events and their ability to articulate their experiences may be influenced by various factors such as memory limitations or social desirability bias. I made efforts to establish rapport and create a safe and comfortable environment for participants to share their experiences, but it is still important to acknowledge the potential for subjective interpretation (Creswell, 2013; Moustakas, 1994).

Thirdly, the study focused on the experiences of support workers during the COVID-19 pandemic, which represents a specific period of time characterized by unique circumstances and challenges. It is crucial to consider the context in which the study was conducted and recognize that the findings may not fully capture the experiences of support workers in other contexts or during different crises or societal difficulties (Creswell, 2013; Moustakas, 1994).

Furthermore, the research was conducted within a specific geographical location, which may limit the generalizability of the findings to other regions or cultural contexts. Cultural factors and variations in support systems and resources may influence the experiences and challenges faced by support workers and individuals with FASD. Therefore, caution should be exercised when applying the findings to different cultural or regional settings (Creswell, 2013).

Lastly, it is important to acknowledge the potential influence of my own biases and perspectives on the interpretation of the data. My background, assumptions, and prior experiences may have shaped the framing of the research questions, the selection of participants,

and the interpretation of the findings. To mitigate this limitation, I employed reflexivity and engaged in ongoing critical reflection throughout the research process (Creswell, 2013; Moustakas, 1994).

Despite these limitations, this phenomenological research study provides valuable insights into the lived experiences of support workers who have worked with clients with FASD during the COVID-19 pandemic. The limitations should be considered when interpreting the findings and applying them to practice and policy. Future research endeavors can build upon this study by exploring a larger and more diverse sample, conducting longitudinal studies to capture changes over time, and considering the influence of cultural and contextual factors on the experiences of support workers and individuals with FASD.

Contributions and Further Directions

Contributions

This phenomenological research study has made several significant contributions to the understanding of the lived experiences of support workers who have worked with clients with FASD during the COVID-19 pandemic. By delving into the rich narratives of support workers, this study has shed light on the challenges, adaptations, and implications for the worker-client relationship during times of societal upheaval. The findings have practical implications for support workers, organizations, and policymakers, offering insights to enhance support strategies and interventions for individuals with FASD. Moreover, this study contributes to the broader literature on FASD and pandemics, filling a gap in research on the specific experiences and needs of support workers in this context.

One key contribution of this study is the identification of the challenges faced by support workers during the pandemic. The findings highlight the difficulties in providing consistent

support, maintaining trust, and addressing the unique needs of individuals with FASD. By acknowledging these challenges, support workers and organizations can better understand the complexities of their roles and develop targeted interventions and training programs to equip support workers with the necessary knowledge and skills to navigate crises effectively.

Furthermore, this study emphasizes the importance of person-centered approaches and effective communication in the worker-client relationship. The insights gained from support workers' experiences can inform the development of best practices that prioritize rapport-building, trust, and the provision of tailored support for individuals with FASD. Practitioners can utilize these findings to enhance their interactions with clients, promote client independence and self-advocacy, and foster better outcomes for individuals with FASD.

Further Directions

Building upon the findings of this study, several avenues for further research and exploration emerge. First, future studies could focus on the experiences of clients with FASD themselves, providing a deeper understanding of their perspectives, needs, and challenges during times of societal upheaval. This client-centered approach would complement the insights gained from support workers and provide a more comprehensive understanding of the worker-client dynamic.

Additionally, there is a need for longitudinal research to capture the long-term effects of the pandemic on individuals with FASD and their support workers. By examining changes in support needs, mental health outcomes, and the sustainability of support systems over time, researchers can identify patterns and trends that can inform the development of targeted interventions and policies.

Moreover, research should extend beyond the COVID-19 pandemic to explore the experiences of support workers and clients with FASD during other crises and societal difficulties. Comparing and contrasting the findings across different contexts would provide valuable insights into the universal and context-specific challenges faced by support workers and individuals with FASD. This broader perspective would contribute to the development of more comprehensive and adaptable support strategies.

Lastly, future studies should consider cultural and regional variations in the experiences of support workers and individuals with FASD. Exploring the impact of cultural factors, social support networks, and available resources on the worker-client relationship would enhance our understanding of the complexities of providing support in diverse cultural contexts.

By addressing these further directions, researchers can continue to expand the knowledge base, enhance support practices, and advocate for the needs of individuals with FASD during times of societal upheaval.

Overall, this phenomenological research study provides valuable contributions to the field of support work for individuals with FASD during the COVID-19 pandemic. The findings and further directions outlined here lay the foundation for future research endeavors that can continue to improve support systems, policies, and interventions, ultimately fostering better outcomes and enhancing the well-being of individuals with FASD.

Reflexivity and Researcher's Personality

As the researcher of this study, it is essential to acknowledge the role of reflexivity and the potential influence of my personality on the research process and findings. Reflexivity refers to the researcher's self-awareness and critical reflection on their own biases, assumptions, and experiences that may impact the research process and interpretation of findings (Finlay, 2002). In

this phenomenological research study exploring the experiences of support workers who worked with clients with FASD during the COVID-19 pandemic, my personality and personal experiences as a support worker during the pandemic may have influenced the research process.

The INTJ personality type is characterized by traits such as analytical thinking, logical reasoning, and a preference for structure and planning (Myers-Briggs Type Indicator, n.d.). These traits may have influenced the research design, data collection, and analysis process. As an INTJ researcher, the study was approached with a systematic and organized approach, ensuring rigorous data collection and analysis procedures. My analytical thinking may have facilitated a deep exploration of the participants' experiences and the identification of underlying themes and patterns.

Furthermore, my experience as a support worker during the pandemic working with individuals with FASD adds a valuable perspective to the research process. My firsthand knowledge and understanding of the challenges, adaptations, and implications faced by support workers and individuals with FASD may have allowed for a more nuanced interpretation of the findings. This experiential knowledge may have contributed to a deeper empathy and sensitivity towards the participants' experiences, enhancing the researcher-participant connection and the trustworthiness of the data.

However, it is important to acknowledge that my personality and experiences may also introduce potential biases and limitations to the study. As an INTJ researcher, there may be a natural inclination towards objectivity and a focus on rationality, which may influence the interpretation of subjective experiences. It is crucial to engage in ongoing critical self-reflection to recognize and challenge any preconceived notions or assumptions that may inadvertently shape the research process or analysis.

To mitigate the potential biases, I actively engaged in reflexivity by maintaining a reflexive journal throughout the research process. This journal allowed for self-reflection, documenting personal experiences and biases, and questioning any assumptions that emerged during data analysis. Regular consultations with the supervisor also facilitated critical discussions to challenge and ensure the research process remained open, transparent, and accountable.

By acknowledging and practicing reflexivity, I aimed to minimize any potential bias and enhance the trustworthiness of the findings. This reflexive approach contributed to a more comprehensive understanding of the worker-client relationship during the pandemic and the lived experiences of individuals with FASD.

In conclusion, my personality as an INTJ and personal experiences as a support worker during the pandemic played a significant role in shaping the research process and interpretation of findings. My systematic approach, analytical thinking, and experiential knowledge enriched the study's depth and insights. However, it is important to recognize and address potential biases through ongoing reflexivity and critical self-reflection. By employing such reflexivity, I aimed to ensure the integrity and trustworthiness of the study, ultimately contributing to a more comprehensive understanding of the worker-client relationship during times of societal upheaval and the experiences of individuals with FASD.

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Appendix A

Subject Line: The Lived Experience of Community Support Workers

Title of Study: The Impact of Covid-19 on Support Workers of Clients with FASD

Hello (Name of Organization),

I'm currently a MSc student at the University of Lethbridge. I'm reaching out today to request approval to use (Name of Organization) employees as participants in my research study.

My goal for this research study is to understand the lived experience of front-line workers who have worked throughout the COVID-19 pandemic while supporting participants with Fetal Alcohol Spectrum Disorder (FASD).

Furthermore, my study will attempt to provide knowledge and clarity surrounding the impact of the pandemic on the worker-client relationship. With the completion of this research, it's my hope that the results can aid in further support for front-line workers and participants during times of societal upheaval.

Who Can Participate?

- Front-line employees who work in the community
- Employed during the COVID-19 pandemic
- Supported participants with diagnosed or suspected FASD during the pandemic
- Can commit to a 1-hour interview over Zoom with myself

Why Participate?

- To take an active role in society and exercise one's autonomy
- To contribute towards the advancement of similar research
- To let one's lived experience be heard and appreciated
- To contribute to the understanding of what it's like to be a front-line worker

Please note that there will be audio recording of interviews. Additionally, an incentive for participation in this study will be offered to participants.

If your organization is in support of this request, I will provide you with an email to forward to your employees. The employees will then contact the researcher directly if they wish to participate.

Please let me know if you have any questions I could answer or concerns I could address. Thank you for your consideration of my research study.

Best,

Sydney Bulmer
University of Lethbridge
MSc Student, Addictions Counselling
bulmer@ualberta.ca

Ethics ID: Pro00124468

Appendix B

Interview Questions

1. What was your experience like working during the pandemic?
2. How did the pandemic impact your ability to support your client with FASD?
3. What aspects of the relationship with your client would you consider important in terms of success?
4. What aspects of your relationship with your client were impacted by the pandemic?
5. Did you notice any changes in your client's wellbeing (mental or physical) during the pandemic?
 - If yes, what exactly?
6. How do you think the pandemic impacted your client and their ability to take care of themselves or access resources?
7. What further support do you think your client could have benefited from?
8. How would further support have been beneficial for your ability to effectively support your client?
9. Did you use additional strategies to support your client in response to the impact caused by the pandemic?
 - If yes, what did you do?
10. Can you tell me an example of when you were tasked in supporting a client and the pandemic impacted your ability to successfully accomplish this?
11. What was your experience like when you encountered a roadblock caused by the pandemic while supporting your client?

12. What recommendations or suggestions would you provide to individuals who were in a similar work situation as you during the pandemic?

Appendix C

PARTICIPANT CONSENT FORM

Title of Study: Support Workers' Experiences with Clients with FASD During the Covid-19 Pandemic

Principal Investigator: Sydney Bulmer
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Supervisor: James Sanders
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You are being invited to take part in a research study. Before you take part, a member of the study team is available to explain the project and you are free to ask any questions about anything you do not understand. You will be given a copy of this form for your records.

Why am I being asked to take part in this research study?

You are being asked to participate in this study because you are a support worker who worked during the Covid-19 pandemic and supported clients with FASD during that time.

What is the reason for doing the study?

The goal of this study is to understand your experience as a support worker having worked during the pandemic while supporting clients with FASD.

What will I be asked to do?

You will be taking part in a 1-hour interview over Zoom or Microsoft Teams about your experience as a support worker. There will be no video recording so you may turn your camera off during the interview if you wish.

The interviews will be audio recorded using Otter.ai transcription software. In addition, the researcher will document with notes during the interview. The transcribed interview will be stored on the researcher's password protected computer. Your name will not be used at any point after the interview to ensure confidentiality.

What are the risks and discomforts?

You are required to reflect on your time working during the pandemic. For you, the pandemic may have been a period of stress and emotional turmoil. You may feel stress of anxiety recounting your experience of working during the pandemic.

You do not have to answer any questions you do not want to. The researcher will remind you that anything you have to say will be confidential. The researcher will provide contact information for Canadian Mental Health Association (CMHA) as a resource for you.

It is not possible to know all of the risks that may happen in a study, but we have taken all reasonable safeguards to minimize any known risks to you.

What are the benefits to me?

While there may not be any direct benefit to you, results from this study may help us learn more about support workers and similar front-line staff who have worked during the pandemic. Additionally, the research will provide insight into the worker-client relationship between workers and their clients with FASD, and similar diagnoses. Moreover, this research will provide insight into how the pandemic, and similar instances, impact vulnerable populations like individuals living with FASD.

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any point during the interview or a maximum of 2 weeks after your interview has taken place. After that point we cannot remove you from the study because your interview will be transcribed, and the data analyzed. To withdraw from the study please contact Sydney Bulmer (bulmer@uleth.ca)

If you choose to withdraw from the study, your information will be destroyed. The researcher will shred any notes that were taken during the interview and the audio recording of the interview will be deleted from the researcher's computer and the Otter.ai database. Per Otter.ai privacy policy, the transcribed interview will be irrecoverable.

Will I be paid to be in the research?

For participating in this study, you will receive a Tim Horton's E-Gift Card valued at \$10. If you choose to withdraw from the study, you will still be entitled to the gift card.

Will my information be kept private?

During this study we will do everything we can to make sure that all information you provide is kept private. No information relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

When your interview is transcribed, we will assign a pseudonym (fake name) to protect your identity. If you would like to choose your own fake-name, please say so in the interview.

The transcribed interview will be stored on the researcher's computer and the Otter.ai database.

The information from this study will be seen only by the researcher and the researcher's supervisor. On occasion, this data will need to be checked for accuracy. For this reason, your data may also be looked at by people from the Research Ethics Board or by the University of Alberta auditors.

What will happen to the information or data that I provide?

The information you provide will form part of Sydney Bulmer's Master's thesis at the University of Lethbridge. It may also be used as part of public or academic presentations, in news or academic publications, as well as for examples during teaching. At no point will you be identified in this work.

While the data is being analyzed it will be stored on the researcher's password protected computer and in encrypted files.

After the study is done, we will store your data for a minimum of 5 years. Files will be encrypted, password protected, and behind secure firewalls. A copy of the data will be stored on the supervisor's secure Google Drive.

Conflict of Interest

The researcher is employed as a Community Support Worker at Turning Leaf Services. You may be employed at the same organization with the same job title. The researcher will clearly state to you that even though you may work at the same organization as the researcher, you do not have to participate if you do not wish to, and there will be no repercussions for not participating.

What if I have questions?

If you have any questions about the research now or later, please contact Sydney Bulmer (bulmer@uleth.ca)

If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca and quote Ethics ID Pro00124468. This office is independent of the study investigators.

The study is being conducted through the University of Lethbridge.

How do I indicate my agreement to be in this study?

Your verbal consent to be in this study will be recorded before the interview begins.

By verbally stating below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study at any time.
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.
- That you agree to the data being stored as part of a data repository.

VERBAL SIGNATURE OF STUDY PARTICIPANT

_____ Pseudonym (if necessary) _____
Name of Participant

Date

VERBAL SIGNATURE OF PERSON OBTAINING CONSENT

_____ _____
Name of Person Obtaining Consent Contact Number

A copy of this information and consent form has been given to you to keep for your records and reference.