Quality of life of children with autism from a family’s perspective during the Covid – 19 pandemic: A comparative case study

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DEDICATION

This thesis is dedicated to my family; My mother, my everything, I wouldn’t be where I am today without her; My father, my backbone, without him I would’ve lost my mind; My brother, my punching bag, without his support I would be lost.

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ABSTRACT

This research explores the impact of the COVID-19 pandemic on the quality of life (QoL) of families with children diagnosed with Autism Spectrum Disorder (ASD). The study specifically aims to explore how the pandemic impacted the psychological, social, physical, and academic domains of QoL for both families and their children with autism. A qualitative descriptive approach was employed, with data collected through online focus groups and one-on-one interviews, with 10 families from the United Kingdom, Kuwait and Saudi Arabia, providing an in-depth view of participants' lived experiences. The data analysis involved both intra-case and cross-case analysis, using Braun and Clarke's thematic analysis approach. The results demonstrated significant disruptions to daily routines, which lead to increased aggressive behaviours and adaptation challenges for children with ASD. Social isolation, exacerbated by social distancing restrictions, heightened feelings of loneliness and emotional distress in both children and parents. Parents faced considerable stress balancing caregiving and work during lockdowns. Despite these challenges, the research also demonstrated a notable resilience among families, who, despite difficulties, strengthened their bonds and discovered positive aspects in their situations. Intra-case analysis provided deep insights into individual family experiences, while cross-case analysis highlighted commonalities and differences across families, offering a nuanced understanding of the pandemic's impact. This research highlights the necessity of a holistic and personalised approach to supporting families of children with ASD during crises, providing valuable insights for improving psychosocial support in similar future events.

Table of Contents

LIST OF TABLES

LIST OF FIGURES

ABREVIATIONS

ACRONYM	DEFINITION
ASD	Autism Spectrum Disorder
BCFQoL	Beach Center Family Quality of Life Scale
CDC	Centers for Disease Control and Prevention
COVID-19	Coronavirus
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM – I	DSM First Edition
DSM – II	DSM Second Edition
DSM – III	DSM Third Edition
DSM – IV	DSM Fourth Edition
DSM – V	DSM Fifth Edition
EUA	Emergency USE Authorizations
FQoL	Family Quality of Life
FDA	Food and Drug Administration
HRQoL	Health-related Quality of Life
ICF	International Classification of Functioning, Disability and Health
IFQoL	International Family Quality of Life Project
IQ	Intelligence Quotient
MERS	Middle East Respiratory Syndrome
MoH	Ministry of Health
NHS	National Health Service
PDD-NOS	Pervasive Developmental Disorder – not otherwise specified
PIS	Participant Information Sheet
PPE	Personal Protective Equipment
PECS	Picture Exchange Communication System
PTSD	Posttraumatic Stress Disorder

QoL	Quality of Life
SARS	Severe Acute Respiratory Syndrome
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus – 2
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
TD	Typically Developing
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
WHOQoL	World Health Organisation Quality of Life

CHAPTER ONE: INTRODUCTION

Children with Autism Spectrum Disorder (ASD) experience the world in profound and distinctive ways; the disorder is complex and refers to a neurodevelopmental condition affecting communication, social interaction and behaviour (Sharma et al., 2018). An autistic child's sensory sensitivities, communicational skills, and social interactions often significantly differ from typically developing (TD) children (DSM-V, 2014, p.50). Navigating in a world that is not typically designed to accommodate their atypical needs can be challenging, requiring families to advocate appropriate changes to be made, to seek therapeutic assistance and to be a source of unwavering support (Meral 2021; Neece et al., 2020). These families, driven by their bond with one another and an understanding of their children's needs, structure their lives around consistency, routine and predictability (Meral 2021; Neece et al., 2020; Sun et al., 2020; Park et al., 2003). A structured environment provides control and security for the children, contributing to their overall health and well-being, enabling them to succeed in a world that does not typically accommodate to their needs.

Yet, the arrival and rapid spread of the Coronavirus (COVID-19) pandemic in March 2020 presented an unprecedented disruption to the world (Yuki et al., 2020; Ciotti et al., 2020). The pandemic resulted in societal lockdowns, school closures, and social distancing protocols, significantly impacting access to services and daily routines (Pierce et al., 2020). Lockdowns and school closures meant the sudden absence of therapeutic assistance and the previously established unwavering support systems, leaving families to navigate their own needs and the needs of their children, alone (Tokatly Latzer et al., 2021). Social distancing protocols disrupted societal circles and routines, damaging vital sources of social development and emotional stability for autistic children (Eshraghi et al., 2020; Fegert et al., 2020; Xie et al., 2020). For families of children with autism, these disruptions were significantly challenging. The constant lockdown changes and unpredictability exacerbated their children's anxiety and behavioural challenges, as well as disrupting access to both support systems and therapies (Neece et al., 2020; Fontanesi et al., 2020). This, in turn, challenged families' coping mechanisms causing ripple effects within families.

1.1 Problem Statement and Research Gap

The autism community continually faces unique challenges that were exacerbated during the pandemic. The pandemic introduced an unprecedented disruption worldwide, profoundly impacting the autism community and their families. The concept of Quality of Life has become a crucial perspective for understanding the experiences of families with autistic children. The concept includes various aspects of their lives, including their psychological, emotional, physical and social well-being (Francisco Mora et al., 2020). Despite the growing body of research exploring the quality of life of family with autistic children, the unprecedented pandemic, and its associated challenges and multifaceted impact, have introduced an additional layer of complexity the families' lives, with limited research on this to-date.

While preliminary research offers valuable insight into exploring the impact of the pandemic on families of autistic children, there is a notable gap regarding in-depth qualitative research that illuminates the lived experiences and perspective of the families. Recent studies have focused on quantitative procedures providing significant but limited insight into the multifaceted and nuanced ways these families faced the challenges brought about by the pandemic. This study addresses this gap by providing rich, robust insights into the lived unique experiences the families of children with autism during the pandemic. Through qualitative methods, this study will explore how families with autistic children adapted to the lockdown disruptions, the methods they employed to cope and the distinctive challenges they faced. By delving into the lived experiences of families, the study seeks to contribute a deeper understanding of the impact the pandemic had on the families' quality of life, to ultimately inform more effective strategies, interventions and resources, tailored to the needs of both the families and their autistic children. Accordingly, this research study aims to address the significant challenges faced by families with autistic children, shedding light on how the pandemic impacted their 'Family Quality of life'.

1.2 Research Aims and Questions

The aims of this research study were to explore the impact of the COVID-19 pandemic on the quality of life of families with children diagnosed with autism spectrum disorder.
More specifically, the breakdown of the aims are:

a) To explore the impact of COVID-19 on the quality of life (i.e., psychological, social, physical and academic) of families with children with ASD.

b) To explore the impact of COVID-19 on the quality of life (i.e., psychological, social, physical, and academic) of children with ASD.

In alignment with these aims, the research questions are constructed as follows:

1. How has the COVID-19 pandemic impacted the overall quality of life for families of children with ASD?

a. **Psychological Impact:** How has the psychological well-being of family members been affected by the pandemic and its associated restrictions?
b. **Social Impact:** In which ways has social interaction and support within families changed during the pandemic?
c. **Physical Impact:** How has the pandemic altered the physical health and daily routines of family members of children with ASD?
d. **Academic Impact:** What has been the effect of the pandemic on the academic support and educational experiences available to children with ASD?

2. What are the specific effects of the COVID-19 pandemic on the quality of life of children with ASD?

a. **Psychological Impact:** How has the pandemic influenced the psychological state of children with ASD?
b. **Social Impact:** What changes have occurred in the social interactions and relationships of children with ASD as a result of the pandemic?
c. **Physical Impact:** How has the physical health and routine of children with ASD been affected by the pandemic?
d. **Academic Impact:** What has been the impact of the pandemic on the academic progress and educational engagement of children with ASD?

1.3 Rationale and Significance

The significance of this study lies in understanding and addressing the profound and lasting impact that the pandemic had on the quality of life of families with autistic children, including assessing the specific impact on the children with ASD themselves as well as their families. The pandemic introduced unprecedented challenges and disruptions to routines, schooling and support services that are crucial for the development and well-being of families with autistic children. Acknowledging and understanding the entire extent of these experiences is essential not only for addressing families’ current needs but also for preparing for the next pandemic or crisis. By exploring the families’ experiences and perspectives of how the pandemic impacted various aspects of their quality of life and the lessons they have learned, this study’s insight aims to inform policies, intervention programmes, and support services, ultimately leading to improved strategies to mitigate the effects of a crisis period on vulnerable populations. The timing of this study is significant due to the ongoing impact and effect of the COVID-19, and the likelihood of future global crises. The experiences faced by families of children with ASD during that period provide valuable perspectives on the resilience and challenges of the families. Despite the growing awareness of the pandemic’s impact, documenting and analysing their experiences is crucial, not only for immediate short-term response strategies, but also for long-term planning.

The potential benefits of this study are multifaceted. The results will provide practical insights for policymakers, educators and practitioners, offering a better understanding of the unique challenges families with autistic children face. This will aid in the creation of more policies and practices that can address the challenges most effectively. Additionally, this study will add to the growing body of research into the special education field and family studies, in turn enhancing the understanding of how global pandemics impact vulnerable populations. This will fill the gaps in the literature regarding the intersection of vulnerable populations and crisis management. Furthermore, the study has the potential to aid in developing targeted interventions and strategies to improve the family quality of life of families with autistic children. The valuable insights gained from this study could aid in developing interventions and resources that better address the needs of the families during and after pandemic periods, thus developing a more supportive environment.

1.4 Structure of the study

This study is composed of eight chapters, beginning with this chapter, Chapter One: Introduction, which provides the reader with the background, context, aim and significance of this study. Chapters two to four provide the readers with a literature review. Chapter Two: COVID-19, concerns the pandemic and the experiences of typically developing and special educational needs individuals. Chapter Three: Autism Spectrum Disorder, explores the historical background, various classifications and prevalence of the disorder. Chapter Four: Family Quality of Life, provides a thorough understanding of Family Quality of Life and discusses the challenges and support systems associated with families of children with autism. Chapter Five: Research Methods, describes the research method design, data collection methods and procedures used in this study. Chapter Six: Results, demonstrates the findings of this study, which is presented using qualitative analysis. Chapter Seven: Discussion, interprets the results in the context of the aims and research questions, whilst comparing them with existing literature. Chapter Eight: Conclusion, summarises the main results, discusses the strengths and limitations of this study and provides recommendation for future research.

Having outlined the research aims, questions and structure of this study, the following chapter will now provide a detailed review of the literature of the COVID-19 pandemic and the prevalence data of the virus.

CHAPTER TWO: COVID – 19

Chapter Two is composed of six sections that are concerned with the COVID-19 pandemic. It begins with a brief introductory section on COVID-19 and follows with a brief overview of the pandemic. The third and fourth section presents the epidemiological and prevalence data on the COVID-19, respectively. Thereafter, experiences of typically developing (TD) and special educational needs individual will be discussed. The final section will provide you with a summary of Chapter Two.

2.1 Introduction

Three years ago, in Wuhan, China, a variety of acute atypical respiratory diseases occurred in Wuhan (Yuki et al., 2020). The disease rapidly spread from Wuhan to other cities across China, and then across the world (Yuki et al., 2020; Ciotti et al., 2020). It was discovered that this respiratory disease was the novel COVID-19, also known as SARS-CoV-2 (severe acute respiratory syndrome coronavirus-2) (WHO, 2020a). The name SARS-CoV-2 was developed after SARS-CoV (Yuki et al., 2020). SARS-CoV was a syndrome that caused acute respiratory distress that had a high mortality rate during the years 2002 and 2003 (Ciotti, et al., 2020). The COVID-19 outbreak originated in China, and it had not been identified in humans previously (WHO, 2020a). The virus mainly affects the individual’s respiratory system, however, it could affect other organs, too (Yuki et al., 2020; Mueller et al., 2020). Several studies have identified that most COVID-19 cases have reported mild symptoms such as a dry cough, fever and dyspnea (Flynn et al., 2020; Yuki et al., 2020; Ciotti et al., 2020). There are various COVID-19 cases that elucidated other mild symptoms including diarrhoea, body aches, a runny nose, nasal congestion and a sore throat (Ciotti et al., 2020). However, these symptoms may not all occur at the same time, or at all. Recently published studies have indicated that some infected individuals do not develop any symptoms and do not fall ill (Yuki et al., 2020). The World Health Organisation (WHO) highlighted that 1 in 6 infected individuals become severely ill and that most individuals recover from COVID-19 without requiring hospital treatments (WHO, 2020a).

2.2 COVID – 19 Pandemic

As previously mentioned, the outbreak of the COVID-19 originated in Wuhan, China, more specifically, the Huanan Seafood Wholesale Market (Xu et al., 2020). As the virus rapidly spread across the world, thousands of infected individuals passed away (Ciotti et al., 2020). This novel spread of COVID-19 led WHO to declare a global pandemic on the 11th March 2020 (WHO, 2020a). The COVID pandemic affected 200 countries and territories, recording 1,400,000 cases worldwide on the 7th April 2020 (WHO, 2020a). The transmission of the virus occurs through the spread of respiratory droplets between individuals. It is now recognised that COVID-19 can produce fatalities and that research has demonstrated mortality rates as significantly higher amongst older individuals (Mueller et al., 2020). Mueller et al. (2020) explain that the severity of the COVID-19 symptoms depends on the individual's age. Recent research demonstrates that the effectiveness of the immune system of an older person makes them more vulnerable than younger people, causing them to be most likely hospitalised (Mueller et al., 2020). Likewise, comorbidities such as obesity, cardiovascular condition and diabetes are risk factors that could be life-threatening to an older COVID-19 patient (Mueller et al., 2020). In the matter of paediatric COVID-19 patients, Hon and Leung (2020) found that their mortality rate is lower when compared to elder patients and that the symptoms tend to be asymptomatic or relatively mild comparatively as their immune system tends to respond to the virus faster than adults. However, the weakness of this theory is that it does not align with most viruses. Hon and Leung (2020) concluded that paediatric immune system responses to COVID-19 is significantly stronger when compared to responses to most other viruses. Even though research has administrated significant differences in paediatric and elderly COVID-19 patients, the reason behind these differences have not yet been found.

Instructive advice was issued by governmental healthcare providers for individuals experiencing COVID-19 symptoms. The instructions proscribed steps on how best to look after oneself to prevent and treat symptoms of COVID-19. The Centers for Disease Control and Prevention (CDC) in the United Stated of America (USA) issued the following steps to help prevent the spreading of the virus:

- 'Stay home except to get medical care'
- 'Get tested'
- 'Separate yourself from other people'
- 'Monitor your symptoms'
- 'Call ahead before visiting your doctor'
- 'If you are sick, wear a well-fitting mask'
- 'Cover your coughs and sneezes'
- 'Clean your hands often'
- 'Avoid sharing personal household items'
- 'Clean surfaces in your home regularly'
- 'Take steps to improve ventilation at home'

(Centers for Disease Control and Prevention (CDC), 2022b)

In addition, the WHO's advice to patients with mild COVID-19 symptoms was to self-isolate for 10 days from the day that the symptoms occur, along with 3 days after symptoms cease (WHO, 2022a). Patients with COVID-19 symptoms were advised to inform all members of their household as well as anyone else that they may have been in contact with, as any person who had been in contact with an infected person was also advised to self-isolate (WHO, 2022a, CDC, 2022b). Individuals with severe symptoms were advised to call emergency services or their general practitioner (CDC, 2022b). In terms of medical management, several vaccines had been developed and tested from various public and private organisations in clinical trials and have been approved. The development of the vaccine requires a long and rigorous process of clinical trials and approval from the U.S. Food and Drug Administration (FDA), manufacturing and distribution (CDC, 2022a) (See Figure 1 below).

Figure 1 - Vaccine development process

(CDC, 2022a)

The Initial Development process began with researching previous studies that caused severe acute respiratory syndrome (SARS) and other related viruses (CDC, 2022a). Thereafter, the phases of clinical trials begin to ensure that the vaccine is effective and safe. These trials involved thousands of volunteers across different ethnicities, race and ages in order to compare different outcomes (CDC, 2022a). The next step involves the FDA assessing the results found from the clinical trials. The process includes the evaluation of the vaccine by reviewing the safety, effectiveness, and quality of the medical products (CDC, 2022a). Additionally, they review the side effects of the clinical trial on volunteers and continue to monitor the potential risks of the vaccine (CDC, 2022a). Once the vaccine is approved the FDA grants the vaccine to the Emergency Use Authorizations (EUA). The final steps are the manufacturing of the vaccine and its distribution to help fight the COVID-19 pandemic. As of February 2022, the approved vaccines by the WHO are the following: -

- Pfizer/BionTech vaccine
- AstraZeneca/Oxford vaccine
- Moderna vaccine
- Sinovac vaccine
- Johnson and Johnson vaccine
- Covovax vaccine
- Sinopharm vaccine

- COVAXIN vaccine
- Nuvaxovid vaccine

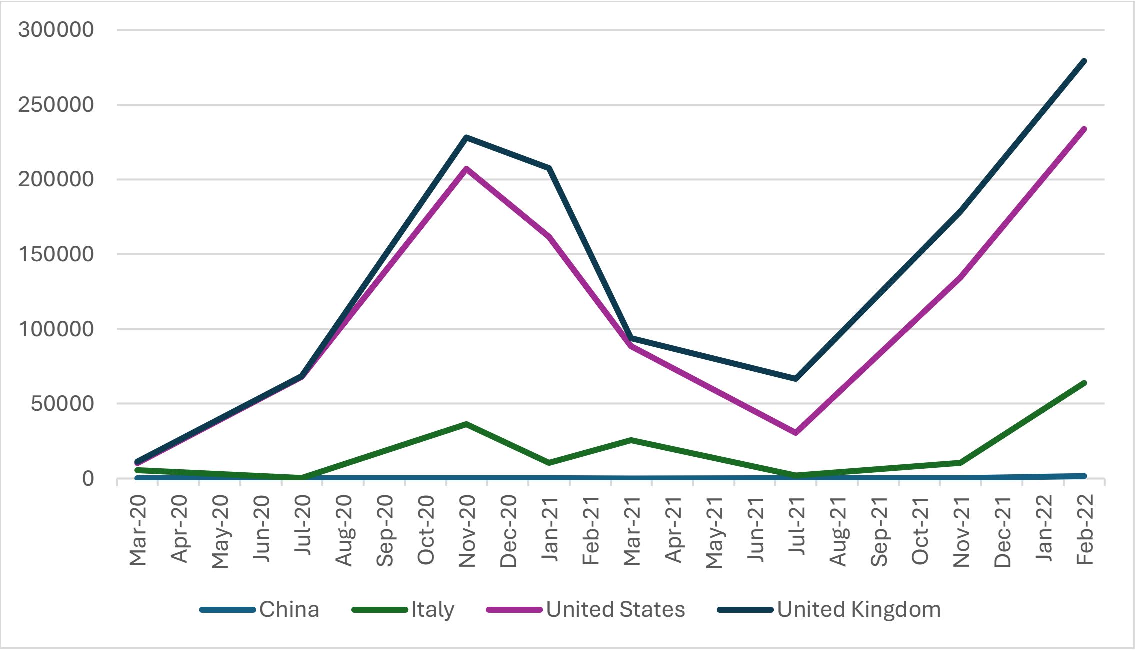
(WHO, 2022c)

It has yet to be determined how strong the protection provided by any of the vaccines is and how long the immunity lasts. The WHO continues to advice vaccinated and non-vaccinated people to continue taking extra measures of precaution and to continue to follow the protocols as written above to prevent infection and transmission (WHO, 2022c).

2.3 Prevalence data

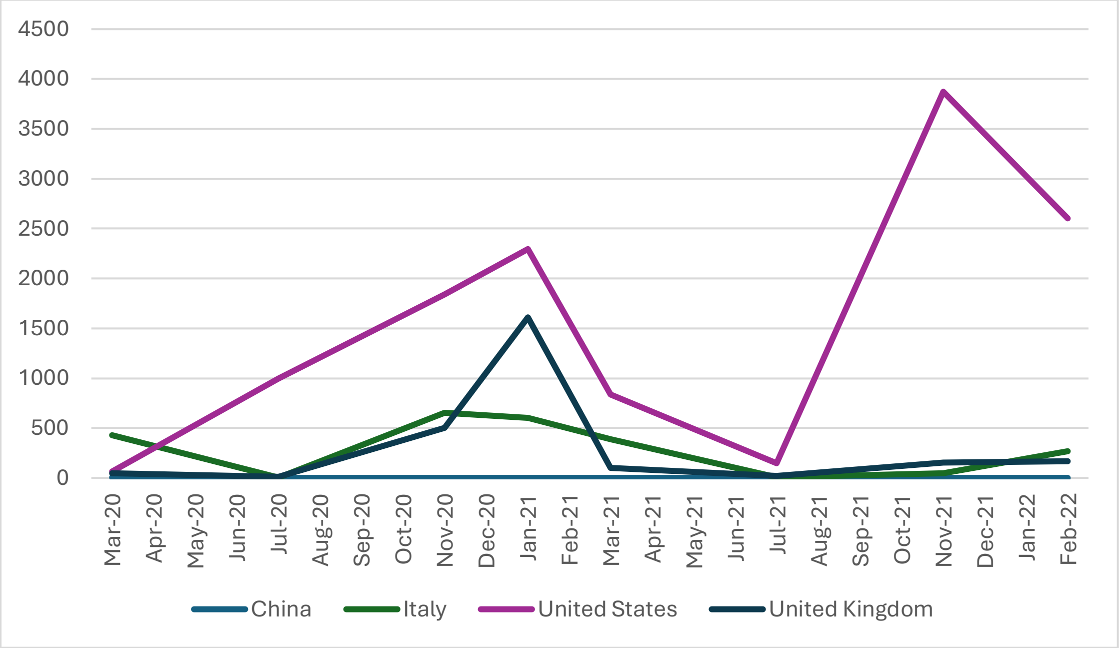
According to the WHO (2020b), following the start of the pandemic, over 3 million fatalities were confirmed and over 180 million cases were reported worldwide. The WHO estimated that the reproductive number of COVID-19 cases is around 2 to 4 cases, higher than the spread of influenza (Yunitri et al., 2022). This caused countries to have to take certain measures to limit the spread to minimise the effect on the country's healthcare system. Rahman et al. (2020) point out that socioeconomic and institutional contexts play a vital role in developing lockdown measures within a country. They explain that these measures indirectly influence the severity of the pandemic on the day-to-day activities of people. This is evident in China, despite being the country that had confirmed the first COVID-19 case, China tackled the virus successfully as their death rate per million is low compared to other countries (WHO, 2022d). China was one of the first countries to impose stringent measures in response to the virus and take control of the outbreak (Brzezinski et al., 2020). However, within a few weeks of the first outbreak in Italy in February 2020, Italy became one of the countries with the highest number of cases after China (Porcheddu et al., 2020). Towards the end of February, several municipalities in Italy were under quarantine. Rahman et al. (2020) argue that having strict social distancing measures is considered an effective way to reduce the spread of the virus. Compared to other countries, Italy was one of the countries that had the longest period of lockdown. However, the CDC still considered Italy as a high-risk country (CDC, 2022c). The USA had one of the highest number infected people in the world. In November 2020, the country had around 10 million infected individuals, and more than 250,000 deaths (Khubchandani et al., 2021). Several states announced that they would close service operation when the WHO declared the COVID-19 as a pandemic. The announcement of community lockdowns caused an uproar among certain communities causing them to protest it (Kowalewski, 2020). The response to the COVID-19 pandemic from the United Kingdom (UK) government was a combination of lockdown strategies and social distancing rules (Flynn et al., 2020). It was not till the end of March 2020 when the UK's government announced their first lockdown (Dropkin, 2020). After almost 12 months into the pandemic, and several changes to the lockdown restrictions, UK government began its steps to ease the restrictions until the lockdown was fully lifted. Regardless of the safety instructions provided by the WHO, CDC and several other governmental health sectors, the daily number of new cases and deaths were still rising. As of 13th of February 2022, the daily confirmed COVID-19 cases in Italy, USA, China, and the UK are 62,221; 169,957; 1,641; and 45,500 respectively (See Figure 1). Additionally, the daily confirmed deaths due to COVID-19, as of 13th of February 2022 in Italy, USA, China, and the UK are 269; 2,603; 3; and 169 respectively (See Figure 2).

Figure 2 - COVID - 19 Cases



(WHO, 2022d; WHO, 2022e; WHO, 2022g; WHO, 2022f)

Figure 3 - COVID - 19 Deaths



(WHO, 2022d; WHO, 2022e; WHO, 2022g; WHO, 2022f)

2.4 Experiences during the COVID-19 pandemic

At the start of the pandemic, data from recent studies reported that the outbreak of the virus was identified in the UK in late January 2020 (Dropkin, 2020). Since then, COVID-19 cases in the UK have significantly increased and several measures have been implemented to reduce the spread of COVID-19 (Dropkin, 2020). These measures were put in place to reduce the impact of the pandemic on the countries' healthcare system, businesses and economic activity, as well as to protect vulnerable people (Rahman et al., 2020; Ghosh et al., 2020). The measures include lockdown strategies, self-isolation, social distancing and several financial interventions. The UK went through several phases of nationwide lockdowns and has had one of the highest rates of deaths with over 50,000 cases during this pandemic (Majeed and Molokhia, 2020). According to Majeed and Molokhia (2020), the disruption brought by the pandemic has increased the UK government's debt and the unemployment rate among UK citizens, as well as causing severe disruption to the National Health Service (NHS). This has led the UK to have a healthcare system in crisis, with a shortage of doctors, causing many to not be able to respond to new challenges (Majeed and Molokhia, 2020). The uncertainty that the UK government showed towards its population led families to feel dissatisfied towards them. The lockdown stipulated restrictions on social interaction, for individuals to work from home and to reduce access to certain services (Pierce et al., 2020). According to Asim et al. (2020) these restrictions, as well as high infection rates and deaths, have negatively impacted the quality of life of individuals and societies. Evidence suggests that the impact could affect an individual's income, personal debt, employment and livelihood (Pierce et al., 2020). O'Connor et al. (2020) points out that the impact could have a long-lasting effect on an individual's mental health and well-being.

Drawing on an extensive range of sources, infected COVID-19 patients could possibly experience trauma and mental health problems due to quarantine and lockdown strategies, hospitalisation, recovery or release from the virus itself (Yunitri et al., 2022; Torales at al., 2020; Rajkumar, 2020). Javed et al. (2020) highlighted that frontline health professionals may also face the same experiences during the pandemic. The rise in COVID-19 cases and the death of peers and family colleagues, along with work overload, fear and shortage of both medicine and Personal Protective Equipment (PPE), increased the risk of mental health problems globally (Yunitri et al., 2022; Marshall, 2020). Research findings into previous COVID-19 outbreaks demonstrated that depression (Rogers et al., 2020), burnout (Magnavita et al., 2021), anxiety (Rogers et al., 2020) and posttraumatic stress disorder (PTSD) (Fan et al., 2021) were the most frequently diagnosed mental health problems from the outbreaks (Yunitri et al., 2022). Throughout the SARS outbreak in 2003, the prevalence rate of diagnosed PTSD individuals ranged from 5% to 18% (Yunitri et al., 2022; Salehi et al., 2021). This prevalence rate was significantly lower compared to the impact of the Middle East Respiratory Syndrome outbreak in 2012, as the prevalence rate of PTSD ranged between 36% and 42.9% (Yunitri et al., 2022; Salehi et al., 2021). Recent research suggests that the impact of the pandemic is common among certain groups and could be more detrimental to their mental health (O'Connor et al., 2020). This was evident following the SARS outbreak as the suicide rate in older adults increased significantly (Yang et al., 2020). Furthermore, early evidence in China during the COVID-19 pandemic demonstrated a high level of distress and mental health issues in the population (Yang et al., 2020; Dong and Bouey, 2020). In the same vein, Spain reported distress amongst young adults and females (Munoz-Navarro et al., 2020). Iob et al. (2020) work on abuse, self-harm and suicide demonstrated that self-harm, abuse and suicidal thoughts were significantly more prevalent among women and Asian, Black and minority ethnic groups in the UK. Moreover, O'Connor et al. (2020) found that individuals with previous mental health disorders experiencing socioeconomic disadvantage have elevated rates of suicide and mental health issues. Collectively, these studies indicate the importance of gaining a clear understanding of how this pandemic has affected an individual's mental health, to best protect individuals from future outbreaks.

Having discussed the experiences of typically developing individuals and COVID-19, it is important to point out that individuals (adults and children) with special educational needs are considered vulnerable groups. The next section of this research will explain their vulnerability and experience with COVID-19.

2.4.1 Comparative Lockdown Measures and Experiences in the UK, Kuwait and Saudi Arabia

The COVID-19 pandemic instigated governments worldwide to adopt strict public health interventions in order to contain the spread of the virus. However, the type, intensity, and duration of these lockdown measures varied significantly across countries. The varied public health measures adopted by the countries included in this study, the United Kingdom, Kuwait, and Saudi Arabia, provide important context for interpreting the research findings. Lockdown measures, particularly their type, duration, and level of enforcement, likely shaped the experiences of families during the pandemic, including access to education, therapies, healthcare, and psychosocial support. The following section offers a comparative overview of the national lockdown strategies in the three countries included in this study.

In the United Kingdom, the first national lockdown was declared on the 23rd of March 2020, requiring citizens to stay at home except for essential purposes such as obtaining food, medicine, or daily exercise (Sherrington, 2022). Non-essential businesses and educational institutions were closed, schools transitioned to remote learning and public gatherings were restricted. The UK government then introduced a tiered approach after the first lockdown was eased in May 2020, with regional variations depending on COVID-19 infection rates (GOV UK, 2020). A second national lockdown was implemented in November 2020, followed by a third national lockdown in January 2021, each accompanied by adaptations in public health policy in response to changing COVID-19 infection rates and the emergence of new variants (Sherrington, 2022). Restrictions began easing in March 2021, following an extensive vaccination program (Sherrington, 2022).

In Kuwait, the response to the pandemic was marked by the imposition of curfews and the suspension of commercial flights and public gatherings from mid-March 2020 (Al-Ayyadhi et al., 2022). Unlike the UK, Kuwait implemented a full national curfew in May 2020, during which residents were prohibited from leaving their homes except for medical emergencies (AlKazi et al., 2023). Prior to that, partial curfews were enforced with hours adjusted as the situation progressed (AlKazi et al., 2021). Following the full curfew, Kuwait adopted a five-phase plan for gradual return to normal life, each phase depended upon epidemiological data and public health concerns (Talal, 2020). The plan included the reopening of government services, resumption of commercial activities, and phased return of public transportation. While some restrictions remained in place through 2021, by October of that year, many restrictions were eased for fully vaccinated individuals. The phased strategy reflects Kuwait's attempt to balance the spread of COVID-19 with societal and economic needs, though prolonged curfews were reported to have intensified family stress, particularly in families with children requiring additional support (Talal, 2020).

Saudi Arabia, similarly, authorised early and robust measures to mitigate COVID-19 transmission (Algaissi et al., 2020). The country's first national curfew commenced on 23rd March 2020, followed shortly by 24-hour lockdowns in major cities including Riyadh, Mecca, and Medina (Algaissi et al., 2020). Residents were only allowed to leave their homes for essential supplies during designated hours and within limited proximity to their homes. Religious practices were temporarily halted, including daily prayers and congregational prayers (Algaissi et al., 2020). These measures were influenced by Saudi Arabia's prior experience with the Middle East Respiratory Syndrome (MERS), which influenced the government's approach to pandemic preparedness (WHO, 2025). By late May 2020, Saudi Arabia began easing restrictions through a phased reopening of workplaces, mosques, and public transport, under strict protocols (AlKazi et al., 2021; Algaissi et al., 2020). The rapid initial measures followed by a gradual return of social activities demonstrated a strategic coordination between public health priorities and religious, social, and economic needs (Algaissi et al., 2020).

These differing national approaches to lockdown highlight the contextual variations in how the pandemic was managed across different countries. The UK employed recurring national and regional lockdowns, Kuwait relied heavily on curfews and a structured easing plan, while Saudi Arabia drew upon earlier pandemic experiences to inform its strict initial measures. These differences are essential to consider in the interpretation of family experiences during the pandemic, particularly in a study examining QoL across these diverse cultural and governmental settings.

2.5 Special Educational Needs (SEN) and COVID – 19

According to Geraghty and Lyons (2021) individuals with SEN are disproportionately impacted during the height of the COVID-19 pandemic. The extra measures for health and safety, such as wearing PPE, hand washing, social distancing, touching surfaces, etc. may be difficult to implement and explain to an individual with SEN (Geraghty and Lyons, 2021). Prior to nationwide lockdowns, families of individuals with SEN had external support and a network of educators, healthcare professionals and social workers to aid them. With the lockdown instructions in place, family members had to fulfil all the individual's needs by taking on the role of a parent, educator and caregiver (Tokatly Latzer et al., 2021). Tokatly Latzer et al. (2021) point out that along with the extra roles that the parents need to play, they would also need to manage their working life and home life. If not managed successfully, this would negatively impact the individual with SEN and affect their life progress (Amaral and de Vries, 2020; Eshraghi et al., 2020; Narzisi, 2020). This is evident in Tokatly Latzer's et al. (2021) study on parents' experience during the COVID-19 lockdown. The study reported that parents have indicated that they needed extra support from practitioners as they did not have the appropriate knowledge and tools to support their children. Contradicting recent research, some parents in Tokatly Latzer's al. (2021) study argue that the lockdowns were beneficial and positive, as parents were able to work closely with their children. However, much of the recent research has emphasised the importance of reopening schools as families expressed their concerns about not being able to support and educate their children (Lim et al., 2020; Pellicano et al., 2020; Yahya and Khawaja, 2020).

According to Yazcayir and Gurgur (2021), travelling to and from school and interacting with colleagues and peers played a major role in spreading the virus. Therefore, having nationwide lockdowns and imposed school closures forced communities and families to develop online learning environments (Parmigiani et al., 2020). Online learning was started to ensure students continue their education to minimise the negative impact that this pandemic has had on education (Yazcayir and Gurgur, 2021). This meant that families would require the appropriate methods and devices to implement online learning environments at home. In addition, the rapid changes to lockdown measures and social distancing made it difficult for educators to prepare and transition from face-to-face learning to remote learning (Tremmel et al., 2020). Several parents expressed their concern about not having the technological devices to support these new measures (Parmigiani et al., 2020). Similarly, various parents of children with special educational needs and disabilities (SEND) faced difficulties and lacked the adequate support for online education during lockdowns (Geraghty and Lyons, 2021; Parmigiani et al., 2020). Children with SEN require extra support which is challenging to implement in online learning (Hurwitz et al., 2021). Further to this, Hurwitz et al. (2021) explained that educators, also went through challenges to adjust the curriculum and adapt it to online education to best meet each child's SEN. Educators of individuals with SEN were expected to develop strategies and pedagogical plans to meet their educational obligations, causing stress among educators (Smith, 2020).

To conclude this section, the research identified that the rapid transition into nationwide lockdowns left families and educators in distress. Based on the literature findings, families and educators of individuals with SEN are currently facing difficulties in the change of routine regarding their life and education. This led to positive and negative experiences for families and practitioners. The following section provides you with a summary of this chapter.

2.6 Summary

In summary, COVID-19 is a virus that affects the individual’s respiratory system and may have an effect on other organs. The symptoms of this virus are dry cough, fever, and dyspnea. The virus has caused over 3 million deaths to-date and has affected over 180 million individuals worldwide, causing the WHO to declare it a global pandemic. Since then, countries have implemented lockdowns and social distancing strategies to help reduce the spread of the virus. These restrictions have impacted societies and individuals (TD and SEN) negatively causing a long-lasting impact on their mental health and well-being. The next chapter will describe in more detail on how the Quality of Life of individuals has been affected during the COVID-19 pandemic.

CHAPTER THREE: AUTISM SPECTRUM DISORDER

Chapter Three begins with an introductory section on Autism Spectrum Disorder (ASD) and proceeds with exploring the historical background and various classifications of ASD throughout the decades. In the following section the prevalence of autism will be examined. Thereafter, an overview of autism will be discussed, and a summary of this chapter will be provided.

3.1 Introduction

Autism Spectrum Disorder refers to range of heterogenous, pervasive features, amounting to a lifelong neurodevelopmental disorder (Sharma et al., 2018). These include Rett's syndrome, Asperger's syndrome, and Pervasive Developmental Disorder – not otherwise specified (PDD-NOS) (Sharma et al., 2018). ASD is a lifelong disorder developed in childhood that affects the cognitive development of an individual, the social development and to varying extents, the physiological development (Frith, 2003). Before proceeding to discuss the various classifications of ASD, a brief historical background of the disorder will be provided in the following section.

3.2 Historical Background

Despite its common usage, the term 'autism' was first used in various disciplines to mean different things. In 1911, the Swiss psychiatrist, Paul Eugen Bleuler, described the symptoms of ASD as a childhood version of schizophrenia (Qian, 2011). Bleuler derived the term 'autism' from the Greek word 'autós' which is meant as self and used the word 'autism' to refer to a schizophrenic patient who 'had withdrawn into his own world' (Qian, 2011).

Thereafter, Leo Kanner, a child psychiatrist, used and described the term 'autism' in observations made during early research (Kanner, 1943). Kanner's observations were on children who demonstrated behaviours that included a lack of ability to form social interactions, difficulties in forming relationships with others, issues with communication and a tendency to perform repetitive behaviours and routines (Kanner, 1943; Ghaziuddin, 2005). The observations of 'abnormal behaviour' that Kanner described was also known as 'Early Infantile Syndrome' (Kanner 1943; Ghaziuddin, 2005). Based on Kanner's observation, he established that these behaviours were derived from two deficits; firstly, a desire of repetition, and secondly, aloofness (Kanner 1943; Ghaziuddin, 2005). In addition, Kanner described children with ASD to have 'an innate inability to form the usual, biologically provided contact with people' (Harris, 2018, p.3). His description of ASD generated insights that has challenged families, psychologists, individuals and doctors in the field of

ASD (Harris, 2018; Roth and Barson, 2010). Kanner focused on the social deviance of the disorder and referred to it as a distinctive feature, and this emphasis has been, and is continuously reflected in various research articles (Atbasoglu, 2020; Harris, 2018; Volkmar et al., 2014; Roth and Barson, 2010).

A year after Kanner's research in 1943, Hans Asperger, a paediatrician, published a paper on identifying children with similar behavioural tendencies, however, the children that were in Asperger's research demonstrated an ability to communicate (Pearce, 2005). The children in Asperger's study had a pattern of one-sided conversations, clumsy movement, lacked empathy and had little ability to form relationships (Sharma et al., 2018; Asperger, 1944). Furthermore, Asperger noticed that parents of autistic children had similar personality traits thus providing his evidence of a genetic link to autism (Asperger, 1944). As a result, Asperger described the symptoms as 'Asperger's Syndrome' (Wing, 1981). Kanner (1949) considered that autistic children were more likely to be born into families with higher Intelligence Quotients (IQ) and developed the hypothesis 'Refrigerator Mothers'. This label was for mothers of the children who were often blamed for their children's impairments. This hypothesis was not acknowledged much until Bruno Bettelheim, a child development specialist, stated that ASD was caused by mothers who were distant and cold towards their children (Cohmer, 2014). 'Refrigerator Mothers' remained unchallenged until Bernard Rimland (1964), a father of an autistic son, who presented the notion that ASD is a biological condition. Despite the rapid increase of research after Kanner's paper, universally, there was no agreed definition of ASD for 40 years (Roth and Barson, 2010). Since then, the meaning of ASD has evolved.

3.3 Classification and Diagnosis

Different classifications and definitions exist in the literature regarding Autism Spectrum Disorder. Various definitions have evolved throughout the years using different classification manuals. The Diagnostic and Statistical Manual of Mental Disorders (DSM) was published by the American Psychiatric Association and is used to diagnose mental health disorders (American Psychiatric Association, 2013). The manual is used to list all categories of mental health disorders, along with their statistics, symptoms and treatments. The first edition of the DSM (DSM – I) was published in 1952 which included 102 different mental health disorders. In the DSM – I, children with autistic symptoms were labelled as schizophrenic (DSM – I, 1952) (See Table 1). In this edition, the diagnostic tool suggests that the schizophrenic symptoms (also known as autistic symptoms) should occur before the child hits puberty (DSM – I, 1952). The DSM second edition (DSM – II), published in 1968, still recognized the autistic symptoms as schizophrenic, however, and also included that these symptoms may lead to mental retardation (DSM – II, 1968) (See Table 2). It was not until the DSM third edition (DSM – III) that a significant change occurred and the term 'autism' was introduced as 'Infantile Autism' in 1980. In 1987 it was replaced with Autistic Disorder in the DSM – III – R (DSM-III and DSM-III-R diagnoses of autism, 1988). The criteria included in the DSM – III and DSM – III – R is not associated with the term schizophrenic anymore and includes a more detailed criteria of symptoms of autism (See table 3). The changes made in both DSM – III and III – R introduced an approach that was useful across all developmental levels and ages (Rosen et al., 2021).

However, the DSM – III – R has a set of 16 detailed criteria which has 3 main domains within the autistic symptoms. These domains are very broad in comparison to the new DSMs, however, they were included in the fourth edition of the DSM (DSM – IV) which was published in 1994 (DSM-IV, 1994). This edition was more elaborate than all previous versions (Rosen et al., 2021) (See Table 4). The term 'spectrum' was not introduced until Wing (1996) established that autism should be viewed on a continuum, stating that there is no typical autistic child. Building on Wing's introduction to the term 'spectrum', the latest version of the DSM, DSM Fifth edition (DSM – V), published in May 2013, changed the term 'Autistic Disorder' to ASD and classified it as a heterogeneous neurodevelopmental disorder (DSM-V, 2014). Frith (2003) draws a distinction on the DSM – V describing the manual as the most detailed criteria for diagnosing an individual with ASD. The criteria in the DSM – V states that individuals with ASD must present a persistent difficulty with social interaction and communication skills, and have restrictive and repetitive behaviours. More specifically, the DSM – V states that autistic individuals should demonstrate the following:

A. 'Persistent deficits in social communication and social interaction across multiple contexts'
    1. 'Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.'
    2. 'Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.'
    3. 'Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.'

B. 'Restricted, repetitive patterns of behavior, interests, or activities'

1. 'Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).'
2. 'Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).'
3. 'Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).'
4. 'Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).'

C. 'Symptoms must be present in the early developmental period'
D. 'Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.'

(DSM-V, 2014, p.50)

In his initial description of ASD, Kanner demonstrated that babies with ASD exhibited motor difficulties at some point in their life (Paquet et al., 2016). Similarly, various studies exemplified that autistic children have shown an impairment in developing motor skills, which could involve motor coordination, standing balance, postural control and the development of fine and gross motor skills (Bhat, 2020; May et al., 2016; Travers et al., 2013; Fournier et al., 2010; Fulceri et al., 2019; Lloyd et al., 2011). Furthermore, in contract with the DSM classifications, the International Classification of Functioning, Disability and Health (ICF) listed an impairment in motor skills as a symptom of ASD (World Health Organization, 2001). However, there is inconsistency with this impairment. Fulceri et al. (2019) explained that despite research, studies have failed to state whether these difficulties are related to the developmental features of ASD or demographical features. Similarly, there is accumulating evidence that states there are delays in the attainment of motor abilities in the early life of ASD (Licari et al., 2019; Paquet et al., 2016; Estes et al., 2015). In addition, Licari et al. (2019) explained that the prevalence of motor difficulties increases with the severity of the diagnostic impairments of ASD, as well as the child's age.

Adding the disorder to the DSM made it possible for autism specialists to diagnose individuals accurately. The autistic disorder is complex and varies with each individual. It is considered difficult to diagnose an individual with ASD as there is no clinical test that can be taken (WHO, 2020f; Ghaziuddin, 2005). The diagnosis process begins with an experienced professional observing the child's behaviour and assessing their development. The chronological age at which the symptoms of the disorder first appear in an individual and the severity of the symptoms can differ considerably (National Research Council, 2001). According to Richards et al. (2017), parents or individuals who have regular contact with autistic children may be able to be the first to identify ASD symptoms. Individuals will demonstrate ASD tendencies in early childhood and could be present as early as 18 months (CDC, 2020d; CDC, 2020e; Johnson and Myers, 2007). Often children do not get a final diagnosis until much older (CDC, 2020d; CDC, 2020e; Richards et al., 2017; Herlihy et al., 2015; Guinchat et al., 2012). As noted by Shen and Piven (2017), the late diagnosis is a result of the disorder as it is developmental, meaning it grows and develops with age. Therefore, some individuals may be misdiagnosed at an early age, and as they grow older and develop more symptoms, they may receive a more accurate diagnosis (Kentrou et al. 2018). Consequently, it can be difficult to acquire an accurate and timely diagnosis (Elder et al., 2017). However, various studied have established that parents' first concerns could precipitate the evaluation of the disorder (Herlihy et al., 2015; Guinchat et al., 2012; Ozonoff et al., 2009).

While a variety of classification and definitions of the term Autism have been suggested in the literature, throughout this study, the DSM – V classification of ASD will be used.

Table 1 - DSM - I Classification

<table>
<tr><th>Type of DSM</th><th>Name</th></tr>
<tr><td>DSM – I (1952)</td><td>Schizophrenic reaction, childhood type</td></tr>
<tr><td colspan="2">Diagnostic Criteria:
Here will be classified those schizophrenic reactions occurring before puberty. The clinical picture may differ from schizophrenic reactions occurring in other age periods because of the immaturity and plasticity of the patient at the time of onset of the reaction. Psychotic reactions in children, manifesting primarily autism, will be classified here. Special symptomatology may be added to the diagnosis as manifestations.</td></tr>
</table>

Table 2 - DSM - II Classification

<table>
<tr><th>Type of DSM</th><th>Name</th></tr>
<tr><td>DSM – II (1968)</td><td>Schizophrenia, childhood type</td></tr>
<tr><td colspan="2">Diagnostic Criteria:
This category is for cases in which schizophrenic symptoms appear before puberty. The condition may be manifested by autistic, atypical, and withdrawn behavior; failure to develop identity separate from the mother's; and general unevenness, gross immaturity and inadequacy in</td></tr>
</table>

development. These developmental defects may result in mental retardation, which should also be diagnosed.

Table 3 - DSM - III Classification

Type of DSM	**Name**
DSM – III (1980)	**Infantile Autism**

Diagnostic Criteria:

A. Onset before 30 months of age
B. Pervasive lack of responsiveness to other people (autism)
C. Gross deficits in language development
D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal.
E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.
F. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.

Table 4 - III - R Classification

Type of DSM	**Name**
DSM – III – R (1987)	**Autistic Disorder**

Diagnostic Criteria: At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C.

A. Qualitative impairment in reciprocal social interaction as manifested by the following:
    1. Marked lack of awareness of the existence or feelings of others (for example, treats a person as if that person were a piece of furniture; does not notice another person’s distress; apparently has no concept of the need of others for privacy);
    2. No or abnormal seeking of comfort at times of distress (for example, does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, for example, says “cheese, cheese, cheese” whenever hurt);
    3. No or impaired imitation (for example, does not wave bye-bye; does not copy parent’s domestic activities; mechanical imitation of others’ actions out of context);
    4. No or abnormal social play (for example, does not actively participate in simple games; prefers solitary play activities; involves other children in play only as mechanical aids); and
    5. Gross impairment in ability to make peer friendships (for example, no interest in making peer friendships despite interest in making friends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer
B. Qualitative impairment in verbal and nonverbal communication and in imaginative activity as manifested by the following:
    1. No mode of communication, such as: communicative babbling, facial expression, gesture, mime, or spoken language;
    2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations);
    3. Absence of imaginative activity, such as play-acting of adult roles, fantasy character or animals; lack of interest in stories about imaginary events;

   4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (for example, monotonous tone, question-like melody, or high pitch);
   5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (for example, immediate echolalia or mechanical repetition of a television commercial); use of “you” when “I” is meant (for example, using “You want cookie?” to mean “I want a cookie”); idiosyncratic use of words or phrases (for example, “Go on green riding” to mean “I want to go on the swing”); or frequent irrelevant remarks (for example, starts talking about train schedules during a conversation about ports); and
   6. Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech (for example, indulging in lengthy monologues on one subject regardless of interjections from others);

C. Markedly restricted repertoire of activities and interests as manifested by the following:
   1. Stereotyped body movements
   2. Persistent preoccupation with parts of objects or attachment to unusual objects
   3. Marked distress over changes in trivial aspects of environment (for example, when a vase is moved from usual position);
   4. Unreasonable insistence on following routines in precise detail
   5. Markedly restricted range of interests and a preoccupation with one narrow interest, e.g., interested only in lining up objects, in amassing facts about meteorology, or in pretending to be a fantasy character.

D. Onset during infancy or early childhood

Table 5 - DSM - IV Classification

Type of DSM	Name
DSM – IV (1994)	**Autistic Disorder**

Diagnostic Criteria: A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:
   a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   b) failure to develop peer relationships appropriate to developmental level
   c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
   d) lack of social or emotional reciprocity
2. qualitative impairments in communication as manifested by at least one of the following:
   a) delay in, or total lack of, the development of spoken language
   b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c) stereotyped and repetitive use of language or idiosyncratic language
   d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   b) apparently inflexible adherence to specific, nonfunctional routines or rituals
   c) stereotyped and repetitive motor mannerisms
   d) persistent preoccupation with parts of objects

3.4 Prevalence

In the recent few decades, there has been a rise in the rate of ASD around the world. Much more research and information on ASD has become available in recent literature. ASD has been known to be one of the most diagnosed childhood-onset neurodevelopmental disorders (Rylaarsdam and Guemez-Gamboa 2019). Much of the available literature on this topic demonstrates that the apparent increase in the prevalence of ASD is due to having clearer diagnostic criteria in the DSM – V and the raise in awareness of ASD among lay persons (Sharma et al., 2018). Ghaziuddin (2005) claims that the prevalence ratio is thought to be applied across all ethnic, racial and socioeconomic backgrounds. In addition, Özerk and Cardinal, (2020) highlighted that it is essential to understand the patterns of the prevalence rate as it could be beneficial for policy development for countries' medical, educational, behavioural analytical and psychological interventions.

Several lines of evidence suggest that the prevalence of autism has increased steadily over the past two decades, and in accordance with the increase, the World Health Organization (WHO, 2020f) has estimated that 1 in 160 children worldwide are diagnosed with ASD (Chiarotti and Venerosi, 2020; Mutabbakani and Callinan, 2020). The dramatic increase in prevalence posed a public health concern (Newschaffer and Curran, 2003). Thus far, recent research in the UK has estimated that 700,000 individuals, along with 1 in 100 children, have been diagnosed with ASD (British Medical Association, 2024). This estimation is significantly higher than previous estimates, as those results suggested that 1 in 64 children were diagnosed with ASD (Roman-Urrestarazu et el., 2021). Previous research in Canada has established that autism cases have risen since the 1960s (Diallo et al., 2018). ASD prevalence in Canada has been estimated to be 1 in every 66 people (Ofner et al., 2018). Similarly, studies of autism prevalence in Italy have shown limited research on autism prevalence (Narzisi et al., 2018). In Southern Italy, the incidence rate ranges between 0.05% to 0.44% in Catania and Emilia-Romagna, respectively, and 0.48% in Piedmont, Northern Italy (Valenti et al., 2019). Moreover, data in New Zealand is very limited regarding prevalence and age of ASD diagnosis (Eggleston et al., 2019; Thabrew and Eggleston, 2018). New Zealand's Ministry of Health (MoH) base their autism rates on research undertaken in the UK. The MoH in New Zealand estimates that ASD only affects 1% of their population (Bowden et al., 2020).

With regards to developing countries, there is very little literature on the prevalence of ASD in China and Kuwait. It has been demonstrated that ASD affects 1% of the Western countries' population (Sun et al., 2019). However, research in China demonstrated that it is unclear whether ASD is prevalent in China (University of Cambridge, 2013). Sun et al. (2019) suggested that ASD in China is presently under-diagnosed. This is apparent through data as it estimated prevalence of 0.12% in China, whereas other population-based studies estimated a much higher prevalence rate (Zhou et al., 2020; Sun et al., 2019; Sun et al., 2013). Zhou at al. (2020) explains that the data presented in these studies were conducted using non-standard methods, thus presenting unreliable data. Since 2012 onwards the prevalence rate of ASD in Oman has been significantly higher when compared to the estimation in 2011, which was 1.4 per 10,000 individual (Fido and Al Saad, 2013; Al-Farsi et al., 2011). Recent studies have estimated a prevalence of 20% of the child population are on the autism spectrum (Chiarotti and Venerosi, 2020). Al-Mamari et al. (2019) explains that this increase is attributed towards a clearer diagnostic service and an increase in autism awareness within Omani Culture. However, various studies have indicated that Omanis are underdiagnosed and under-reported (Al-Mamari et al., 2019; Al-Farsi et al., 2011). Al-Farsi et al. (2011) suggested that Oman requires a more extensive diagnostic and rehabilitation service. In the same vein, Alnemary et al. (2017) have highlighted that research in the Arab world is very limited, stating that the average number of published ASD articles in the Arab world per year is 5.7 articles and the total number of articles published between the years of 1992 and January 2014 is a total of 142 publications. Gaad (2011) indicated that despite ASD being the most commonly diagnosed disorder in the Middle East, the Middle East demonstrates a lack of awareness and knowledge of the condition. For example, reports of autism prevalence in Kuwait are contradictory; the Kuwaiti Ministry of Information (2016) reported a prevalence of autism from 1.5–2% in every 100 children. However, Al-Kandari (2014) estimated a prevalence rate from 60 to 70 individuals per 10,000, whereas other studies estimated a rate of 1.4 to 29 per 10,000 (Salhia, 2014). This supports the notion of the occurrence of autism in developing countries as there are limited data sets.

3.5 Summary

Autism Spectrum Disorder refers to a range of neurodevelopmental disorders; it is a long-term childhood disorder affecting the cognitive and social development of affected children, and to a varying extent their physiological development, too. The symptoms of ASD appear to affect how individuals experience the world around them and how they communicate. Autism’s definition has evolved throughout the years, impacting research, diagnoses, interventions and education. Indeed, ASD has been more prevalent in the past two decades, however, the disorder has been around for more than 70 years. The dramatic rise in prevalence has suggested that having detailed classification and precise diagnostic tools will have positively benefited people with ASD. Collectively, this chapter outlined several classifications and definitions of Autism Spectrum Disorder across several decades, as well as ASD’s prevalence in different parts of the world.

CHAPTER FOUR: Family Quality of Life (FQoL)

Chapter Four delves into an exploration of the aspects of Family Quality of Life (FQoL), with a particular emphasis on families of children with ASD. It will be structured to provide a thorough understanding of FQoL and its theoretical underpinnings. Following this, the chapter discusses the challenges and support systems associated with families of children with ASD, placing them within the framework of societal changes during the pandemic. The remaining part of this chapter will conclude with an analysis of the gaps in the existing literature and how these findings contribute to this research.

4.1 Introduction

FQoL is an integrative, multidimensional concept that is used to predict the dynamic sense and well-being of a family across several domains (Francisco Mora et al., 2020). The role of FQoL can be described as an extension of the individual's Quality of Life (QoL) experiences within the context of their family (Brown and Brown, 2014). The multidimensional concept encompasses multiple domains, including emotional and physical well-being, social inclusion, individual development, human rights and interpersonal relationships (Vanderkerken et al., 2019). A vigorous understanding of FQoL is crucial when analysing situations that families of children with ASD experience. These families, on a regular, face unique challenges and require certain needs that can affect their QoL significantly (Jansen-van Vuuren et al., 2021).

The advent spread of the COVID-19 pandemic brought an additional layer of complexity to families. During this period, families across the world were instructed to isolate, thus reducing mobility and social interaction, among other restrictions (Rahman et al., 2020; Ghosh et al., 2020). Furthermore, in order to limit the spread of the virus there were restrictions on hospital visits, access to non-emergency care and elective procedures, among other similar matters, were restricted, postponed or cancelled (Ferreira et al., 2021; Provenzano et al., 2020). The virus caused individuals and families to face a threat during unprecedented measures, often affecting families with special needs disproportionately (Geraghty and Lyons, 2021). Accordingly, in this chapter, a comprehensive review of the literature on FQoL is undertaken, particularly as it relates to families of children with ASD. It aims to shed light on the coping mechanisms and unique challenges these families adopted in navigating the unprecedented disruptions. The next section will delve more deeply into FQoL and its core elements and intricacies.

4.2 Family Quality of Life

4.2.1 Quality of Life and Its Evolution to Family Quality of Life

The concept of Quality of life (QoL) is multidimensional. QoL is a broad and multifaceted complex and “allows for a detailed evaluation of adaptation, both positive and negative, across several domains of functioning” (Vasilopoulou and Nisbet, 2016, p.38). The multifaceted concept is influenced by an individual’s level of independence, social interactions, physical health and psychological condition (Mohsen et al., 2022). The WHOQoL refers to QoL as the individual’s perception of their place in life (WHOQoL Group, 2012). The context of which the individual views their life is related to their expectations, goals, standards, and concerns, relating to their values and cultures (WHOQoL Group, 2012). This definition reflects several dimensions of the individual’s life and takes into consideration the social relationships, independence, physical and psychological condition, culture, environment and personal beliefs (Pinto et al., 2017; Pennacchini et al., 2011).

In 1992, Borthwick-Duffy (1992) uses the term QoL to refer to three perspectives: (1) QoL should be defined as the conditions of an individual’s life, (2) QoL is based on the individual’s satisfaction with their life’s conditions, (3) QoL can only be defined by combining the individual’s conditions and the satisfactions. This definition is close to Landesman’s (1986) view of QoL. Edgerton’s (1990) definition is similar to Borthwick-Duffy’s (1992), however, Edgerton describes satisfaction as a vital criterion on its own, reflecting the individual’s welfare. In contrast to the previous definitions, Cummin (1992) defines QoL as an objective measure of an individual’s life condition, and a subjective measure of their satisfaction towards it, as well as weighting it across the significance of each domain of their QoL. Other researchers believe that QoL could be seen as an individual’s belief of their own culture, promoting their health and wellbeing (Pinto et al., 2017). Considering previous research findings, health and healthcare disciplines have gained most research in the field of QoL (Pinto et al., 2017; Pennacchini et al., 2011). Wilson and Cleary (1995) provided a model of QoL that is popular among several studies. The Wilson and Cleary (1995) model connects the physiological and functional health along with the individual’s overall QoL and general health perceptions and symptoms (Post, 2014). This model was found to be a comprehensive assessment of health-related quality of life (HRQoL) models to all individual’s, regardless of their culture, health, age and illness (Ojelabi et al., 2017).

Wyatt (2005) proposes that the variety of different definitions of QoL is an attempt to measure many aspects of an individual’s life. However, over time, practitioners and researchers have come to understand the necessity to transcend personal experiences, which thereby evolved the concept of FQoL.

4.2.2 Family Quality of Life’s definition, components, and measurement tools

FQoL acknowledges the interlinked nature of family members; their shared experiences, aspirations and challenges contribute significantly to the family’s overall well-being (Zuna et al., 2009). Rillotta et al. (2010) defines family as “people who are closely involved in the day-to-day affairs of the household and support each other on a regular basis; whether related by blood, marriage or by close personal relationship”. Various researchers and practitioners have defined FQoL in a way that reflects its multi-dimensional nature. For instance, Turnbull et al. (2004, p.29) described FQoL as the “goodness of family life”. Their description to the term refers to the complex interactions among the family’s support, needs, strengths, and features, as well as other contextual factors (Jansen-van Vuuren et al., 2021; Chiu et al., 2013; Turnbull et al., 2004). Similarly, Poston et al. (2003) define FQoL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact across diverse domains”. Other researchers, such as Park et al. (2003) define FQoL within the context of families with children who have SEN, highlighting the significance of the family’s ability in engaging day-to-day activities and routines. This definition is close to Zuna et al.’s (2009) view of FQoL, where they explain that FQoL is “the degree to which the family system functions in a manner that is considered to be acceptable over time, in achieving valued outcomes through its activities, and the extent to which these outcomes enable the family to maintain or enhance its well-being.” Collectively, there is a widespread agreement that FQoL is a multidimensional concept focusing on several core domains (family interactions, physical well-being, parenting and professional support) that are influenced by factors at the individual and environmental levels (Vanderkerken et al., 2019).

Given that the FQoL model is integrative and multidimensional, Francisco Mora et al. (2020) see that this model is difficult to assess. FQoL is used to measure the conditions of whether or not the needs of a family are met, whether the members of the family are enjoying their life together and if they have been able to pursue and achieve the goals that are important to their life and happiness (Lei and Kantor, 2021; Garrido et al., 2020; Turnbull et al., 2004; Park et al. 2003). The current most used FQoL measurement tools are the International Family Quality of Life Project (IFQoL) (Francisco Mora et al., 2020; Brown, et al., 2016) and the Beach Center Family Quality of Life Scale (BCFQoL) (Francisco Mora et al., 2020; Hoffman et al., 2006). Each tool has its own operational definition of

FQoL and has its own dimensions to evaluate. The IFQoL project's purpose is to provide families a voice in recognising and improving parts of their life that they are struggling with (Isaacs et al., 2007). The IFQoL is based on a nine-domain FQoL concept, including (a) family health; (b) financial well-being; (c) family relationships; (d) social support; (e) support from disability services; (f) spiritual and cultural beliefs; (g) careers; (h) enjoyment of life; and (i) community involvement (Isaacs et al., 2007). The BCFQoL focuses on the conceptualisation, measurement, and application of knowledge obtained in evaluating policy, disability services and legislation (Brown et al., 2016). The BCQoL is based on a five-domain FQoL concept (Brown et al., 2016). The domains include: (a) parenting; (b) family interaction; (c) emotional well-being; (d) physical and material well-being; and (c) support for individuals with disabilities.

FQoL provides a valuable perspective for assessing and understanding the well-being of families in a variety of contexts. Based on research, the well-being of one family member can greatly impact the entire family, lowering FQoL (Poston et al., 2003). Bowen's Family Systems Theory provides a powerful viewpoint on FQoL (Brown, 1999). Brown (1999) explains that Bowen offers a valuable theory for understanding the interconnected emotional and behavioural dynamics within family units. Rather than viewing individuals as separate entities, Bowen visualised the family as an emotional system in which members affect and react to one another in predictable patterns, with the aim of identifying how these patterns develop in response to anxiety and help regulate it within the family system (Brown, 1999).The level of anxiety in the family will be decided by the current levels of external stress and sensitivity to certain themes that have been transmitted through generations (Brown, 1999). Brown (1999) points out that if members of the family lack the mental capacity to think through their answers to relationship issues, and behave anxiously to perceived emotional demands, this could lead to a condition of chronic anxiety. Accordingly, the primary aim of Bowen’s Family Systems Theory is to reduce chronic anxiety through 2 steps: (1) “facilitating awareness of how the emotional system functions”; and, 2) “increasing levels of differentiation, where the focus is on making changes for the self rather than on trying to change others” (Brown, 1999 p. 95). The theory suggests that the family functions through a closely connected emotional framework and the condition of the FQoL depends on the complete well-being of each family member. Its emphasis on the priority of fostering healthy and productive communication between close relations is conducive to the relational aspects of FQoL (Brown, 1999). This systems-based perspective provides a valuable theoretical foundation for research that explores how external stressors, such as the COVID-19 pandemic, impact the functioning and well-being of families. Given that this study focuses on families raising children with autism, a framework that emphasises relational dynamics and interdependence, rather than individual deficits, is particularly relevant.

While Bowen’s theory consists of eight core concepts (Brown, 1999), this study draws selectively on the components most relevant to exploring how families adapt and function emotionally. The concepts of emotional fusion and self-differentiation are particularly valuable in highlighting how emotionally over-involved relationships can heighten stress within families, especially during times of uncertainty or change (Brown, 1999). In these circumstances, personal boundaries may become unclear, allowing anxiety to spread rapidly across the family system. Similarly, Bowen’s concept of triangulation, which is the tendency to manage tension in a two-person relationship by involving a third party (Brown, 1999), is conceptually relevant to understanding how tension can be managed or redirected within caregiving dynamics. Additional components of the theory, such as the family projection process and the nuclear family emotional system, offer further insight in exploring how emotional patterns are maintained and passed on within family relationships over time (Brown, 1999).

The differing ways in which FQoL is defined and conceptualised highlight its complexity and allow for a more multidimensional approach to research in this area. Understanding the multidimensional nature FQoL throughout Bowen’s Family theory would provide a thorough framework for examining family members’ experiences. Rather than adopting Bowen’s theory as a rigid framework, it is used here as a conceptual tool to inform the study’s broader theoretical positioning. The systemic, relational of Bowen’s theory aligns well with the interpretivist approach underpinning this study, which offers a way to understand behaviour contextually and relationally, rather than through a medicalised lens. This distinction is particularly important in autism research, where families often describe their experiences as not only shaped by the ASD diagnosis, but also by the surrounding emotional and social dynamics. This framework could be insightful when applying it to families of children with SEN, especially families of children with ASD, which will be explored in more detail in the next section.

4.3 FQoL with Children with Autism

It was not until the late 1990s that research into the field of FQoL of Special Educational Needs (SEN) was addressed (Samuel and DiZazzo-Miller, 2019; Brown et al., 2006). This multidimensional social construct is used to evaluate the strengths and challenges families of individuals with SEN encounter (Samuel and DiZazzo-Miller, 2019). Different theories exist in the literature regarding FQoL of families of children with special educational needs (Allik et al., 2006; Brown et al., 2006; Lee et al., 2008; Jones et al., 2017). The academic literature based on the FQoL of families of children with ASD has painted a negative picture; having an autistic family member can be challenging for all members of the family, and as a result, families are not always able to adapt and meet each member's needs. Therefore, FQoL is an important factor to examine as it may make it easier for family members to deal with the challenges and obstacles if the shortfalls are addressed (Lei and Kantor, 2021).

4.3.1 Parents / Carers

Research on parental health identified concerns regarding the FQoL of families of children with ASD. Data from several studies presented that parents of children with autism demonstrate higher levels of anxiety, stress and depression, compared to parents of TD children or parents of children with other disabilities (Pozo et al., 2014; Feldman et al., 2007; Hastings et al., 2005; Baker-Ericzen et al., 2005). Conversely, various studies of parents of children with SEN have demonstrated that the effects of the disorders vary between mothers and fathers (Pozo et al., 2014; Keller and Honing, 2004; Pelchat et al., 2003; Krauss, 1993). Pozo et al. (2014) claim that maternal stress is associated with the needs and demands of childcare. Jones et al. (2017) also conveyed that parents with older autistic children reported a lower HRQoL score than parents of younger autistic children. According to Eapen and Guan (2016) and Lang et al. (2010), a large number of mothers of children with ASD demonstrated high rates of depression compared to mother of TD children. In contrast to previous research, Wang et al. (2006) reported no significant difference in FQoL levels in the views of mothers and fathers of children with SEN. This view is questionable as Pozo et al. (2014) argue that the severity of the disorder had a direct link to a mother's FQoL, as their experience of primary caregivers.

In their systematic review, Vasilopoulou and Nisbet (2016) highlighted that the emotional state and well-being of parents of children with ASD can affect the overall health of the child. This view is demonstrated by Friedman and Chase-Lansdale (2002) and several other researchers as they draw attention on how parental stress can cause challenges in problem-solving skills and coping strategies (Allik et al., 2006). In previous studies of children with ASD, the characteristics of the disorder have been found to play an important role in the adaptation of their parents. Pozo et al. (2014) identified that the severity of the disorder is positively associated with parental stress. This view is supported by Lecavalier et al. (2006) who wrote that self-injuries and behaviour problems have a direct link to parental stress. Pozo et al. (2014) claim that as the behaviour problems increase, parents view the problem as less manageable and predictable. Some studies have, in addition, indicated that families with autistic children may encounter challenges and access to early interventions and early diagnosis

(Jones et al., 2017). This, in turn, caused parents to feel extremely stressed and anxious. Dyson (1997) and Dunst et al. (1986) noted that having social support could potentially alleviate parental stress and improve both their well-being and attitude towards raising their autistic child. This view is supported by Phetrasuwan (2003) who writes that having support predicted a positive psychological state within the family. Bayat's (2005) work on parents of children with ASD indicated that parental perception of their child's disorder affected their FQoL. The study's result demonstrated that a positive perception of the disorder brought the family stronger and closer, showing a strong FQoL. In addition, the parental coping strategy in response to stress is a variable that influences parental adaptation. According to Pozo et al. (2014) parents who take on active avoidance coping strategies have reported high levels of stress and mental health issues, whereas parents who take on positive reframing strategies have reported less stress. Pisula and Kossakowska (2010) have demonstrated that parents of children with ASD often adopt avoidance coping strategies, differently to parents of TD children.

A broader perspective has been adopted by several studies that report characteristics of the disorder as not the only factors that affect parents' adaptation. Vasilopoulou and Nisbet's (2016) work provided an in-depth analysis of the FQoL of parents of children with ASD. In their systematic review, the results indicated that compared to parents of TD children, the FQoL of parents of children with ASD is significantly poorer. Factors such as lack of support, child behavioural difficulties, unemployment and motherly instincts have demonstrated an association with lower parental FQoL (Vasilopoulou and Nisbet, 2016). Similarly, the results presented in several studies supported Vasilopoulou and Nisbet's (2016) work and expounded that factors such as impaired physical and mental health, lack of family coherence and social isolation in parental health can prevent parents from raising their child with ASD (Allik et al., 2006; Johnson et al., 2011; Kuhlthau et al., 2014; Eapen and Guan, 2016).

4.3.2 Autistic Child

As previously mentioned in Chapter Three, ASD refers to a group of prevalent developmental disorders. The disorder is characterised by affecting the social and cognitive development, as well as the physiological development, to a varying extent. Several studies have indicated that despite early behavioural interventions which have proven to be successful, the disorder will remain having a lifelong detrimental impact on the social, mental, physical and academic development (Rao et al., 2008; Eldevik et al., 2009; Ozonoff et al., 2005; Kamp-Becker et al., 2011; Ikeda et al., 2013; Arim at al., 2012). Some authors have found that the social deficits--such as impaired social competence and limited social-emotional reciprocity--within the disorder, can affect a child's day-to-day functioning

(Ayed et al., 2021; Ikeda et al., 2013; Ozonoff et al., 2005; Rao et al., 2008; Knott et al., 2006). Kuhlthau et al. (2009) identified that friendships, age-appropriate play and processing emotions are the daily challenges that autistic individuals face. These challenges, along with the deficits in communicational skills and physiological deficits, often affect the individual’s social adjustment (Kuhlthau et al. 2009).

Previous studies have reported that children with ASD tend to face higher rates of stress, anxiety and depression compared to TD children (Kuhlthau et al., 2009; Gurney et al., 2006; Hill et al., 2004). Kuhlthau et al. (2009) published a large study on the QoL of children with ASD, in the USA and Canada, using a validated HRQoL measure. The results demonstrated a lower QoL score, compared to TD children, among all subscales (psychological health, physical health, social functioning, emotional functioning and school functioning). Likewise, prior research on the QoL of autistic children has elucidated poorer QoL than children with chronic health problems and TD children (Bent et al., 2020; Ikeda et al., 2013; Cottenceau et al., 2012; Kuhlthau at al., 2009). Considering the lower QoL scores, the role of the family and their adaptability plays a dominant role in the FQoL (Lei and Kantor, 2020). Lei and Kantor (2020) reported that positive family cohesion, adaptability and social support enhances FQoL levels. These parent and family influences negatively impact the diagnosed child and can potentially counteract the intervention's positive effects. When compared to parents of both TD children and children with other developmental disorders, the deficits in children with ASD are linked to a slew of problems in families, including decreased parenting efficacy, increased parenting stress and an increase in mental and physical health problems (Karst and Van Hecke, 2012; Eapen and Guan, 2016; Lang et al., 2010). In addition to financial problems, Karst and Van Hecke (2012) highlighted that raising a child with ASD may affect the overall family well-being and increase the rate of parental divorces. These parent and family impacts have a detrimental impact on the autistic child and can possibly counteract the effects of early interventions (Karst and Van Hecke, 2012).

All of the studies reviewed here have outlined that families of children with ASD are at a greater risk of experiencing a lower FQoL compared to families without a child with ASD. The research to date has established that social support, family cohesion and FQoL have all been shown to be crucial factors in the well-being of families raising children with ASD. The limitations of the disorder have a lifelong impact on the families, and based on the previous chapter, the effects of COVID-19 are likely to be longstanding. Thus, a better understanding of the relationship between the COVID-19 pandemic and FQoL is provided in the following section.

4.4 Impact of COVID-19 on FQoL

When COVID-19 spread globally, infecting more than 200 countries, and caused more than 40,000 fatalities worldwide (WHO, 2020b), research to-date highlighted that the consequences of COVID-19 are likely to be longstanding because of how it pervades the processes and structure of a family system, thus impacting on the FQoL/QoL (Yunitri et al., 2022; Torales at al., 2020; Rajkumar, 2020; Prime et al., 2020).

The COVID-19 virus caused individuals and families to face an unprecedented threat and to undergo restrictions to curb the spread of the virus; as well as the symptoms of the COVID-19, people in affected countries also experienced abrupt changes to relationships, resources and routines -- the limits on physical engagement have had a significant impact on families (Vanderhout et al., 2020). The lockdowns instructed families to remain at home, which could possibly contribute to concerns and conflicts within the family unit (Ferreira et al., 2021). Shek (2021) pointed out that families staying at home during the nationwide lockdowns could create conflicts among family members. Family members may not have personal space, may have additional responsibilities and may have an increase in parental supervision and involvement (Shek, 2021; Fisher et al., 2020). In a study investigating health and social concerns during the pandemic, Olivera and Fernandes (2020) reported concerns of child abuse, domestic violence and conflicts between families and parents during nationwide lockdowns in the pandemic. Janssen et al. (2020) explained that even though some families were able to deal with the extra responsibilities, the pandemic had a negative impact on parents. Parents and family members had to take on new roles and responsibilities as playmates and educators, while managing their full-time roles as caregivers and the stressful changes in finances, social relationships and the workplace (Vanderhout et al., 2020). Ng et al. (2013) identified that job-related issues, such as unemployment, can contribute a major risk factor to mental health difficulties. Dramatic changes to an individual’s work life and job, including economic crises, could seriously impact an individual’s health (Ferriera et al., 2021; Fernandez et al., 2015; Christodoulou and Christodoulou, 2013; Ng et al., 2013). This caused continuous threat-imposed fear within families which intensified their anxiety causing a reduction to the QoL/FQoL (Ferriera et al., 2021).

The pandemic is ongoing, and the social consequences are expected to last a long time. Ravens-Sieberer et al. (2020) explained that children and young adults are particularly at risk of negative consequences caused by lockdown social restrictions; given their age, social contact is crucial for their development (Fegert et al., 2020; Xie et al., 2020). This was evident in Ravens-Sieberer et al. (2020) as their study demonstrated that children and adolescents’ QoL and mental health were reduced during the pandemic. In addition, they found depressive symptoms such as anxiety and stress within children and adolescents. A recent study by Mertens et al. (2020) found that the fear generated by the pandemic, and the social media exposure could possibly result in a chronic and onerous fear, resulting in a high level of anxiety. Similarly, Prime et al. (2020) demonstrate that social disturbances from the pandemic will cause caregivers to experience increased psychological discomfort, affecting the quality of relationships between caregivers themselves, as well as between parents and children and among siblings.

Nationwide lockdown meant that face-to-face schooling was suspended for a set period in several countries (Sá et al., 2020). As a result, children were staying at home for what appeared to be prolonged periods, with no planned indoor or outdoor physical activity, leaving them vulnerable to excessive sedentary behaviour (Sá et al., 2020). Bishwajit et al. (2017) investigated the effects of physical inactivity which concluded that individuals who have a lower rate of vigorous physical activity can be at a higher risk of depression. Furthermore, several studies have indicated that the lack of physical activity and depression could lead to obesity and anxiety (Ferreira et al., 2021; Sousa et al., 2017; Garimella et al., 2016). Based on several parents' views, social isolation led to more screen time, which resulted in increased sedentary time and decreased physical activity (Sá et al., 2020). Similarly, Puccinelli et al. (2021) explains that low physical activity levels and family monthly income were all linked to a higher presence of both anxiety and depressive symptoms.

Collectively, these studies provide important insights into the physical and mental impact of the COVID-19 pandemic on families. The unprecedent measures caused growing concern within families, however, such studies remain narrow and focus on families with TD children. The next section moves on to focus on the effects of COVID-19 on the FQoL of families with children with ASD.

4.5 FQoL of Families with Children with Autism during COVID-19

Although help is required on a regular basis, the COVID-19 pandemic has further increased the family support needs of people with ASD (Meral, 2021). With widespread panic, anxiety, and fear of the virus spreading, it is expected that the FQoL will be largely affected during the COVID-19 pandemic. A study by Cheng et al. (2022) conducted in China highlighted the impact of pandemic-related stress on parents of autistic children. The study demonstrated that heightened stress levels among parents were significantly associated with a decline in FQOL. Interestingly, the study also revealed that increased parental involvement in children's learning had a mitigating effect, improving FQOL outcomes despite heightened stress. Beyond economical struggles, social isolation, mortality rates and increased anxiety, a further significant impact of COVID-19 is the family burden of meeting their autistic children's educational and therapeutic needs at home due to the lack of professional support (Meral 2021; Neece et al., 2020; Sun et al., 2020). The lack of professional support was due to the closing of schools, childcare and afterschool programmes. This led to family members taking on extra roles to assist in meeting the needs of their child (Eshraghi et al., 2020; Fontanesi et al., 2020), a trend that is still reported in more recent studies. Furar et al. (2022), for example, found that families did not have access to healthcare services during the pandemic, which intensified parents' stress levels and raised concerns about developmental regression. Some studies reported that taking on roles without formal training or education increased levels of burden and stress among family members (Isensee et al., 2022; Tokatly Latzer et al., 2021), which is consistent with more recent literature from Indonesia, where declines in children's HRQoL were linked to reduced educational and family support (Windarwati et al., 2024). These findings suggest that while families tried to fill educational and social support gaps, the absence of professional input had lasting consequences. Similarly, Kaur et al. (2024) found that financial and economic strain and job insecurity in Indian families further intensified the challenges of balancing caregiving and financial survival, reinforcing earlier findings that suggest the pandemic deepened pre-existing inequalities for families of autistic children.

More often than not, raising a child with ASD requires outside professional support in order to meet the child's educational, health, social and psychological needs (Meral, 2021). Given the heterogeneity of the disorder, Guldberg et al. (2011) reported that it is crucial that interventions are tailored to the unique needs of the child. Based on recent research, parents of children with ASD expressed some significant educational challenges as it was difficult for them to meet the needs of the child (Fontanesi et al., 2020; Masters et al., 2020). Pellecchia et al. (2020) found that remote learning may not be as effective for autistic children, further complicating the challenges that families face. These issues remained prevalent throughout the later stages of the pandemic, with parents continuing to report difficulties accessing suitable resources or managing autistic children's behaviour during remote schooling (Furar et al., 2022; Kaur et al., 2024). Some fathers reported that they did not have enough time to spend with their family due to work-related struggles, leaving the rest of family members to take on additional roles (Meral et al., 2021). Further research by Child: Care, Health and Development (2024) examined changes in child well-being and FQOL over time. While children's overall well-being remained largely consistent, the study found a significant decrease in FQOL in later stages of the pandemic compared to earlier phases. This suggests that the long-term nature of the crisis may have a cumulative impact on family systems, even when immediate effects appear manageable. Importantly, this decline was observed in families already accessing mental health services, indicating that even those with prior support systems were not immune to decline.On the other hand, Meral (2021) also reported positive FQoL results as several parents expressed that their autistic child's verbal behaviour increased due to the higher family interaction during the lockdowns. Additionally, recent research demonstrated signs of relief from less exposure to sensory overload and social pressures (Fumegalli et al., 2021), while Spain et al. (2018) noted a reduction in anxiety levels among autistic children who thrived in consistent home routines and less social interaction These findings were demonstrated in more recent work by Ng et al. (2025), who found that parents identified both challenges and benefits during the pandemic. For some, increased family bonding and a calmer home environment allowed autistic children to function more comfortably than in pre-pandemic conditions. This body of research demonstrates the diversity of family experiences and highlights the importance of not assuming the pandemic was uniformly negative for all. Hidayat et al., 2020 and Pennefather et al. (2018) propose that children with autism benefit from the routine and consistency provided by a structured remote learning environment at home. However, such results have failed to comply with data from other studies, as families in recent research reported negative psychological impacts of the lockdowns (Neece et al., 2020; Fontanesi et al., 2020; Coyne et al., 2020). Tokatly Latzer et al. (2021) and Mutluer et al. (2020) argued that parents' anxiety levels during the COVID-19 pandemic are linked to the severity of ASD-related behavioural difficulties and their autistic child's ability to thrive is linked to their parent's coping mechanisms. Recent studies have added further layers to this discussion by exploring spiritual and cultural coping. Araz et al. (2024), for example, found that while parents of autistic children in Turkey reported only moderate levels of QoL, many relied on spiritual beliefs and personal faith systems to manage their emotional well-being, an aspect that was largely overlooked from early-pandemic literature.

A significant number of families of children with ASD voiced concern and distress about their children showing behavioural and academic regressions as a result of disruptions in routines, social distancing measures and decreased medical, behavioural and educational services (Stankovic et al., 2020; Yahya and Khawaja, 2020; White et al., 2021; Tokatly Latzer et al., 2021; Pecor et al., 2021). Pecor et al. (2021) propose several measures to improve the QoL for families such as organising socially distanced outdoor activities as a stress-relieving strategy, having extra support at home to assist family members with essential daily activities and/or providing parents with respite care. The importance of these suggestions have been further highlighted in recent research suggesting that long-term service disruptions has resulted in lingering family fatigue and emotional exhaustion (Windarwati et al., 2024; Kaur et al., 2024). Other research has indicated that providing psychological support for family members through online counselling, wellness checks and social gatherings could also enhance their morale and ease their strain during the COVID-19 pandemic (Althiabi, 2021; Kotera et al., 2021; Stankovic et al., 2020).

In summary, the COVID-19 pandemic has significantly impacted the QoL of families raising children with ASD, intensifying existing challenges related to care, education, and emotional well-being. Although declines in FQoL were reported across many family types, the impact was particularly significant for families of autistic children due to their increased reliance on external support systems and the unique nature of their children's needs. However, recent studies also reveal differences in experiences, with some families reporting moments of adaptation, or even a sense of relief from certain social demands. These findings highlight the importance of viewing FQoL as a multidimensional and context-sensitive construct. Future research should continue to investigate how factors such as level of impairment, parental education levels, cultural background, and resource availability shape family outcomes, particularly during times of crisis.

4.6 Conclusion

This chapter has demonstrated that the concept of Quality of life has been studied for years, yet there is no single agreed definition. Quality of life is used across multiple disciplines to measure different domains and has different concepts derived from the definition itself. Family quality of life shares similar goals to quality of life. It refers to circumstances in which a family's basic requirements are met, family members enjoy their time together as a unit and family members have the chance to pursue and achieve goals which are vital to their pleasure and fulfilment. During COVID-19 the virus caused individuals and families to face unprecedented challenges in addition to measures to limit the spread of the virus; these unprecedented challenges and measures imposed on families to make dramatic, negative changes to their lives, thus affecting and causing a reduction to their FQoL. Even though there are extensive studies achieved during the past decades on the QoL of families, the assessment of FQoL of children with ASD, with and without the COVID-19 pandemic, is lacking. The following chapter will move on to describe this research study’s rational, design and research method.

CHAPTER FIVE: RESEARCH METHODS

Chapter Five describes the research method, design and rational used in this research study. In addition, this chapter also includes the data collection methods used in this study, as well as a justification for the methods employed. Thereafter, the research design and the recruitment procedure will be described. Lastly, the trustworthiness and ethical considerations will be examined, with a summary of this chapter and a research study plan will be provided.

5.1 Research Aims

This research study aims to explore the impact of the COVID-19 pandemic on the quality of life of families with children diagnosed with autism spectrum disorder.
More specifically, the aims of this research study are:

c) To explore the impact of COVID-19 on the quality of life (i.e., psychological, social, physical and academic) of families with children with autism.

d) To explore the impact of COVID-19 on the quality of life (i.e., psychological, social, physical, and academic) of children with autism.

In order to achieve the research aims as outlined above, a qualitative descriptive approach was conducted using focus group interviews with the families of children with autism, and where possible, individual interviews with each member of the family. A more detailed explanation of the methods adopted is given in the following sections.

5.2 Research Approach

The research approach adopted for this study is a qualitative descriptive research approach (Sandelowski, 2000). In the following sections, a detailed definition of qualitative descriptive research is provided below as well as the rationale in choosing this research approach.

5.2.1 Qualitative Research: definition

Qualitative research is, at its core, an exploratory method that aims to understand underlying motives, opinions, and reasons (Austin and Sutton, 2014).

Portney and Watkins (2009 p.18) explained that qualitative research:

"is more concerned with a deep understanding of a phenomenon through narrative description, which typically is obtained under less structured conditions."

Qualitative researchers suggest that viewing a phenomenon in its context is the key to understanding it (Atieno, 2009). Atieno (2009) clarifies that some qualitative researchers immerse themselves in the research as it is considered the best approach to comprehending what is happening. The origins of qualitative techniques can be traced back to sociologists and psychologists since the 1940s (Merton and Kendall, 1946; Merton et al., 1956). However, it has gained acceptance and use in a variety of academic fields, such as sociology, education, feminist research, communication and media studies, health research and marketing research (O.Nyumba et al., 2018). Rather than simply collecting numeric data, Hicks (2009 p.7) explains that the:

> *"Techniques of qualitative research rely heavily on accurate reporting in a natural environment, without control or restriction impose by the investigator. Moreover, unlike quantitative research where small aspects of an individual's behaviour are selected for study, in qualitative research, the individual as a whole and in relation to their social setting is described."*

Various studies have pointed out that due to its holistic approach, qualitative methods are useful when researching individuals' experiences (O.Nyumba et al., 2018; Hicks, 2009). Each definition's key point is that the qualitative technique largely depends on the data that the researcher collects after being intimately involved and interdependent with the study's participants. More specifically, qualitative research strategies depict and explain people's experiences, behaviours, interactions and social situations without using statistical methods or quantification (Aspers and Corte, 2019; Atieno, 2009; Smythe and Giddings, 2007).

5.2.2 Qualitative Descriptive Research and Philosophical Underpinning

Sandelowski (2010) articulates that researchers' justification of using the qualitative descriptive approach is for researchers who seek a descriptive summary of individuals' experiences and perceptions, particularly in areas where little is known about a particular topic. This is similar to Kim et al.'s (2016) view, as they explain that qualitative descriptive studies intend to provide a comprehensive narrative of events in the vernacular of such events. Utilizing the 'who, what, and where' of experiences is ideal for this method (Kim et al., 2016, p. 23). In the context of this study, a qualitative descriptive approach could be considered as the most appropriate approach because it aids the researcher in providing a detailed and credible synopsis of each family's unique experiences and captures the complex challenges and struggles, they have faced during the pandemic. Bradshaw et al. (2017) argues that this approach acknowledges the subjective nature of the study, and the participant's different experiences, and will allow the researcher to demonstrate the results in a way that directly reflects this study's research question. A qualitative descriptive approach provides a direct reflection of the participants' experiences and presents a degree of flexibility that is unequalled by other qualitative approaches (Neergaard et al., 2009; Sandelowski, 2000). For example, in this study, Sandelowski (2010) highlights that this approach is not bound to a certain theoretical perspective. As a result, it captures a wide range of research questions, while accommodating a variety of participants' perspectives. This versatility is helpful, particularly when the goal of any study is to present a comprehensive and lucid picture of a phenomenon (Sandelowski, 2010). In addition, findings from these studies are often presented in layman's terms, which increases their accessibility, making them relevant to a wider audience, such as policy makers, practitioners and other interested parties (Willis et al., 2016; Neergaard et al., 2009). As a result, this approach will strengthen this research by ensuring that the participants' viewpoints are represented accurately, providing detailed insights into their lived experiences during the pandemic, particularly in areas where research is limited.

The qualitative information gathered for this study specifically focuses on non-numeric information. The advantage of this strategy is that it seeks to address issues by understanding the experiences and significance of human lives and the social world (Fossey et al., 2002). In this case, the researcher should let the questions arise and change as they become familiar with the subject matter of their study rather than approaching measurement to create a fixed instrument or collection of questions. Each qualitative method involves a particular way of thinking about data and using techniques as tools to change data to achieve a purpose (Atieno, 2009). Measuring data qualitatively is based on open-ended questions, interviews, and observations (Portney and Watkins, 2009). Portney and Watkins (2009) explained that the goal of the qualitative research could be as simple as describing the current state of affairs, or it could be to investigate associations, develop theories or come up with hypotheses. Combining the methods can be utilised in certain ways to ensure consistency throughout the research process, and each step of the research process is connected to the one before it (Atieno, 2009). According to Drisko (1997), acquiring information from numerous sources can help researchers to achieve comprehensive or complete answers to answer the research aims and questions (Drisko, 1997).

However, there are downfalls with the qualitative descriptive approach, as with all research methods. Although this approach has the advantage of providing a direct description, it has a limitation when deeper theoretical insights are required (Neergaard et al., 2009). The lack of a theoretical framework may present challenges during data interpretation, particularly for novice researchers (Neergaard et al., 2009). Doyle et al. (2020) point out that various studies have critiqued this approach in terms of scientific rigor. The risk of producing a superficial account exists if research studies are not conducted with the necessary degree of scientific rigor (Vaismoradi et al., 2013). The issues with the credibility of this approach have often been linked with inconsistency in decision-making within the research study, along with a lack of transparency (Doyle et al., 2020). Consequently, it is imperative to approach qualitative descriptive research with a critical mindset, ensuring that the descriptions are authentic and have undergone a rigorous analysis (Doyle et al., 2020).

5.2.2.1 Philosophical Underpinning

Given the aims and qualitative descriptive methodology of this research study, the Interpretivist philosophical approach would be best suited. Interpretivism is one of the foundational philosophies for qualitative research studies (Alharahsheh and Pius, 2020). This philosophical paradigm emphasises the importance of interpreting and comprehending an individual's behaviour and experiences within their historical context and socio-cultural (Alharahsheh and Pius, 2020). The focus of this paradigm would be on understanding the meaning and experiences of the participants' narratives from their own perspectives (Alharahsheh and Pius, 2020). This would be particularly suited to exploring the complex experiences of families with autistic children during the pandemic. As the literature review demonstrated, challenges were brought on by the global epidemic for individuals and governments everywhere. Research has shown that the pandemic has had an effect on every area of a person's quality of life (Yunitri et al., 2022; Torales at al., 2020; Rajkumar, 2020; Prime et al., 2020). Concern has been raised in recent research about the two primary symptom domains of autism, the social and communicative domains, about how it can be impacted by the quick and unexpected changes that families have had to undertake. Children with autism and their families would face behavioural and emotional difficulties as a result of these changes. The use of the qualitative descriptive approach with Interpretivism in this study would allow the researcher to find out the perspectives and personal opinions of families with children with autism on how the COVID-19 has impacted their Family Quality of Life. Interpretivism enables the researcher to emphasise the importance of context, whilst acknowledging that participants' views and experiences are influenced by their cultural, social and historical backgrounds (Alharahsheh and Pius, 2020). Understanding personal experiences is made easier by using qualitative research methodologies. This method offers a number of tools for identifying the traits and parameters of the research subject (Jackson and Bazeley, 2019). Research suggests that qualitative approaches are particularly suitable for comprehending the subjective experiences of health and disease by individuals and groups, and the influence of social, cultural, and political aspects on health and disease, in addition to the interactions between participants and healthcare environments (Al-Busaidi, 2008).

Given that this research study was to comprehensively explore the multifaceted impacts of the COVID -19 pandemic on families of children diagnosed with ASD, a qualitative descriptive approach was chosen. By utilising this approach, this study seeks to capture the range and complexity of experiences, by providing participants' direct reflections. Each family member can offer information and points of view that have not yet been considered in research. What constitutes good, qualitative research is whether the data presents the participants' actions, subjective meanings and social contexts (Fossey et al., 2002). The qualitative data collection methods were adopted to measure the impact of the COVID-19 pandemic on the QoL of families of children with ASD from both a focus group and one-on-one interviews.

Through employing online focus groups and one-on-one interviews, this study prioritised capturing participants' perspectives with the use of their own words, ensuring that each experience is genuinely described. The interviews were analysed using a hybrid of inductive and deductive thematic analysis method outlined by Braun and Clarke (2013). This analytical method supports the Interpretivist paradigm as it allows themes to emerge both from the data reflecting each participant's perspective and from existing frameworks, (Naeem et al., 2023). This, in turn, facilitates a deeper understanding of how the pandemic impacted the families' QoL, highlighting the varied ways they perceived and handled their challenges. The researcher was capable of gaining additional insights by combining the two interview techniques rather than by using just one type of data collection tool. The use of the focus groups allowed the researcher to explore differences in family members' opinions and discussions (Parker and Tritter, 2021). The one-on-one interview method enables the researcher to delve more deeply into the participant's unique experiences and gives them greater freedom to express themselves (Kruger et al., 2019). This will make it possible for the research study to represent in depth and detail the myriad challenges, shifts, and coping strategies in quality of life of families with children with ASD during the pandemic.

In adopting the Interpretivist approach, the researcher plays a pivotal part in shaping the findings of the study, as they are thoroughly involved in the construction and interpretation of the data (Schwandt, 1994). As such, the researcher's personal and cultural background, experiences, and worldview unavoidably impact the entire research process (Holmes, 2020). Jamieson et al. (2023) suggest that qualitative research involves reflexivity and positionality, where the researcher evaluates their role, background, reflection and experiences throughout the study. The process of reflexivity and positionality ensures that the data collected is not only fixated in participants' experiences, but that it also critically examined and influenced through the researcher's interpretations (Holmes, 2020). Through this Interpretivist lens, this study emphasised the importance of subjective experiences, context and meaning, providing an exhaustive and empathetic representation of the participants' narratives (Alharahsheh and Pius, 2020). This study will thoroughly engage with the participants' accounts and acknowledge the complexity of their experiences, and offer valuable insights into the multifaceted challenges the families faced during the pandemic. A more detailed explanation of the researcher's role, reflexivity and interview methods are explained in the following sections.

5.2.2.2 Researcher's Role and Reflexivity

This section aims to elucidate the researcher's personal background, reflexive practices, relationship with participants and the potential impacts on this study. By doing so, the researcher seeks to enhance the transparency and trustworthiness of this study (Ahmed, 2023), allowing readers to understand the research from their own perspective.

Personal Background and Reflexivity

My journey to this PhD and this research is deeply rooted in my diverse cultural background and life experiences. Born and raised in Kuwait to an Iranian father and a Kuwaiti mother, I navigated a multicultural upbringing that introduced me to a unique perspective on both identity and belonging. This cross-cultural experience, combined with my education in private English schools, has equipped me with fluency in English, Arabic and Persian, enabling me to connect with different cultural backgrounds. My educational path reflects an integration of business and education, with a focus on special education. I completed my bachelor's degree in Management Information Systems in Kuwait, followed by a master's in Special Educational Needs in the UK. This interdisciplinary background has helped shape my approach to research, allowing me to view challenges and complications from multiple angles. Professionally, my experiences have been varied and formative. From working in summer camps to tutoring at a university skills lab, and from project management to coaching Volleyball, each role has contributed to my knowledge of human interaction and organisational dynamics. Particularly significant was my involvement in a project where I combined my passion and education to lead a project aimed at raising funds for Kuwait Center for Autism. My subsequent work as a teaching assistant in special needs schools further deepened this passion and commitment. These professional experiences, especially working with children with special needs, have profoundly shaped my research interests. I’ve consistently sought creative ways to incorporate physical activity and movement into educational strategies for the children I worked with, drawing from my personal experience with physical activity as a means of coping with life’s challenges.

Reflexively, I recognise that my research motivation stems from personal experiences. Having faced challenges as a non-Kuwaiti living in Kuwait, I developed a heightened awareness of social inequalities and the importance of education as a pathway to opportunity, thanks to strong support of my mother. This background has embedded in me a deep empathy for neglected groups and a drive to contribute to improving their quality of life. My interest in researching the impact of the pandemic on families with children with autism is somewhat informed by my own experiences with physical activity as a coping mechanism. Having recently faced personal challenges and physical limitations, I've gained a renewed appreciation for the role of physical activity in maintaining mental health and quality of life. This personal insight fired my curiosity about how families may have navigated similar challenges during the pandemic.

I'm aware that my preconceptions about the negative impact of the pandemic, particularly on vulnerable populations, may have influenced my approach to the research. To mitigate any potential bias, I committed to maintaining an open mind and I let the data guide my outcomes. My core principle of fairness and equality for all reinforces my research approach. While I aim for objectivity, I acknowledge that my realist worldview may shape how I interpret data and construct meaning from participants' narratives. As I began this research journey, I remained observant of how my background shaped my perspective. I committed to ongoing reflexivity, continuously assessing how my experiences, values, and assumptions might have influenced each stage of the research process. This is crucial in ensuring the validity and trustworthiness of the data. The validity and trustworthiness are addressed in detail in Section 5.6.

Relationship with Participants

This study focused on families of children with ASD, exploring the impact of the pandemic on their QoL. While I don't have personal experience of ASD within my immediate family, my professional background as a teaching assistant in special needs schools, and my involvement in projects supporting children with ASD, offered me some familiarity with the challenges faced by these families. I acknowledge that I occupy a unique position as both an insider and outsider in relation to the participants. My experience of working with children with ASD allows me to approach the study with some understanding of the field. Although I did not know any of the participants personally, I was aware of the inherent power imbalance that exists between a researcher and their participants, particularly in qualitative research involving vulnerable populations (Anyan, 2013). This was further heightened by the fact that I do not share lived experiences of parenting a child with ASD, which positioned me as an outsider in significant ways. To address this, I aimed to establish rapport with participants and emphasised that they are the experts in their own experiences. (Anyan, 2013). I aimed to create a comfortable, non-judgmental environment where participants felt motivated to disclose and share their stories confidently. All families were recruited through organisations, ASD-related networks, and social media platforms, and I ensured a clear and respectful introduction process at every stage. During both recruitment and the start of each interview, I reintroduced myself as a PhD student from the University of Leeds, explicitly clarifying that I am a student and not a clinician. I made it clear that participants had the right to pause, stop, or withdraw at any time, and I reassured them that they were in control of the interview, even if I was the one leading it. This was particularly important when working with children and young people with autism, whose comfort and sense of independence were central to my approach.

Building rapport with participants was a crucial aspect of this study, given the sensitive nature of this topic. I approached each interview with respect, active listening and empathy, ensuring that participants felt comfortable to share their personal experiences. My multilingual background also helped in establishing connections with some participants from diverse cultural backgrounds. Thus, to further balance the power dynamic, I made several accommodations to ensure participants could engage on their own terms. For families who preferred to use Arabic, I provided the interview questions in both English and Arabic in advance and invited them to respond in whichever language they felt most comfortable with during the interview. When children were involved, I reassured parents that they could preview the questions prior to the interviews, be present during the interviews, and intervene if needed. In some cases, children would deviate from the topic and talk about unrelated interests. Rather than interrupting, I allowed them space to speak freely and gently guided the conversation back to the questions afterwards. This helped establish trust and respect for the child’s voice.

Ethical considerations were critical in my approach to participant relationships. I was assured that all participants were fully informed about the research process and their right to withdraw at any time. This included being transparent about the research aims, obtaining informed consent, and ensuring confidentiality. I also respected participants’ preferences for privacy, particularly in terms of video settings. For example, in one focus group, a participant named Family D – Daughter, a young autistic girl, chose to not appear on camera during the family focus group interview, which I fully supported without drawing attention to it. In the following one-on-one interview, she chose to turn her camera on and complete the conversation with me. Her father later explained that this was the first time she had ever done so with someone outside her social group, and that he was proud of her for taking that step. I was deeply moved by this moment, as it highlighted the importance of creating a safe and empowering space. Throughout the research process, I observed that while some families opened up more than others, all participants shared their experiences freely without pressure. When participants seemed more reserved or hesitant, I accepted that without probing for more information, allowing them to lead the pace and depth of the discussion. I maintained to ongoing reflexivity regarding my relationships with participants. I thoroughly documented all interviews and interactions, noting any biases or assumptions that may have arisen, and considered how they may have influenced data collection and analysis. By maintaining awareness of the relational dynamics, I aimed to conduct research that is both academically rigorous and beneficial to the participants involved.

Impact on Research Process

As an interpretivist researcher, I acknowledge that my background, experiences and positionality inevitably impact every stage of the research process. This section discusses these potential impacts and outlines strategies to ensure the integrity and trustworthiness of the study. My personal and professional experiences have influenced the research design. My background in special education, and personal understanding of the significance of physical activity in maintaining health and mental well-being, directly influenced my choice to study the impact of the pandemic on the quality of life of families of children who have ASD. This insider knowledge provided valuable insights allowing me to build rapport with participants, but also required careful reflection to avoid projecting biased experiences onto participants. Additionally, during data collection, I was aware that my presence as a researcher may have influenced participants' responses. The experience I had of working with children with special needs made some participants more comfortable sharing their experiences. For instance, initially, some participants were hesitant to appear on video, but as the interviews progressed and they felt more comfortable, they opted to be visible, demonstrating a relaxed and expressive body language, with further engagement. However, I was cautious not to assume understanding or fill in gaps based on my own knowledge and experience. To mitigate this, I used open-ended questions and actively encouraged participants to elaborate on their unique experiences with probing questions (the data collection methods are addressed in detail in Section 5.4) (Patton, 2002). In the data analysis phase, I recognised that my personal experiences with trauma and the importance of physical activity in my life could have influenced how I interpreted participants' experiences. To mitigate potential bias, I maintained a reflexive document to examine my thoughts, feelings, and decision-making. This aided me in identifying and addressing any unnecessary influence that my positionality may have had on the research process. Additionally, I consulted with my supervisors to ensure my analysis is practical rather than based on personal assumptions. While my positionality presented obstacles, it also offered benefits to the research process. My multicultural background and experience in special education provided a unique lens to view and understand the complexities of participants' experiences. My empathy and understanding of the challenges faced by participants helped me to build rapport and elicit rich, detailed narratives. By reflecting on my positionality and actively seeking to mitigate bias, I aimed to present a balanced and credible account of the impact that the pandemic had on the quality of life of families with autistic children.

5.3 Participants

The study aimed to involve 8 to 10 different families of children with ASD from diverse backgrounds. A total number of 10 families took part in this research study (see tables below). Convenience sampling was employed to recruit participants (Stratton, 2021). Convenience sampling is a method where participants are recruited based on their availability and proximity to the researcher’s location (Stratton, 2021). Using this sampling strategy, participants were easily approachable and readily available, such as families who are a part of certain organisations or networks that could be reached via social media channels. To identify potential participants, the researcher utilised different methods of communication and social media platforms, focusing on ASD-related networks. This included the use of social media platforms (Instagram, Facebook and Twitter), autism online networks (Autism Research Leeds and Facebook Channels and Groups, see below), and word of mouth. Thereafter, the researcher then reached out to group organisers and networks via messages, emails or phone calls, providing a brief introduction of the study and to herself. Once potential participants expressed interest, the researcher then sent them either a detailed email about the study or posted an advert within the network or group. This email and advert included detailed information about the study, inviting interested participants to contact the researcher directly. Three families had a non-verbal autistic child. One family had two autistic twins and a father with a late autism diagnosis. One family had two autistic siblings and an autistic mother and father. Two families were singles mothers raising an autistic child. A more detailed account of the family participants is demonstrated below.

5.3.1 Targeted Organisations and Networks

5.3.1.1 Facebook

- Autism / ADHD Parents Leeds
- Autism & Aspergers Awareness
- Ohana Parent Support Group
- Leeds Parents of Children with Special Educational Needs
- Leeds autism parents meet/support group
- Autism & Parent Support UK; Living a SENsational Life #SENsationalWarriors
- Autism Support UK
- Leeds Autism and Asperger's Group
- AUTISM PARENTS SUPPORT GROUP
- Autism parents support group in United Kingdom

5.3.1.2 Twitter

- Beyond Autism
- Autism Networks
- Leeds Autism AIM

5.3.2 Inclusion criteria for families

- All families have a child diagnosed with autism spectrum disorder (ASD).
- The autistic child met the criteria of ASD of the Diagnostic and Statistical Manual of Mental Disorder (DSM – V) (See Chapter Three).
- The autistic child has been assessed and diagnosed by a health professional and an autism specialist.

The tables provided below offer a detailed breakdown of each family interviewed.

Table 6 - Participant's Information

Family	No. of Family Members	No. of Siblings	No. of Autistic Children	Autistic Child's age	Autistic Child's Education
Family A	4	2	2	10 and 10	Mainstream School
Family B	5	2	1	10	Special School
Family C	2	0	1	7	Special School
Family D	4	2	2	12 and 14	Home Educated
Family E	2	0	1	11	Special School
Family F	3	1	1	12	Special School

Family G	5	2	2	12 and 14	Special and Mainstream School
Family H	4	2	1	12	Special School
Family I	6	3	1	12	Not Educated
Family J	3	1	2	12 and 11	Special School

Table 7 – Family A

Family A	Gender	Age	Role	Academic Level	Country	Interviewed
Family A – Mother	Female	-	Mother	Employee	United Kingdom	Yes
Family A – Son 1	Male	10	Autistic Child	Student	United Kingdom	Yes
Family A – Son 2	Male	10	Autistic Child	Student	United Kingdom	Yes
Family A – Father	Male	-	Father	Employee	United Kingdom	No

Family A consisted of the mother, her two autistic twin brothers and the father. The interviewer was able to interview with the mother and her twin sons individually as well as in a focus group setting. The father did not participate in the study.

Table 8 - Family B

Family B	Gender	Age	Role	Occupation	Country	Interviewed
Family B – Mother	Female	-	Mother	Stay at home mom	United Kingdom	Yes
Family B – Son 1	Male	10	Autistic Child	Student	United Kingdom	No
Family B – Son 2	Male	14	Brother	Student	United Kingdom	No
Family B – Daughter	Female	13	Sister	Student	United Kingdom	No
Family B - Father	Male	-	Father	Employee	United Kingdom	No

Family B consisted of the mother, her three children (two TD and one autistic child) and the father. Only Family B - Mother was interviewed by the interviewer. No other members of the family participated in the study.

Table 9 - Family C

Family C	Gender	Age	Role	Occupation	Country	Interviewed
Family C – Mother	Female	-	Mother	University student	United Kingdom	Yes
Family C – Son	Male	7	Autistic Child	Student	United Kingdom	No

Family C – Mother is a single mom raising her autistic son. There was no mention of the Family C – Son's father, so he was not contacted and no other family members participated in the study.

Table 10 - Family D

Family D	Gender	Age	Role	Occupation	Country	Interviewed
Family D – Mother	Female	-	Mother	Employee	United Kingdom	Yes
Family D – Father	Male	-	Father	Employee	United Kingdom	Yes
Family D – Son	Male	12	Autistic Child	Home - educated	United Kingdom	Yes
Family D – Daughter	Female	14	Autistic Child	Home - educated	United Kingdom	Yes

The members of Family D were the mother, father, and their two children. All family members are diagnosed with autism. The interviewer had the opportunity to interview all family members both in one-on-one settings and in a focus group.

Table 11 - Family E

Family E	Gender	Age	Role	Occupation	Country	Interviewed
Family E – Mother	Female	-	Mother	Employee	United Kingdom	Yes
Family E – Daughter	Female	11	Autistic Child	Student	United Kingdom	No

Family E – Mother is a single parent raising her autistic daughter. The parents in Family E are divorced, and the father is not involved in the daughter's life. The mother was the only member in Family E who participated in the study.

Table 12 – Family F

Family F	Gender	Age	Role	Occupation	Country	Interviewed
Family F – Mother	Female	-	Mother	Employee	Kuwait	Yes
Family F – Son 1	Male	12	Autistic Child	Student	Kuwait	No
Family F – Son 2	Male	7	Brother	Student	Kuwait	No

Family F – Mother is a single parent raising two boys (one TD and on autistic). The only information provided regarding the father is that they are divorced. The mother was the only member in Family F who participated in the study.

Table 13 - Family G

Family G	**Gender**	**Age**	**Role**	**Occupation**	**Country**	**Interviewed**
Family G – Mother	Female	-	Mother	Stay at home mom	United Kingdom	Yes
Family G – Son 1	Male	14	Autistic child	Student	United Kingdom	No
Family G – Son 2	Male	12	Brother	Student	United Kingdom	No
Family G – Son 3	Male	4	Brother	Nursery school	United Kingdom	No
Family G – Father	Male	-	Father	Employee	United Kingdom	No

The members of Family G included the mother, father, and their three sons. The mother and Son 1 have been diagnosed with autism, while Son 2 and Son 3 are currently awaiting a diagnosis. The interviewer was able to interview Family G – Mother; no other family members participated in the study.

Table 14 - Family H

Family H	**Gender**	**Age**	**Role**	**Occupation**	**Country**	**Interviewed**
Family H – Mother	Female	-	Mother	Employee	Saudi Arabia	Yes
Family H – Son 1	Male	4	Brother	Student	Saudi Arabia	No
Family H – Son 2	Male	12	Autistic Child	Student	Saudi Arabia	No
Family H – Son 3	Male	14	Brother	Student	Saudi Arabia	No
Family H – Father	Male	-	Father	Employee	Saudi Arabia	No

The members of Family H included the mother, father and their three sons (Two TD and one autistic). The interviewer managed to interview the mother only; no other family members participated in the study.

Table 15 - Family I

Family I	Gender	Age	Role	Occupation	Country	Interviewed
Family I – Mother	Female	-	Mother	Stay at home mom	Saudi Arabia	Yes
Family I – Son 1	Male	12	Autistic Child	Home - educated	Saudi Arabia	No
Family I – Son 2	Male	12	Twin Brother	Home - educated	Saudi Arabia	No
Family I – Daughter 1	Female	14	Sister	Student	Saudi Arabia	Yes
Family I – Daughter 2	Female	24	Sister	Employee	Saudi Arabia	Yes
Family I – Father	Male	-	Father	Physician	Saudi Arabia	No

Family I consisted of both parents (mother and father), and their 4 children (3 TD and one autistic). Son 1 and Son 2 are twin brothers; Son 1 has been diagnosed with autism and Son 2 with Borderline Personality Disorder. The interviewer had the opportunity to conduct one-on-one interviews with Family I – Mother, and her two daughters, Daughter 1 and Daughter 2, as well as a focus group session with them. No other family members participated in the study.

Table 16 - Family J

Family J	Gender	Age	Role	Occupation	Country	Interviewed
Family J – Father	Male	43	Father	Physician	Kuwait	Yes
Family J – Son 1	Male	12	Autistic Child	Student	Kuwait	Yes
Family J – Son 2	Male	11	Autistic Child	Student	Kuwait	Yes

Family J – Father is a single parent raising two autistic boys. His ex-wife passed away in 2020. The interviewer was able to conduct individual interviews with Family J - Father and his two sons as well as a focus group session with them.

5.4 Data Collection Methods and Procedure.

The University of Leeds Faculty of Biological Sciences Research Ethics Department provided ethical approval for this study. Post-gaining ethical approval, autism institutes, schools and social media groups were approached via emails, messages and phone calls from the lead researcher (Seyedeh Aliya Abaft). They all received an explanation, email or advert briefly explaining the details of this research study. Once they showed interest in the study, an email with the Participant Information Sheet (PIS) attached was sent explaining all the necessary details of the study. Families were given one week to read the PIS and contact the researcher with any questions. If a family had not responded after one week, the researcher followed up and contacted the family to ask if they had any concerns or questions regarding the study. Once the family fully understood the requirements of their participation and were willing to participate, they were provided with a consent form to sign. The consent form explained to the participant that they would be agreeing to partake in this study and that they would be able to withdraw their participation at any given point. After signing the consent form, the researcher and the participant then picked a date and time to collect the data. The data collection methods chosen to collect qualitative data consisted of two different instruments: Online Focus Groups and Individual (one–on–one) Interviews. Using both instruments allows the researcher to collect data that work together to illuminate day-to-day lives of the families. Online one-on-one interviews allow for a more in-depth analysis of the participant's experiences and feelings, whereas online focus group interviews are useful for exploring all of the participants' ideas and attitudes (Kruger et al., 2019). Kruger et el. (2019) indicate that focus groups encourage interaction and discussion with participants, which enables them to build on each other's responses, leading to richer and comprehensive data. Therefore, given that children with autism often struggle to communicate (DSM-V, 2014), the use of focus groups will aid in facilitating communication by allowing the children's families to be present for support, thereby creating a safer and comfortable environment (Adler et al., 2019). This, in turn, can reduce the children's anxiety which is often triggered by unfamiliar environments, particularly for children with ASD. In addition, online focus groups provide families with flexibility in scheduling, making it possible for them to participate from the comfort of their own homes (Trier-Bieniek, 2012). Accordingly, to reduce participant stress, each family's interviews were scheduled on the same day as spreading the interviews over multiple days would have been less convenient for several participants. Firstly, each family was interviewed in a focus group. Thereafter, where possible, each family member was interviewed individually. A more detailed account of the methods and procedures are explained below.

5.4.1 Online data collection

In recent years, there has been an increasing interest in the use of video technologies for both professional and personal purposes (de Villiers et al., 2021; Miller and Sinanan, 2014); COVID-19 and the associated lockdowns played a significant factor in fast-tracking the trend (Parker, 2021). The COVID-19 pandemic gave researchers the chance to conduct research through the use of online platforms, such as Zoom and Microsoft Teams. Field research that was initially done face-to-face had to be changed to online due to imposed social distance practises. As a result, face-to-face interviews were conducted through video-based research which enabled the interviewer and interviewee to see one another and communicate via videocall (de Villiers et al., 2021). However, despite the growing use of online data collection, this method has received very little attention in previous literature (Dodds and Hess, 2020; Tucker and Parker, 2019; Granello and Wheaton, 2004). Granello and Wheaton (2004) pointed out that not all individuals will be capable to accessing up-to-date technology or are computer literate. Seitz (2015) makes a similar point in his study and discusses the technical issues and challenges of using online platforms. These issues and challenges include poor internet connections and software glitches. These disruptions can make it difficult for both the researcher and the participant to maintain a seamless data collection process.

Some authors, including Madge (2007) and Andersson and Titov (2014), have claimed that privacy and ethical concerns are one of the main disadvantages of online data collection. Participants in Andersson and Titov (2014) have raised their concern that using technology to collect data may cause issues in terms of privacy, such as a participant's private information being collected, stored and used without their consent. Some researchers have also suggested that the main argument for face-to-face interviews is the collection of contextual data (de Villiers et al., 2021; Miles et al., 2014; Gillham, 2005). It has previously been observed that traditional researchers prefer face-to-face interviews as it enables researchers to establish and maintain rapport with interviewees and enable the researcher to visually assess the interviewee's environment, thus allowing for the collection of contextual data (de Villiers et al., 2021; Farooq and de Villiers, 2017; Fontana and Frey, 1998). de Villiers et al. (2021) argue that video interviews may make it harder to build and maintain rapport. Participants could turn their cameras off as they wouldn't feel comfortable exposing their homes to strangers. This is consistent with the data obtained by Denham and Onwuegbuzie (2013), who denoted that online data collection can limit the researcher from reading non-verbal signs, such as body language and facial expressions.

In this particular study, the use of online interviews was beneficial. Similarly to Kvale and Brinkmann (2008), who argued that researchers can benefit from the use of video interviews as they would be able to read the body language and the observe facial expressions of the participants, the same was found through carrying out this study. Initially, some participants were uncomfortable with being visibly on video, as requested by the participant and demonstrated by their hesitant demeanour. However, as the interview progressed and they were more at ease, and their comfort level was reflected as they requested to be visible on video and their body language was relaxed. In addition, when participants discussed their experiences during the pandemic, their facial expressions strongly conveyed their emptions, providing rich insights into their feelings, which are crucial for a comprehensive understanding of their experiences during the pandemic. Furthermore, Cantrell and

Lupinacci (2007) argue that online data collection offers the chance to gather data without being limited to the participant's geographic location. They suggested that having no constraints on the location is beneficial when working with vulnerable participants and sensitive topics. In addition, Trier-Bieniek (2012) argues that the ability to collect data without being constrained by location can lead to considerable savings on accommodation and travel costs. Therefore, catalysed by the conditions of COVID-19, this research conducted its data collection through the use of individual and family focus group online interviews.

5.4.2 Family Focus Group Interviews

Focus groups interviews allowed the researcher to inquire into family member's experiences in addition to obtaining reactions from the rest of the members, as well as discussing their reactions (Acocella, 2011). Furthermore, compared to other data collection methods, focus groups engage fewer participants for a shorter period of time, with a flexible agenda of open-ended questions that permits further probing (Acocella, 2011). This allows the interviewer to investigate and/or acquire fresh insights into a particular subject or novel occurrence by fostering talks between participants in the group (Dodds and Hess, 2020; Cyr, 2016).

The focus group interviews focused on the family's views and perceptions of the impact of the COVID-19 pandemic on the FQoL, focusing on the children's academic attainment and on each family member's QoL, physical activity and social development. With the use of this method, the researcher was able to understand the family's views and experiences on their day-to-day lives during the nationwide lockdown (Rubin and Rubin, 2012). The focus group questions were developed by the researcher and approved by the researcher's supervisors. When developing the questions, the researcher considered the key topics that needed to be addressed with the participants during the interview. In addition, based on the research aims, the interview questions were broad enough to elicit a variety of replies, yet narrow enough to generate useful data. The interview included a series of in-depth open-ended questions, such as 'How do you feel about the COVID-19?', 'What were your concerns when they announced there will be a nationwide lockdown' and 'How do you think it affected you as a family?', as well as probing questions, such as 'Can you elaborate more on that?', 'Can you give me an example?' and 'Why do you think that happened?'. In order to conduct the interviews in a way that meant data could be aggregated and analysed, the researcher followed a semi-structured interview guide, whilst allowing the researcher to not be rigidly bound to the interview questions, which allowed the participants to raise any enquiries regarding the questions, which in turn built trust and rapport (Braun and Clarke, 2012). Furthermore, the researcher had the flexibility to rephrase and/or reword questions to better suit that particular individual's interview (Rubin and Rubin, 2012). Moreover, the open-ended questions, in a semi-structured approach, allowed the researcher to collect more information and explore detailed responses from family members, whilst not being restricted to standardised interview questions (Patton, 2002). Probing questions were used after certain questions to elicit further information from family members. After receiving the ethics committee's approval, the researcher conducted a practise focus group interview with a family friend to test out several online platforms for focus group interviews. The researcher then conducted a pilot test of the interview questions with the first family group participants. The practice and pilot interviews went smoothly whilst using both Microsoft Teams and Zoom as videocall platforms. Modifications were made to some of the focus group questions, as some families were single-parent households, with an only child. The researcher conducted all focus group interviews. The duration of the interviews lasted between 60 to 75 minutes. The focus group interviews were video recorded after obtaining consent from the family members. Using video recordings meant that the researcher did not need to focus too heavily on note-taking, which could have interrupted the flow of the interview and been distracting for participants. Additionally, the recordings aided in capturing moments such as laughter, silence and intonation (Tessier, 2012).

5.4.2.1 Focus group procedure

Where possible, all family members (parents, children and siblings) were interviewed once, as a focus group, during that data collection period. The period of data collection was from June 2022 to October 2022; all families were interviewed separately. Each family had either one child, or more than one child diagnosed with ASD. The family focus group interviews were conducted online via Microsoft Teams or Zoom (online communication platforms). The date and time of the interviews were set at a convenient time that suited each family. The average time of the focus group interviews lasted 45 minutes. The timeframes of the focus group interviewing process were adjusted to the needs of the families, whilst being long enough to collect rich, nuanced, high-quality data. Family members were informed that their well-being is the top priority and that if at any given point a family member felt uncomfortable, tired, or did not wish to continue, they were at liberty to pause the interview or withdraw at any point. Family members were asked to share their experiences of the impact that the pandemic had on the family quality of life. Semi-structured interviews were the method of questioning in the focus groups. The focus group interviews included a series of in-depth open-ended questions, such as 'Can you tell me what it was like for you as a family when they first announced that there would be a lockdown?'; 'Can you tell me about how your family's daily life has been affected?'; and, 'Did you have the school's support and extra therapeutic input during lockdown period?' -- Please see the Appendix for examples. During all focus group interviews, the researcher used probing techniques to encourage family members to divulge further information on their personal experiences and to share the challenges they have faced due to the COVID-19 pandemic. All focus group interviews were video recorded on Microsoft Teams or Zoom. Prior to recording, all families were informed that the interviews were recorded in order to give the participants a chance to object, but if no objection was given, the researcher then recorded the interviews.

5.4.3 One-on-one Interviews

There was a follow-up one-on-one interview with family members, following approval. Parents were invited to be present if the family member was a minor. The questions asked in the one-on-one interviews were tailored to depending on which member of the family was being interviewed, meaning that the parents had a different set of questions to the children. For instance, 'How did your sibling's lifestyle change during the pandemic?' and 'As a sibling, what roles did you have to take over to support the family?' are examples of questions that were asked only during sibling interviews. However, during the parents' interview, questions such as 'As a parent, how did you feel when they announced the nationwide lockdown?' and 'Did you use any strategies to manage difficult behaviours, especially behaviours during these times?', were asked (see Appendix for list of questions). Additionally, as the researcher interviewed some of the autistic children, the questions were catered to the child's level of functionality. For example, questions such as 'Did it upset you when you found out that there will be a lockdown?' and 'Did you enjoy staying at home during the lockdown?' were asked during the interviews with the autistic children. In addition, a range of communication methods such as Picture Exchange Communication System (PECS) were made available to assist autistic children with their communication, in case of a child being unable to communicate verbally (please see the Appendix for examples). PECS is an augmentative communication system used for SEN children who have social and communicational difficulties (Thiemann-Bourque et al., 2016; Lerna et al., 2012; Yoder and Lieberman, 2009). Although PECS was made available for the interviews, the autistic children who were interviewed were able to grasp the questions without them, therefore the researcher did not need to use them.

The method of questioning for the one-to-one interviews is also semi-structured. As the researcher did not need to strictly adhere to the questions of the interview (Braun and Clarke, 2012), this aided in questioning the autistic children as PECS could be used as an effective tool to facilitate functional communication between the child and the researcher (Lerna et al., 2012). In addition, the one-on-one follow-up interviews allowed each family member to have an equal chance to share their opinions and experiences of the COVID-19 pandemic. The interviews were also video recorded, following approval from the children's parents and the children themselves. According to several studies, using recordings during interviews may alter how participants respond to questions (Padgett, 2016; Lietz and Zayas, 2010). This could imply that whatever is captured on the recordings may not accurately reflect the participant's viewpoint. However, in this case, the researcher took care to record every interview question and to answer exactly as they were uttered and observed. In order to try to establish validity in these situations, it would be up to the participant and the researcher to make sure that all of the data would be reliable and they would have to establish validity through the data collecting and analysis processes, according to Zohrabi (2013). As a result, the researcher did not encourage any responses from the individual; instead, they just used probing approaches to get as many responses as they could.

5.4.3.1 One – on – one procedure

Each family member was asked to be interviewed individually. Unlike adults, minors were not interviewed alone, a parent/carer was asked to be in the room, too. The one-on-one interviews were considered as follow-up individual interviews with each family member to allow them to speak more freely, and allowed the researcher to ask them more questions about their perspectives and personal experiences regarding the impact of the COVID-19 pandemic on their life. TD family members were asked to discuss their individualised experiences related to social, academic, psychological and physical domains of their FQoL. Questions such as 'Can you tell me a little bit about the emotional toll the nationwide lockdown took on you?', 'How did your relationship change with your family and sibling during the nationwide lockdown?', 'What strategies or methods did you and your family use to reduce any anxiety that you and your sibling were feeling?', and 'Did you use any strategies to manage difficult behaviours, especially behaviours during these times?'. In addition, where possible, autistic children were interviewed one-on-one whilst having a parent/carer in the room. PECS was made available to assist autistic children with their communication, however, the researcher did not need to use them. The interview questions focused on the child's FQoL/QoL during the COVID-19 pandemic, such as 'How did you feel when you found out about the COVID-19?', 'Did you go out or do any types of exercising?', and 'How did your lifestyle change during the lockdowns?'. Each question was catered to the child's level of functionality. Similarly to the focus group interviews, the one-on-one interviews were conducted online via Microsoft Teams or Zoom and open-ended and probing questions were asked. The duration of the interviews with the adults lasted between 30 and 60 minutes; the duration of the minor interviews lasted between 15 and 30 minutes. Prior to starting the interview, family members were informed that the interviews were recorded and once consent was provided, the researcher recorded the interviews.

5.5 Data Analysis and Procedure

The data collected was analysed using a hybrid of inductive and deductive thematic analysis method outlined by Braun and Clarke (2013). This method assists in data organisation and provides a detailed account of the data. Initially, an inductive approach was taken, in line with Braun and Clarke's (2006) framework, where codes and themes were derived directly from the data without the influence of pre-existing theories. The qualitative data was gathered through online focus groups and one-to-one interviews. Each interview was recorded and transcribed. Transcription was followed by a familiarisation process where the researcher repeatedly read through the data. The interview transcripts were reviewed line by line, and data were categorised based on recurring emotions, experiences, and key expressions. Each family's data were organised separately in Excel (see Figure 7 for an example), where positive and negative experiences were colour-coded across different domains (e.g., anxiety, aggression, academic changes). This approach enabled a visual mapping of individual family experiences and helped trace the emotional tone and contextual factors behind each theme. As these patterns emerged, a more deductive lens was introduced. Drawing on existing FqoL literature, the study adapted key concepts to align with the themes emerging from the participants' experiences. While the final domains used in this research (psychological, social, physical, and academic) were not identical to those in previous models, they were informed by the multidimensional structure of FQoL theory and reflect the lived experiences expressed by the families in this study. The researcher developed mind maps to visually organise and formulate initial ideas and patterns, as well as identifying potential themes from the data. The next step involved using an open coding technique to generate codes from the data (Corbin and Strauss, 2008). Open coding involves systematically reviewing the data and the responses of each participant and assigning codes into categories that were relevant to the research aims. For instance, repeated expressions of anxiety were initially coded inductively, but were later organised into the psychological domain. This recursive process, moving between the coded data, the existing literature, and an evolving framework of FQoL, helped refine both the structure and meaning of the themes. Once the initial coding process was completed, potential themes and patterns were developed. The final stage of analysis involved reviewing and collapsing categories into higher-order themes and subthemes, as seen in a secondary summary table (see Figure 8). These reflected both the subjective experiences of families and their relevance to broader conceptual domains of FQoL. This approach supports what Braun and Clarke (2013) describe as a reflexive thematic analysis, where inductive and deductive elements co-exist. The use of Excel for coding, visual colour-coding, and constant comparison across families ensured transparency and depth in the analytic process. This process was repetitive and rigorous, as the researcher continuously refined the themes to accurately reflect each participant's experience, and focused the data within the scope of this study's aim. The final step involved a thematic analysis of the data.

In addition to using a hybrid inductive-deductive approach, the analysis process also involved critical engagement with literature and iterative theme development. This required ongoing reflection and comparison between emerging data and the existing literature. As themes began to develop, the researcher revisted key studies on FQoL and pandemic-related stressors in families with autistic children to critically examine whether the findings aligned with, extended, or challenged previous research. This interplay between data and theory ensured that the final themes were both grounded in participants' lived experiences and aligned with the ongoing research discussion in the field. Each identified theme explored how the COVID-19 pandemic impacted on the quality of life of families with autistic children. The data collected from the 10 families was analysed using a two-stage approach, involving both intra-case and cross-case analysis techniques (Miles et al., 2014; Walton et al., 2019). The first stage involved an in-depth, intra-case analysis, also referred to as within-case analysis, of each family's experiences and perspectives (Miles et al., 2014). This approach with intent was chosen to provide a rich, contextualised understanding of the unique experiences and challenges faced by each family (Miles et al., 2014). By exploring the data of each separate family, the researcher was able to capture the nuanced, multifaceted factors that impacted their FQoL during the pandemic. The intra-case analysis involved closely examining each family's focus group interview transcripts, one-on-one interview transcripts and observational notes to develop a comprehensive understanding of their lived experiences. This process made it possible for the researcher to identify distinct themes, patterns and idiosyncrasies that were unique to each family.

Following the intra-case analysis, the researcher conducted a cross-case analysis. Cross-case analysis was applied to compare and contrast themes emerging from each family's interview (Livne-Tarandach et al., 2015). After intra-case analysis was completed across individual family datasets, the researcher identified shared codes and grouped them based on underlying meaning. These were then refined into broader categories and organised into the thematic domains. Positive and negative experiences were colour-coded within Excel to visually highlight contrasts in the data, and to examine how different families navigated the same domain with different outcomes. For example, while several participants described school closures as stressful, others identified them as opportunities for bonding or reduced anxiety. This dual coding approach allowed for a more nuanced representation of the data, acknowledging both the challenges and the unexpected positives that arose during the pandemic. Throughout the process, the researcher repeatedly returned to both the transcripts and the literature to ensure alignment, credibility, and depth. The decision to incorporate both analytical techniques was a calculated decision. By combining both analytical methods, the researcher was able to generate findings that reflected both shared experiences and unique circumstances of the participant families (Livne-Tarandach et al., 2015; Miles et al., 2014). The figures below illustrate the approach used to analyse the data and demonstrates mind maps used to aid in analysing the data.

Figure 4 - Qualitative Data Analysis Process

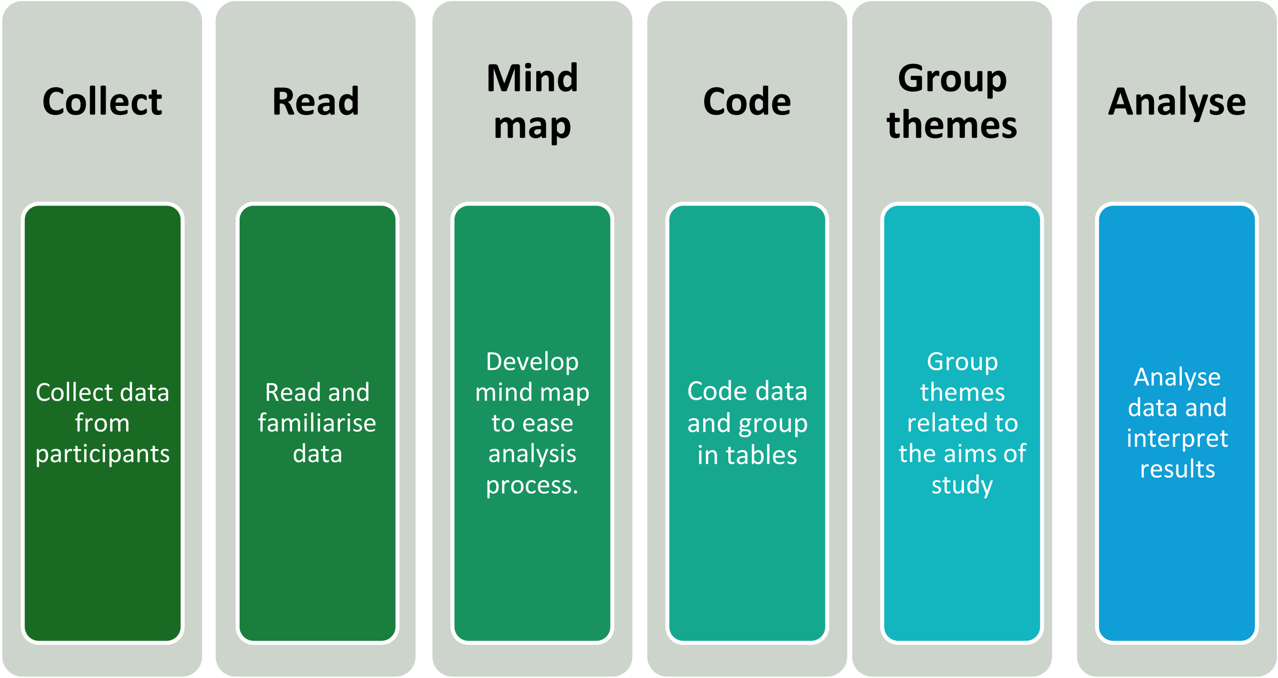


Figure 4 illustrates the overall approach of qualitative data analysis employed in this study. The figure provides a step-by-step overview of how the data was analysed, starting from data collection through to the final step which was the thematic analysis.

Figure 5 - "Positive Themes" Mind Map

Figure 5 demonstrates a mind map that illustrates the positive impacts of the pandemic as discussed by the study participants. This figure categorises some of the themes that emerged from the data.

Figure 6 - "Negative Themes" Mind Map

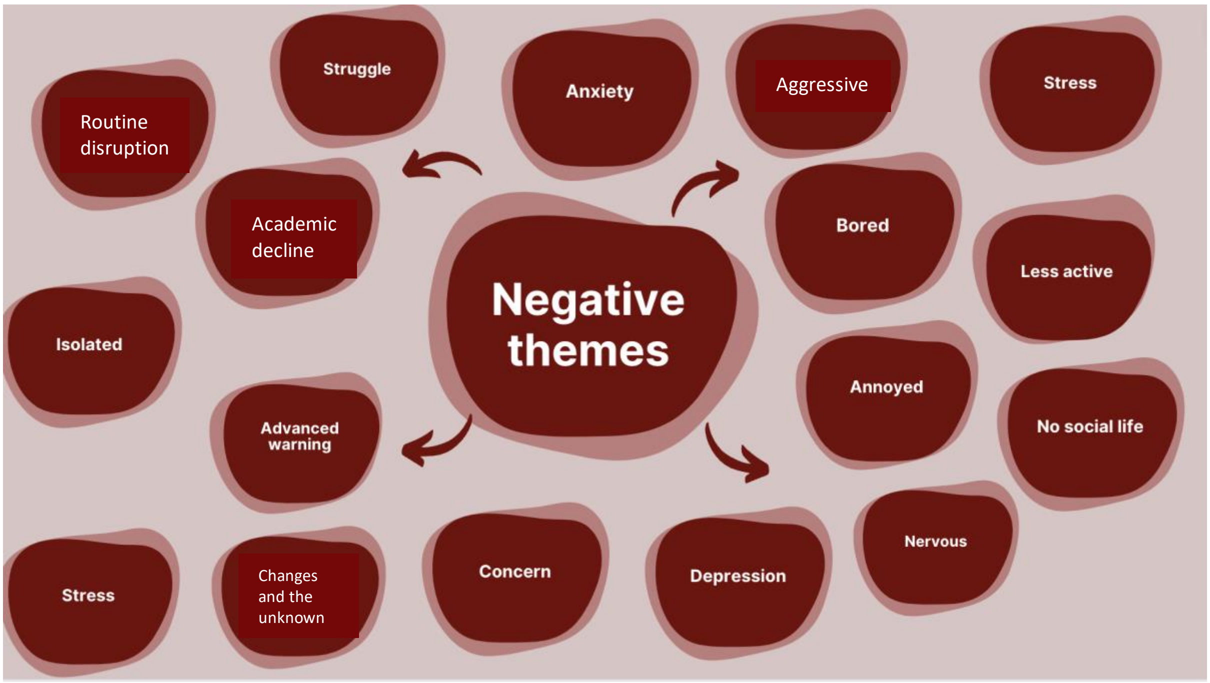
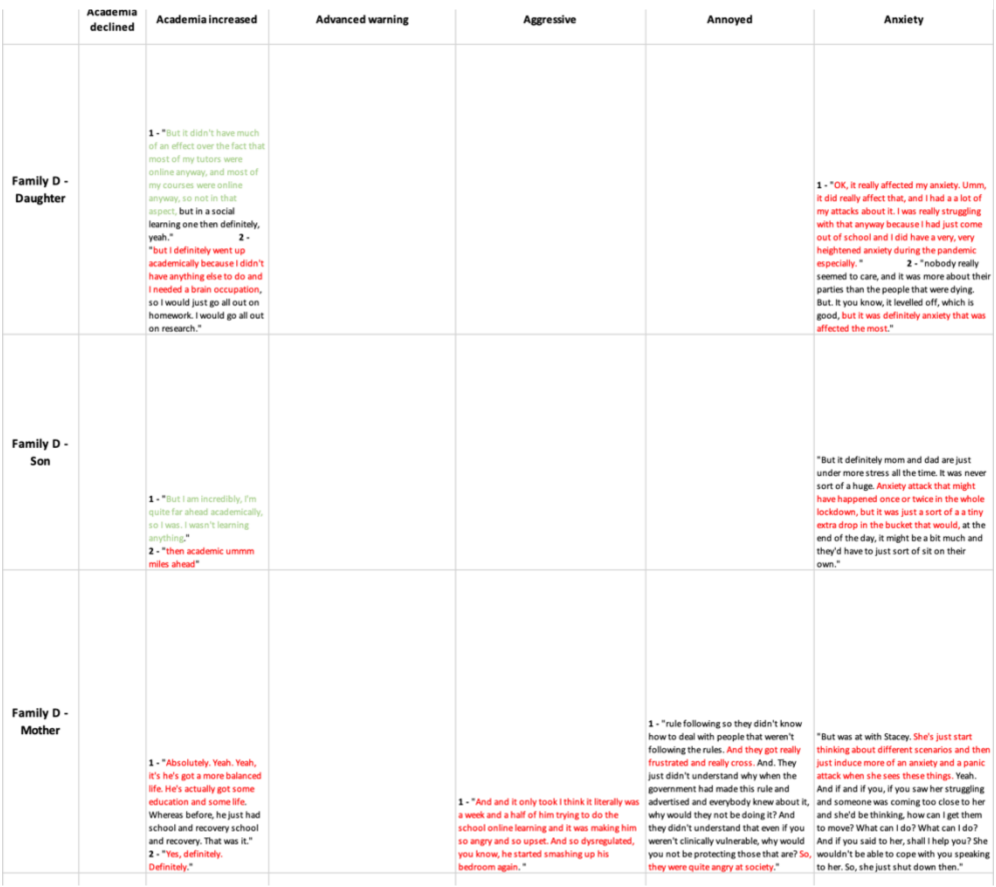


Figure 6 demonstrates a mind map that illustrates the negative impacts of the pandemic as discussed by the participants. This figure provides a detailed breakdown of the challenges and difficulties faced by families during the pandemic.

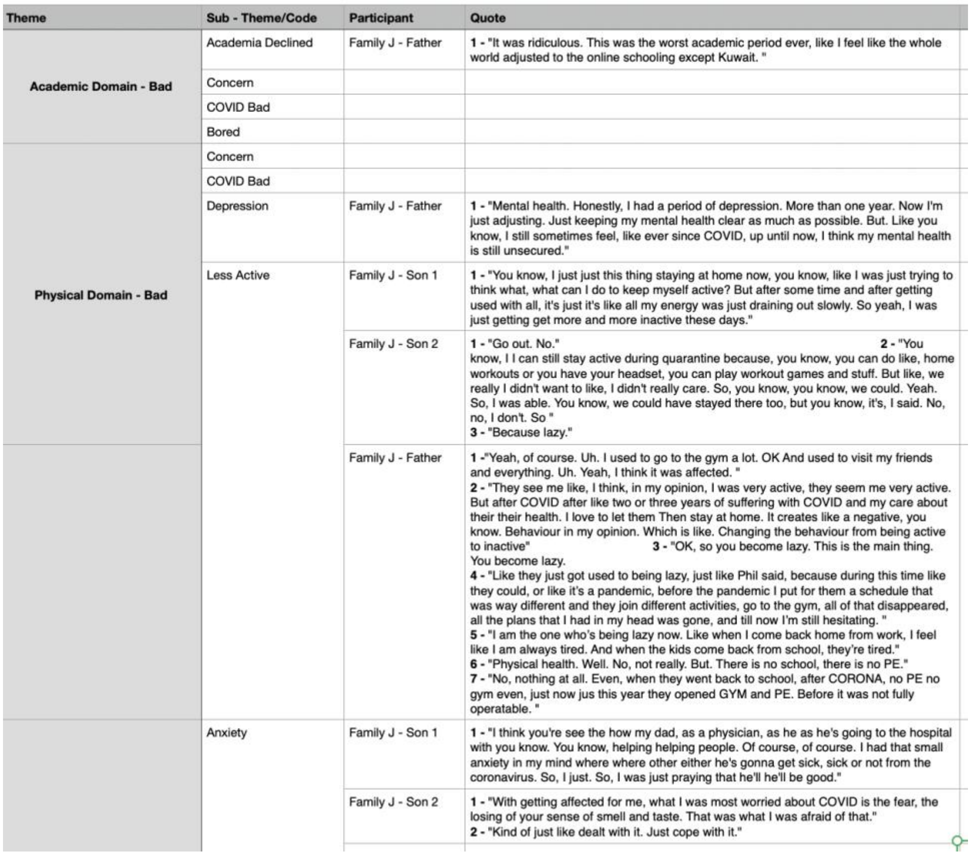
Figure 7 - Colour - coded Coding Sheet



	Academia declined	Academia increased	Advanced warning	Aggressive	Annoyed	Anxiety
Family D - Daughter		1 - "But it didn't have much of an effect over the fact that most of my tutors were online anyway, and most of my courses were online anyway, so not in that aspect, but in a social learning one then definitely, yeah." 2 - "but I definitely went up academically because I didn't have anything else to do and I needed a brain occupation, so I would just go all out on homework. I would go all out on research."				1 - "OK, it really affected my anxiety. Umm, it did really affect that, and I had a a lot of my attacks about it. I was really struggling with that anyway because I had just come out of school and I did have a very, very heightened anxiety during the pandemic especially. " 2 - "nobody really seemed to care, and it was more about their parties than the people that were dying. But. It you know, it levelled off, which is good, but it was definitely anxiety that was affected the most."
Family D - Son		1 - "But I am incredibly, I'm quite far ahead academically, so I was. I wasn't learning anything." 2 - "then academic ummm miles ahead"				"But it definitely mom and dad are just under more stress all the time. It was never sort of a huge. Anxiety attack that might have happened once or twice in the whole lockdown, but it was just a sort of a a tiny extra drop in the bucket that would, at the end of the day, it might be a bit much and they'd have to just sort of sit on their own."
Family D - Mother		1 - "Absolutely. Yeah. Yeah, it's he's got a more balanced life. He's actually got some education and some life. Whereas before, he just had school and recovery school and recovery. That was it." 2 - "Yes, definitely. Definitely."		1 - "And and it only took I think it literally was a week and a half of him trying to do the school online learning and it was making him so angry and so upset. And so dysregulated, you know, he started smashing up his bedroom again. "	1 - "rule following so they didn't know how to deal with people that weren't following the rules. And they got really frustrated and really cross. And. They just didn't understand why when the government had made this rule and advertised and everybody knew about it, why would they not be doing it? And they didn't understand that even if you weren't clinically vulnerable, why would you not be protecting those that are? So, they were quite angry at society."	"But was at with Stacey. She's just start thinking about different scenarios and then just induce more of an anxiety and a panic attack when she sees these things. Yeah. And if and if you, if you saw her struggling and someone was coming too close to her and she'd be thinking, how can I get them to move? What can I do? What can I do? And if you said to her, shall I help you? She wouldn't be able to cope with you speaking to her. So, she just shut down then."

Figure 7 demonstrates a screenshot from the Excel sheet used for coding the transcribed interviews. It illustrates how experiences were colour-coded to identify patterns and inform the development of themes.

Figure 8 - Theme Development Table from refined Codes



Theme	Sub - Theme/Code	Participant	Quote
Academic Domain - Bad	Academia Declined	Family J - Father	**1 -** "It was ridiculous. This was the worst academic period ever, like I feel like the whole world adjusted to the online schooling except Kuwait. "
	Concern		
	COVID Bad		
	Bored		
Physical Domain - Bad	Concern		
	COVID Bad		
	Depression	Family J - Father	**1 -** "Mental health. Honestly, I had a period of depression. More than one year. Now I'm just adjusting. Just keeping my mental health clear as much as possible. But. Like you know, I still sometimes feel, like ever since COVID, up until now, I think my mental health is still unsecured."
	Less Active	Family J - Son 1	**1 -** "You know, I just just this thing staying at home now, you know, like I was just trying to think what, what can I do to keep myself active? But after some time and after getting used with all, it's just it's like all my energy was just draining out slowly. So yeah, I was just getting get more and more inactive these days."
		Family J - Son 2	**1 -** "Go out. No." **2 -** "You know, I I can still stay active during quarantine because, you know, you can do like, home workouts or you have your headset, you can play workout games and stuff. But like, we really I didn't want to like, I didn't really care. So, you know, you know, we could. Yeah. So, I was able. You know, we could have stayed there too, but you know, it's, I said. No, no, I don't. So " **3 -** "Because lazy."
		Family J - Father	**1 -**"Yeah, of course. Uh. I used to go to the gym a lot. OK And used to visit my friends and everything. Uh. Yeah, I think it was affected. " **2 -** "They see me like, I think, in my opinion, I was very active, they seem me very active. But after COVID after like two or three years of suffering with COVID and my care about their their health. I love to let them Then stay at home. It creates like a negative, you know. Behaviour in my opinion. Which is like. Changing the behaviour from being active to inactive" **3 -** "OK, so you become lazy. This is the main thing. You become lazy. **4 -** "Like they just got used to being lazy, just like Phil said, because during this time like they could, or like it's a pandemic, before the pandemic I put for them a schedule that was way different and they join different activities, go to the gym, all of that disappeared, all the plans that I had in my head was gone, and till now I'm still hesitating. " **5 -** "I am the one who's being lazy now. Like when I come back home from work, I feel like I am always tired. And when the kids come back from school, they're tired." **6 -** "Physical health. Well. No, not really. But. There is no school, there is no PE." **7 -** "No, nothing at all. Even, when they went back to school, after CORONA, no PE no gym even, just now jus this year they opened GYM and PE. Before it was not fully operatable. "
	Anxiety	Family J - Son 1	**1 -** "I think you're see the how my dad, as a physician, as he as he's going to the hospital with you know. You know, helping helping people. Of course, of course. I had that small anxiety in my mind where where other either he's gonna get sick, sick or not from the coronavirus. So, I just. So, I was just praying that he'll he'll be good."
		Family J - Son 2	**1 -** "With getting affected for me, what I was most worried about COVID is the fear, the losing of your sense of smell and taste. That was what I was afraid of that." **2 -** "Kind of just like dealt with it. Just cope with it."

Figure 8 presents a table developed during the theme refinement stage. It shows how initial codes from the Excel sheet were organised into overarching themes and subthemes

5.6 Establishing Validity and Trustworthiness of the Data

Numerous studies have frequently debated the reliability and validity of qualitative research (Giddings and Grant, 2009; Onwuegbuzie and Burke Johnson, 2006). Validity and trustworthiness must be evaluated within the context of the data's richness and rigour in order to assure this study's quality (Giddings and Grant, 2009). To ensure the validity and trustworthiness of the data, the methodology for this research would need to be sound. In this study, a relativist approach to this study's rigor was employed to ensure the validity and trustworthiness of the data; the relativist approach acknowledges that rigor is dependent on the context of a study (Sparkes and Smith, 2009) and would be evaluated based on a study's aims, context and nature of the study (Burke, 2016; Gergen, 2014; Tobin and Begley, 2004). This approach is particularly suited to Interpretivist qualitative research as this study seeks to understand the participants' perspectives and experiences during the pandemic (Burke, 2016). The relativist approach requires several strategies to be employed to ensure rigor and trustworthiness of the data (Burke, 2016). The strategies applied in this research include Coherence, Reflexivity, Credibility, Dependability and Transferability (Burke, 2016; Tracy, 2010; Lincoln and Guba, 1986). The following sections will define and discuss the strategies that were employed in this study.

5.6.1 Coherence

In terms of coherence, this criterion refers to the manner in which all data collection techniques and analyses complement one another while providing a meaningful picture (Smith and Caddick, 2012). Lieblich et al. (1998) explain that coherence can be proven by tying all of the evidence together and comparing it to current ideas and earlier research. Therefore, to achieve coherence in this study, several strategies were adopted to ensure consistent alignment across all stages in the research process. The use of one-on-one interviews and focus groups were vital to achieve coherence. By using precise and well-described methods and research approaches to collect the opinions of each family member, as well as focusing on recording the participants' experience in an accurate and transparent manner, the research's quality was ensured. In addition, qualitative descriptive methods were used to collect and analyse data, thereby, establishing validity, with the goal being to ensure that the instruments used in this study are consistent and reliable (Harrison et al., 2020; Giddings and Grant, 2009). The methods employed allowed for deep, rich data collection, which is vital for exploring the complex experiences of the families interviewed. The depth of each research is measured by how much information was gathered (Smith and Caddick, 2012). This would be in reference to the calibre of the data gathered and the interpretation and analysis of the data (Smith and Caddick, 2012). According to Lieblich et al. (1998), to support the interpretation of the analysis, and the reader's judgement, quotations from the interviewee's should be provided, in addition to alternative explanations of the analysis. Therefore, coherence was achieved by ensuring that the entire study, including research design, methodology and analysis were logically connected and aligned with this study's aims and theoretical framework. The aims were clearly defined to focus on the impact of the COVID-19 pandemic on the QoL of families of children with ASD, which guided this study's process. By using both methods, the researcher would then be able to cross-reference and check the data, and whether the data was consistent. Giddings and Grant (2009) contend that the method used to gather and analyse the data, rather than the researcher's ability to interpret the data, determines the reliability of the research. In this scenario, reliability means that the results of the research should be stable and consistent over time (Giddings and Grant, 2009). Maintaining consistency meant that the study achieved a unified context that was structured logically, ensuring that the research process was seamlessly aligned, and connected directly to the families' experiences (Tracy, 2010). To determine if the data is reliable and coherent, these and other criteria were considered during the data collection process. They are discussed in the following sections.

5.6.2 Reflexivity

Subramani (2019) points out that it has become a standard practice to include an explicit discussion of the researcher’s positionality and its impact on the research in academic theses and articles. This process was a fundamental aspect of this study to maintain rigor (Subramani, 2019). Reflexivity is involved by ensuring that the researcher’s bias, experiences and assumptions were continually recognised and addressed during the data collection and analysis (Jamieson et al., 2023). As previously mentioned, the use of one-on-one interviews and focus groups allowed for a detailed exploration of each family member’s experience, while focus groups provided them a setting where family members could interact and build on each other’s experiences (Kruger et al., 2019). Furthermore, according to Hong and Pluye (2018), the reliability of a source is affected by the research methodology adopted and any potential bias on the part of the researcher. Given the researcher’s extensive background in special education and project management, the researcher brought a unique perspective that enriched and positively affected the study. To mitigate any improper influence, the researcher continuously documented their thoughts, perspectives and reflections during data collection and analysis (Evans et al., 2018). The process of reflecting on and evaluating one’s own biases, and their impact on creating or interpreting knowledge, stems from the belief that knowledge cannot be separated from the individual who creates it. (Duffy et al., 2020; Alvesson and Sköldberg, 2018). For instance, during the interviews the researcher was aware of how their background may have shaped the way the questions were asked, and how they interpreted the participants’ responses. The research did not encourage any certain outcomes but attempted to draw out honest and credible responses. As the researcher continuously revisited these reflections, they were able to adjust their approach to be more open and responsive to the participants’ narratives, ensuring their perspectives were authentically documented (Duffy et al., 2020). Accordingly, reflexivity and transparency were maintained throughout this process; the researcher remained aware of her perspectives, decisions, protentional bias and how they may have shaped the study. The results were presented in a manner that clearly linked the analytical themes to the research aims, providing a coherent and comprehensive understanding of the multifaceted impact of the pandemic on the QoL of these families. By employing this strategy, the research maintained coherence throughout, leading to credible, and rigorous findings, as well as contributing to the ethical integrity of the research process and design (Duffy et al., 2020; Malaurent and Avison, 2017).

5.6.3 Credibility

Credibility was considered and used in this study when gathering and analysing the data. Credibility refers to the degree to which the researcher has interpreted the study's findings to reflect the participant's perspectives (Smith and Caddick, 2012; Lincoln and Guba, 1985). According to Drisko (1997), a study's findings should be an authentic and accurate depiction of the participants' reflections. During the focus group and one-on-one interviews, the following tactics were taken into account and used to enhance credibility and avoid biased information. The one-one-one interviews allows participants to express themselves freely in a private setting, leading to personal detailed accounts, while focus groups facilitated interaction among family members, aided in surfacing diverse perspectives and shared experiences (Kruger et al., 2019). The credibility of the datasets was ensured through the adoption of these methodologies, as well as the inclusion of participant feedback. The feedback will confirm the credibility of the captured data and initial analysis carried out so that the insights gained will accurately reflect their perspectives and experience. Moreover, all interviews were videorecorded to ensure that neither the researcher nor the study techniques influenced the participants, altering the results. The use of recordings during interviews may change how participants answer to questions, according to multiple research (Padgett, 2016; Lietz and Zayas, 2010). This could signify that the participant's perspective may not be accurately reflected in the material that was recorded. In this research study, however, the researcher made sure to accurately record every interview question and response as they were said and witnessed. The recordings also made it easier to record things like laughter, stillness and tone, as well as allowing the researcher to concentrate on the interview itself while the families were less distracted by the researcher's note-taking (Tessier, 2012). Additionally, the researcher remained vigilant her own biases (Lietz et al., 2006). Triangulating the data aided in ensuring validity and credibility of the data, which involved using both online focus and individual interviews as methods to collect data. By using both methods, the researcher would then be able to the cross-reference the data, to determine whether the data was consistent. In this scenario, reliability means that the results of the research should be stable and consistent over time (Giddings and Grant, 2009). Giddings and Grant (2009) contend that the method used to gather and analyse the data, rather than the researcher's ability to interpret the data, determines the reliability of the research. By triangulating these methods and engaging deeply with the participants’ responses through prolonged analysis, the researcher ensured that the data was credible and authentically reflected the participants' experiences (Tracy, 2010).

5.6.4 Dependability

In this study, dependability was ensured by meticulous documentation of the entire research process (Forero et al., 2018; Lincoln and Guba, 1986). The study’s design, data collection methods and analytical procedure were thoroughly documented and outlined alongside the rationale for their use. The researcher maintained a comprehensive audit trail that recorded all decisions, detailed notes, reflections, changes and interview transcriptions throughout the research process (Forero et al., 2018). Along the same lines, Nowell et al. (2017) and Tobin and Begley (2004) make a similar point in their study where they write that researchers can establish dependability by ensuring that their research is logical, thoroughly documented and transparent. For instance, any changes or adjustments during the interviews were recorded alongside the researcher's reflections regarding how the changes or adjustments may have impacted the data. By providing this transparency, readers are informed of the study's progression, and understood how the data was gathered, analysed and interpreted, which reinforced the dependability of the study (Nowell et al., 2017; Lincoln and Guba, 1985). Additionally, meetings were held with the researcher's supervisors to discuss the research process, analysis and results, which aided in challenging any assumptions made by the researcher and ensuring consistency in the analysis. This extensive approach to documentation and reflection strengthened the dependability of this research, allowing for adaptation in future research (Forero et al., 2018; Lincoln and Guba, 1986).

5.6.5 Transferability

Transferability was vital to consider in this study given that the aim of this study was to focus on the impact of the pandemic on the QoL of families with autistic children. Due to the findings of the study being context-specific, efforts were made to ensure that the insights could be relevant to other similar contexts or populations (Forero et al., 2018; Lincoln and Guba, 1986). Some researchers have mentioned that this criterion is challenging because qualitative research is essentially designed not to aim for replicability (Stahl and King, 2020; Roberts et al., 2019). Other researchers, however, who have looked at Transferability, have noted that if findings cannot be adapted to similar future situations, the original study's impact is reduced (Stahl and King, 2020). Stahl and King (2020) note that qualitative researchers have argued that findings and observations from one context can often be applied to another and that this can only occur when the study provides detailed, vivid descriptions of the context, allowing others to apply the findings to their own situations. This was achieved by generating rich descriptions of the entire research process, including participant demographics and data collection. For instance, contextual information was provided by participants, including details about their child's ASD, age range of the children involved, socioeconomic backgrounds, the family's structure and geographical locations. The data collection from the interviews demonstrated narratives that captured detailed accounts of the families' experiences, coping strategies, and changes in routines. They also expressed the emotional and psychological impacts of the pandemic, offering insights on how they navigated through the challenges posed by COVID-19. These detailed findings, along with detailed descriptions of the research context, enable researchers and practitioners to assess the relevance and applicability of the findings to their own context, thus, enhancing the transferability of this study (Stalmeijer et al., 2024; Stahl and King, 2020). Furthermore, the findings were discussed in relation to existing literature, allowing for broader conceptual transferability (Stalmeijer et al., 2024). The study included a diverse range of participants; diversity of the participants, whether geographically or specific family dynamics, contributed to the broader findings and a more comprehensive understanding of the phenomenon, enhancing the transferability of the study (Stalmeijer et al., 2024). Stalmeijer et al. (2024) suggest that by providing this level of detail, and in recognising the aspects of the research context, the researcher enhanced the research's transferability while respecting the unique experiences of the participants, allowing for relevant application or consideration of the findings in other contexts.

5.6.6 Summary

Burke (2016) explained -- when addressing the issue of quality and trustworthiness within their own study -- that researchers may use a variety of criteria relevant to the characteristics and complexities of their work. This helps researchers to determine the quality of the methods they used and to ensure their reliability (Burke, 2016). Adopting the relativist approach to establish rigor, combined with using variety of criteria and selecting a qualitative descriptive approach as a data collection method, ensured this study's validity and trustworthiness of the data were maintained (Tracy, 2010). The researcher of this study integrated an approach of maintaining coherence, and employing reflexivity, whilst ensuring credibility, dependability and transferability.

5.7 Ethical Considerations

This research study was conducted online via the use of Microsoft Teams and Zoom. The researcher was based in Leeds, United Kingdom. Certain measures, such as ethical review procedures, were implemented in order to comply with the UK law and procedures; an Ethical Approval was granted to the researcher for from the University of Leeds (UOL) Faculty Research Ethics Committee. This allowed the researcher to approach schools, autism centres and to use different social media platforms to advertise and start the data collection process. Moreover, a Disclosure and Barring Service (DBS) Certificate and a Police Certificate were in place. Issues of recruitment, confidentiality and data storage, risks and safeguarding were all considered.

5.7.1 Recruitment

Participation in this research study was voluntary. The PIS included information on confidentiality, consent forms and withdrawal rights. The ability to leave the study at any moment was made clear to the participants. The participant was only contacted if they had already expressed interest in participating in this study. The PIS demonstrated all pertinent details of the study and described its ethical and practical implications. Similarly to the PIS, the consent form aided the participants and allowed them to decide for themselves whether they wanted to participate. The participants had the freedom to leave without providing a reason. After their participation, the researcher made sure that their data set would be withdrawn and not used in the data analysis if they choose to quit. Additionally, since the majority of the participants are children and special educational needs, special attention was given to children with autism and young people themselves, to ensure that ethical standards were not only met but applied throughout the research process. For child participants, both parental and child consent were obtained. In addition to adult-appropriate materials, children were provided with their own simplified PIS and consent forms, written in age-appropriate language and supported by pictures. The purpose of the study and what would happen during the interviews was explained to them clearly, and prior to each interview, the researcher checked if the participants had any questions or needed clarification. It was also confirmed that the participants understood the interview would be recorded, and that they were free to stop at any time. Although PECS materials were made available in case they were needed, they were not used in the interviews. Children who were non-verbal or described by parents as unable to understand or engage with the questions were not interviewed, in accordance with parental guidance.

Cultural and contextual sensitivity was another vital consideration. Families were based across the UK, Kuwait, and Saudi Arabia, and the researcher remained flexible and responsive to their preferences and circumstances. Interviews were scheduled at times chosen by the families themselves, including evenings and weekends, particularly due to the variation in weekday and weekend schedules between Kuwait, Saudi Arabia, and the UK. For example, one mother, a single parent, had to reschedule her interview multiple times due to parenting and work demands, and the researcher continuously reassured her that this was not a problem. Prioritising participant well-being and convenience over strict scheduling helped maintain an ethical stance based in care and understanding. These preferences were respected fully, and arrangements were made accordingly.

5.7.2 Confidentiality and Data Storage

Discussing personal topics which could potentially be embarrassing or upsetting if shared, required a high level of confidentiality. The interview questions probed into various aspects of the participants' life and were therefore deemed to be a "sensitive" topic (Lee and Renzetti, 1993). The researcher assured the participants that they would not be required to answer any questions if they did not want to in order to allay their concerns. They had the option to withdraw whenever they felt these inquiries had upset them to the point of withdrawal. The researcher was also informed about techniques for talking about delicate subjects and listening empathically. However, the researcher would have had to report information to the appropriate authorities, the participant and the supervisor if the participant had revealed any unsettling information. The participants' information is kept confidential, and all research data is anonymised. Each participant received a unique ID that is unrelated to any information that can be used to identify the participant. The adoption of the distinctive ID assures the participants' identity and confidentiality in all areas of data gathering and analysis. There are no paper copies of the data because it was all collected online; it is stored on the UOL's firewalled M-drive. Additionally, only the researcher and her supervisors will have access to both the anonymised and non-anonymised data. Digital ethics were also carefully considered due to the online nature of data collection during the COVID-19 pandemic. Microsoft Teams and Zoom were used as a secure platform, and families were given the option to keep their cameras off if they preferred. Some children, like Family D - Daughter, initially chose to remain off-camera during the family focus group interview but later felt comfortable enough to turn the camera on during the one-on-one interview, a shift that underscored the importance of maintaining a flexible, respectful, and participant-centred environment. All interviews were audio and video recorded with consent, and the recordings were stored securely on encrypted, password-protected drives.

5.7.3 Risk and Safety

Even though this study involves minimal risks, the appropriate measurements and risk assessments will be taken and put in place. The possibility that the families may have talked about sensitive or upsetting subjects posed a risk. In this instance, the researcher made sure that the participants knew they were not required to answer any questions that would make them feel disturbed or distressed. Sensitive issues were handled with care and the researcher would have ended the interview if there were any indications of upset or stress. Emotional safety and informed participation were prioritised throughout the study. During interviews, some parents shared deeply personal experiences, including their own mental health challenges such as depression. In such instances, care was taken to listen without judgement and to avoid probing for more information than the participant was comfortable sharing. If any signs of emotional discomfort or distress were observed, the researcher paused or gently shifted the conversation and always reminded participants that they were in control of what they wished to share. The primary concern of the researcher was the participants' well-being; as a result, the participant's right to quit from the research study at any moment throughout participation was guaranteed.

5.8 Summary of the Research Study Plan

The aims of this research study were to explore the impact of the COVID-19 pandemic on the family quality of life of families with autistic children. To achieve these aims, the study consisted of two phases: the first phase involved the participant recruitment process, searching for participants, approaching them once they had shown an interest and recruiting them once they have agreed to participate. The second phase involved the data collection process which consisted of contacting the participants to set a date and time for the interviews before conducting the interview itself and analysing the data.

CHAPTER SIX: RESULTS

Chapter Six will demonstrate the results of this research study, which aimed to explore the impact of the COVID-19 pandemic on various domains of the FQoL of families of children diagnosed with ASD. A qualitative descriptive approach was adopted, intending to accomplish this study's aims, which utilised focus group interviews with families, and where possible, individual interviews with family members. A presentation of the themes developed will be provided, and thereafter, the cross-cutting themes, negative cases and anomalies, finishing with chapter conclusion.

6.1 Overview of Data Collection, Analysis and Participants

As indicated in the previous chapter, the study included 10 diverse families to gain a comprehensive perspective of the impact that the COVID-10 pandemic had on the FQoL of families of children diagnosed with autism. All family members' identities have been kept anonymous, and pseudonyms were assigned to ensure their privacy. The families were found from Kuwait, Saudi Arabia and the UK. The recruitment process adopted the convenience sampling method, aiming to access families associated with social networks, organisations, and educational institutions. Each family demonstrated their own distinct characteristics, which included the number of autistic children in the family, the number of family members, their educational settings and their age. Among these families, four families were headed by single parents, while the other six families had both parents involved. Furthermore, six families consisted of only autistic children, while the other four families had a combination of both typically developing (TD) and autistic children. The diversity among the families enables a comprehensive exploration of the impact of COVID-19 on the FQoL of the participants. The data analysis was conducted in two stages. First, an intra-case analysis was performed, examining the experiences and perspectives of each individual family in-depth. This allowed for a deep understanding of the unique circumstances and challenges faced by each family. Following the intra-case analysis, a cross-case analysis was undertaken, comparing the findings across the families. This enabled the researcher to identify common themes, as well as unique experiences, that cut across the families. In the following sections, an introduction to each family will be provided, before delving into the specific findings related to the four domains of FQoL: the physical, academic, psychological and social experiences of both the autistic children and their families.

6.1.1 Introduction to Each Family

Family A

Family A - Mother, is a mother of 2, spends time working in an educational setting and is a student. Her husband, Family A - Father, is also employed. Family A reside in the United Kingdom. The twin sons, both 10 years old, Son 1 and Son 2, attend a mainstream, inclusive school. During their interviews, both the one-on-one and family focus group, the mother, along with her twin sons, provided valuable insights into their journey during the pandemic. Family A – Mother discussed the challenges of isolation and the struggles of balancing her work life while educating her sons. She highlighted how overwhelming this was, as she eventually decided to transition them back to traditional schooling. Family A – Mother additionally shared how she and her family found solace in outdoor activities, such as going for walks and exploring new places. The father opted not to participate in the interviews.

Family D

Family D – Mother is both a student and a working professional, while her husband, Family D – Father, is employed full-time. The family resides in the United Kingdom. Both parents and their children have been diagnosed with autism. Their daughter, Family D – Daughter (14 years old), has been home-educated from a very young age due to challenges she faced in a traditional school setting. On the other hand, their son, Family D – Son (12 years old), initially attended a mainstream inclusive school, but due to the challenges he experienced during the pandemic, he transitioned to home-education. All members of Family D participated in both one-on-one interviews and a family focus group, sharing their perspectives on how the pandemic impacted their lives. The family offered valuable insights into their experiences in navigating the complexities of the disorder, home education and the impact that the pandemic had on their lives.

Family I

Family I – Mother assumes the role of a full-time caregiver, while her husband works in the medical field. Family I resides in Saudi Arabia. The family includes twin sons, aged 12, one of whom, Son 1, is autistic and home-educated, while the other twin, Son 2, is diagnosed with Borderline Personality Disorder and attends a mainstream school. Family I – Daughter 1, aged 14, attends a mainstream school, while Family I – Daughter 2, aged 24 who graduated during the COVID-19 pandemic, is now employed. Family I – Mother and her 2 daughters participated in both the focus group and one-on-one interviews. The family's experiences and perspective on the pandemic was particularly insightful as they discussed the shared challenges of managing siblings with different neurodiversity disorders and how the lockdown restrictions affected them as a family. In addition, Family I also explained that their situation was heightened as their father, who works in the medical field, had to continue working during the pandemic, thus introducing an additional layer of complexities to their experiences. Family I – Father, and both of his sons, opted not to participate in the interviews.

Family J

Family J – Father, a Kuwaiti single parent residing in Kuwait, is employed in a full-time medical profession. The family's dynamics shifted abruptly when Family J – Father's ex-wife, who had been the primary caregiver of their children, passed away one month before the WHO's announcement of the COVID-19 pandemic. Following her passing, Family J – Father assumed full responsibility of raising their two sons. Both sons, Son 1, aged 12, and Son 2, aged 11, are diagnosed with autism and attend a special educational school in Kuwait. The family's experiences, particularly the father's transition into a single-parent household, provide valuable insights into the complexities of parenting his sons amid the challenges posed by the pandemic. Additionally, throughout both the focus group and one-on-one interviews, Family J shared how Family J – Father continued working during the pandemic as he is a full-time medical professional. They shed light on how they adapted and navigated the complexities brought by the pandemic.

Family H

Family H – Mother, a parent of three sons, temporarily paused her professional career during the pandemic to become a full-time caregiver. Family H resides in Saudi Arabia. Family H's youngest son, Son 3, aged 4 and the eldest son, Son 1, aged 14, attend a mainstream school, while the middle son, Son 2, aged 12, attends a special educational school, as he is diagnosed with autism. Family H - Mother shared in her one-on-one interview her decision to temporarily step away from work during the pandemic. Her interview provided a valuable narrative into her experiences of managing her family while facing challenges brought by the pandemic. Family H – Father, and all 3 sons, opted not to participate in the interviews.

Family G

Family G - Mother, a stay-at-home parent, in the UK, is an autistic mother of three sons. Her eldest son, Son 1 (aged 14), is also diagnosed with autism. In the interim, her 12-year-old and 4-year-old sons, Son 2, and Son 3, are currently awaiting diagnoses. Son 1 attends a special educational school, whereas Son 2 and Son 3 attend a mainstream school. In her one-on-one interview, Family G – Mother expressed how her experience during the pandemic was particularly challenging as all her medical treatments were halted due to the pandemic's restrictions. Additionally, she provided insights into the experiences of parenting children with autism, especially while awaiting diagnosis and additional support. Family G – Father and the three sons opted not to participate in the interviews.

Family B

Family B – Mother is a stay-at-home parent of two sons and a teenage daughter. Her 10-year-old son, Son 1, is diagnosed with autism and attends a special educational school in the UK. Her daughter, Family B – Daughter, aged 13, and eldest son, Son 2, aged 14, attend a mainstream school. In her one-on-one interview, Family B – Mother reflected on her approach to parenting and accommodating the diverse needs within her household. She highlighted the challenges her family faced, especially as they faced the struggles the pandemic had on her children. Family B – Father, and the children, opted not to participate in the interviews.

Family F

Family F – Mother is a working single mother from Kuwait with two sons; one is diagnosed with autism, and the other is TD. Her 12-year-old autistic son, Son 1, attends a special educational school, while her younger son, Son 2, aged 7, attends a mainstream school. In her one-on-one interview, Family F – Mother expressed that she took a proactive approach and relocated to her mother's house during the pandemic. This decision was made to deal with the challenges of the pandemic and to ensure additional support for her sons, as she had to work during the pandemic and was not able to work from home. Family F – Mother's sons opted not to participate in the interviews.

Family E

Family E – Mother is a single parent to an 11-year-old autistic daughter in the UK. She finalised her divorce and assumed full parental responsibility during the COVID-19 pandemic. Her daughter attended a special educational school. During this time, Family E – Mother also faced the additional challenge of her own mother falling ill. In response, Family E – Mother requested to work from home, in order to provide her family with the necessary care. In her one-on-one interview, Family E – Mother offered insights into the challenges she faced as a single mother and as a carer for her mother. However, she expressed that the pandemic made her very lucky as she was able to work closely with her daughter, while managing the intricacies of work and familial responsibilities amidst the challenges. Family E – Daughter opted not to participate in the interviews.

Family C

Family C – Mother is a single parent who balances her roles as a student and a stay-at-home caregiver in the UK. She has a 7-year-old autistic son, Family C – Son, who attends a special educational school. Acknowledging the challenges posed by the pandemic, Family C - Mother sought additional support from the UK government, and was provided with the assistance of a care worker. This decision was driven by her struggle to navigate the complexities of parenting a child with autism while managing her mental health issues. Family C – Mother's experiences, shared through her one-on-one interview, offer a valuable perspective on the resilience of a single mother managing her education, parenting and seeking additional support to provide the best care for her son during the pandemic. Family C – Son opted not to participate in the interviews.

6.2 Presentation of Thematic Analysis

The thematic analysis of the results identified two main overarching themes that encapsulate the multifaceted experiences of families during the COVID-19 pandemic. These themes encompass the Positive (Theme 1) and Negative (Theme 2) impacts of the virus on families' QoL.

6.2.1 Intra-case Thematic Analysis

Theme 1: Positive Impacts

The first overarching theme explores the positive impacts experienced by families during the pandemic. This theme is separated into four distinct sub-themes each providing an individual perspective on how each family member found moments of hope, strength and acceptance. The sub-themes explore the positive impacts from an educational aspect (Academic Domain), health and physical well-being aspect (Physical Domain), social interactions and connection aspect (Social Domain) and psychological health aspect (Psychological Domain).

Subtheme: Academic Domain

Family A

Family A – Mother's narrative demonstrated that due to lockdown restrictions, her sons' school transitioned to online learning, however she explained that there was a difficulty in accessing them. Therefore, she expressed to create her own curriculum at home, with the support of her brother-in-law's online math tutoring classes. She explained:

> *Family A – Mother: "But it went online--and he--uh, allowed us to have cheap access to tutors. So I started to do tutoring that online, one-to-one, tutoring in maths, and, he went from, umm, no maths, to a reasonable math skill, during that time" (p. 3)*

Family I

Family I – Daughter 1's interview demonstrated that that she experienced a relatively seamless transition to online learning. She explained that her school provided their students with extensive support to ensure they adjusted well to the new system that was brought about by the pandemic.

> *Family I – Daughter 1: "Like for me, my high school years were mostly online, like one year and a half I was online. Like as soon as we went online from the first week, they gave us a week to introduce like the online world for us, and teach us everything, like how to use Google Meet, Google Share, how to use the emails, how to work on documents, how to submit and do our homework." (p. 11)*

In addition, Family I – Daughter 1 expressed how the transition to online learning alleviated her stress and anxiety that were induced when she attended school in person. Despite acknowledging that her online learning was reduced, Lily explained that that the decrease in studying aligned with the decrease in stress levels.

> *Family I – Daughter 1: "For me, stress, of course, got so much lesser, as long as I don't go out, I don't get anxious, or get worried... Also, in terms of stress, I used to get really stressed for school and when I study, so when it became online, no one studied, I didn't need to study. Like there was no more stress, I was relaxed. The stress got less." (p. 5)*

Regardless of the reduced study time, Family I – Daughter 1 did mention that she did learn new things, particularly from school.

> *Family I – Daughter 1: "But I learned obviously I learned new stuff, I learned from school, and I learned new stuff about the virus and how to handle it and what to do and what not." (p. 6)*

> *Family I – Daughter 1: "Introduce like the online world for us, and teach us everything, like how to use Google Meet, Google Share, how to use the emails, how to work on documents, how to submit and do our homework." (Family I's Family interview, p. 11)*

On a similar note, Family I – Daughter 2, expressed that online learning positively impacted her writing skills.

> *Family I – Daughter 2: "It's not like in my personality, but personally my skills for writing has gotten much better. Because like I started writing more." (p. 9)*

Family J

Family J – Son 2's interview demonstrated that at the onset of the lockdown, the school's closure didn't impact him. However, as time progressed, he felt happy in the continued school closures.

> *Family J – Son 2: "Alright, so when the lockdown was announced, the, uh, I didn't really care much because we did barely sit outside, but I was happy because, you know, first they said alright, no school for two weeks, then [it] kinda escalated. Then we basically had no school for like the year. And that was amazing." (p. 7)*

Family E

Family E – Mother's narrative showcased that the pandemic had a significant, positive impact on her and on Family E – Daughter's academic progress. She emphasised:

> *Family E – Mother: "It's got better. It's got better and I understood, it made me realise what teachers are doing as well, and it put me on the right track, where I'm going as well, what I'm doing because before I didn't know what I was doing and since locked down [lockdown], it changed me, gave me time to think." (p.6)*

Additionally, she expressed how the pandemic provided a break from reality, allowing her to focus on her daughter's needs:

> *Family E – Mother: "Positives was where I was very lucky. I was able to spend time with her working from home, and that was quite a positive, just break." (p. 2)*

Subtheme: Physical Domain

Family A

Despite the negative impact of COVID, Family A – Mother emphasised the unexpected benefits. She explained that having autistic children allowed her family to travel further distances and leave her house for longer periods than families with TD children. This enabled them to participate in numerous outdoor activities, such as long walks and cycling:

> *Family A - Mother: "Well, there was other benefits. So the great benefit was that. Uh autistic people were allowed to leave their houses for longer and travel further than other people, so it meant that we just used to because my husband wasn't working. But he was put on furlough, which was a need for not to work. So that was good because we could go out for really, really long walks and we could travel quite far. And there was no people. So we will be in the forest, it's just us as a family, it was beautiful weather, so we just really enjoyed green spaces. We went cycling. We did lots of outdoor stuff." (p. 5)*
>
> *Family A - Mother: "Yeah, we -- we did, we did more activity than -- than we do now" (p.7)*

Similarly, Family A – Son 1 mentioned:

> *Family A – Son 1: " We went for walks. In two different. Most forests and public footpaths." (Family A Family Interview, p. 6)*

Family I

During the lockdown, Family I – Daughter 1's narrative demonstrated the efforts her school made to ensure students remained physically active. She explained how the Physical Education (PE) classes were conducted online, and once a month, the school offered students to participate in yoga classes to alleviate stress:

> *Family I – Daughter 1: "I remember during the lockdown one of the physical things that we had during school, our PE classes, we would actually like open the camera and do exercises together with the teacher and every once in a while, like each month for example, they would like offer us to attend a yoga class to just get us off the stress of this whole situation." (p. 3)*

In a similar note, Family I – Daughter 1 mentioned using digital platforms, such as TikTok, as a form of physical activity.

> *Family I – Daughter 1: "And honestly, one more thing is in the beginning of the lockdown, everyone started to--everyone started being introduced to TikTok, so I would try to do the TikTok dances with my friends and like, yeah, so I consider that a physical aspect." (p. 3)*

Family D

Family D – Mother expressed that the pandemic aided to family's physical well-being. She discussed how the family prioritised their physical health and engaged in different forms of physical activity.

> *Family D – Mother: "We all got fitter. And, and we were really shocked." (Family D Family interview, p. 44)*
>
> *Family D – Mother: "I was really surprised to see that Family D – Son in amongst his pig peer group, was-- was fit and strong." (Family D Family interview, p. 44)*
>
> *Family D – Mother: "Yeah, and we went out for lots and lots of walks. We went all over, didn't we? And we drove to places as well, even when we weren't supposed to, because we drove somewhere for exercise." (Family D Family interview, p. 24)*
>
> *Family D – Mother: "I think they've learned how important physical exercise is and how much it should feature in their day, and definitely they're both learned that they think they've learned more about how to manage their, um, capabilities." (p.9)*

Family E

Family E – Mother expressed during the interview how because of the lockdown, she had to adapt to work from home and take care of her family. However, based on her narrative, she viewed this situation as blessing in disguise as it allowed her to focus more on her family. She explained how she utilised her home garden for her daughter to engage in physical activities, emphasising water play activities:

> *Family E – Mother: "But because we have the garden, it wasn't so bad because I had, like, I made sure that she did water play. And she went to shops. It kind of compensated it. Especially the second lockdown, but, but it did. And then after, I mean, yeah, it did quite a bit. Yeah, it--it, but I made sure she did like obstacle courses like in. I mean, like, there was like a, like a plank, a wooden plank. And I put that in the garden, and she'd walk on it. And, and put pegs on the, on the thing […] but she was getting fed up of being in the garden." (p.7)*

Family C

Despite the COVID-19 restrictions, Family C – Mother emphasised the importance of adapting to the situation she was in and finding creative ways to avoid her son being less active. Therefore, she managed to engage her son in different activities, emphasising playtime, going for long drives and importance of sensitive play:

Family C – Mother: "Umm, we did manage to do some, umm sensitive play at home, umm, lots and lots of driving, going for long driving, umm, yeah, just like spending time and lots of play, lots of stimulating, sensitive play, basically." (p. 6)

Family F

Despite the lockdown restrictions, Family F – Mother explained that she used to participate in some form of exercises at home and outdoors.

Family F – Mother: "So we used to walk sometimes. I used to take my other son, he's slightly overweight, and he would get tired quickly, and I take him back home, and I used to continue walking alone, because I used to go to the gym and during lockdown they closed the gyms, so I used to walk to compensate. And brought some gym equipment at home to workout. And also, my gym used to do online workouts, so I used to put it on the TV and me and the kids would workout together, that was the time everything was online, so we would workout and they would jump and play with me. Like we moved a little bit, you can say. Just anything to move." (p. 6)

Subtheme: Social Domain

Family A

The lockdown restrictions allowed Family A to spend more quality time together. Family A – Mother denoted that her family grew closer:

Family A – Mother: " Yeah, I think we got closer with the children" (p. 9)

In addition, Family A - Mother and her sons noted how they lockdown provided them with the opportunity to bond through participating in activities together.

Family A – Mother: " Lego. That's what we used to do." (p. 7)

Family A – Son 1: " It-- it's like a big chess board. And chess pieces make all made of Lego every single bit of it." (p. 9)

Family A – Son 2: "Play, play-- play Google Earth" (p. 4)

Family A – Son 2: "Oh ok, making banana bread." (p. 5)

Family I

Each member of Family I expressed how the pandemic brought them closer together. Family I – Daughter 1 explained how they would bond together whilst watching movies and television shows:

> *Family I – Daughter 1: "We would also start shows together, and we wouldn't, […] like if I wanted to watch an episode, I was not allowed to watch it alone, we would have to watch it together... one day we would like to have a movie night and would like [make] popcorn and just all sit all together in the living room, and we would watch." (p. 5)*

Family I – Daughter 2 discussed how her bond with her mom and her sister grew and they became closer:

> *Family I – Daughter 2: "I became more closer the most with Family I – Daughter 1 and my mom. Like my dad when he goes to bed, my brother Family I – Son 2 goes to his room and plays online, so us girls sit together and we talk and have deep conversations, things like that. This is what got us closer together, these times." (p. 4)*

Family I - Mother pointed out how spending more time with family had a positive impact on Family I – Son 1's behaviour:

> *Family I - Mother: "But his negative behaviour all changes and good, better because now he spends more time with his siblings." (p. 3)*

With respect to Family I's social life, Family I – Daughter 1 discussed how she and her friends maintained their social interaction as they couldn't meet in person due to the COVID-19 restrictions.

> *Family I – Daughter 1: "I remember when the lockdown, when the first day we had lockdown. My friends and I would daily, on a daily basis, we would FaceTime each other [...] just to feel their presence, even though they're not here physically." (p. 3)*

Family I – Daughter 2, however, described her experience during COVID-19 as an opportunity to develop her social skills. She explained:

> *Family I – Daughter 2: "Umm, social life, like I feel like I learned how to communicate with people I've never met to get the job done. Like the girls from university, the girls that were with me in the group, for the graduation project, I've never met them before. Like when we met, we only met through voice calls." (p. 5)*

Family I – Mother, on the other hand, expressed that the pandemic acted as a filter, which helped her identify and retain the most meaningful relationships:

> *Family I – Mother: "Like for me, the COVID period was like filtering people out period. Like the only relationships that stayed are the strong ones. Like the real friends." (p. 10)*

In addition, Family I – Mother's narrative placed a significant emphasis on the support of her family and how she relies on her children:

> *Family I – Mother: "Like my main support are my children. All of them." (p. 3)*

In the same vein, Family I – Daughter 1 noted how her extended family, both from her mother's and father's side, consistently made efforts to check on the family and to specifically asking about Family I – Son 1:

> *Family I – Daughter 1: "My mother's family, like my mother's side of the family and my father side of the family, they would usually like on a weekly or daily basis, they would call in to check on us and on Family I – Son 1 [...] Alhamdullilah, we have the support needed that they would like regularly check in on us." (p. 7)*

Family J

Family J – Son 2 noted that he was already engaging in social activities via digital platforms before the lockdown restrictions were implemented. With that being the case, when the restrictions were enforced, Family J – Son 2 expressed that him and Family J – Son 1 use applications, such as Discord, to stay in contact with friends and participate in peer-to-peer gameplay:

> *Family J – Son 2: "So we just use this application called Discord. Basically, we just added each other. You know when COVID wasn't a thing we were already talking online, playing games online. So, you know, when lockdown happened, I'll just, you know, I just get on Discord, say "hi" to my friends who play a couple [of] games and stuff, so we still stayed in contact online though, and do we play games, I guess." (p. 2)*

> *Family J – Son 1: "You know, going on Steam, Roblox, those two games" (p. 2)*

Despite the challenges that were posed by the pandemic, Family J – Son 1 and Family J – Son 2 both highlighted the relationship between both brothers had not been affected. Both brothers expressed that the circumstances did not impact friendship:

> *Family J – Son 1: "No, I just thought, of course this is the same thing, even in lockdown it was the same." (p. 2)*

> *Family J – Son 1: "Or, you know, there's just, like, a one rare moment where, you know, you know, when whatever you order, like new snack something, we just, we just decided to give the taste test together to see if they taste good or not. And it's just what we usually do" (Family J Family interview, p.33)*

> *Family J – Son 2: "The same." (p. 4)*

Family D

Regardless of a lack of social activities during the lockdowns, Family D – Mother's narrative of how her family participated in communal activities increased morale and aided in societal support. She expressed how they collaborated with their neighbours and found ways to connect with the community:

> *Family D – Mother: "[...] coming together as a community and ordering food together and helping each other." (p. 3)*

> *Family D – Mother: "And you know, we did like a little newsletter to keep [up] everyone's spirits. Our neighbour did one to keep everyone spirits up. We all checked [in] on each other all the time and it made you remember what was important in life, actually. So that you know, for me, some real positives came out of that in terms of really noticing everyone's mental health." (p.3)*

On a similar note, Family D – Daughter's account provided a wider narrative of her perspective on the societal implications of the lockdowns. She highlighted that despite the societal barriers of the lockdown, she found an opportunity to learn and connect with her community and family:

> *Family D – Daughter: "I feel like we learned a lot from it as a society [...] it's changed a lot of things for the worse and a lot of things for the better." (p. 2)*

> *Family D – Daughter: "Community. Definitely family, which is not something that we have already noticed until we were stuck together in a bubble. So definitely community and family, social relationships as well." (p. 5)*

Additionally, Family D – Father mentioned that due to their autistic characteristics, he and his family do not socialise frequently. Despite that, during the pandemic they had to adapt, thus increasing their social interactions by utilising online platforms to stay connected with friends and family.

> *Family D – Father: "I suppose we did do more socialising because when we got kind of scooped up by other people doing big Zoom calls or quizzes, not-- not regularly, but every couple of months when somebody suggested something we would do something we've never done before. But yeah, we were not social creatures at the best of times." (p.31)*

Another significant aspect of Family D's interviews is Family D – Father's narrative. He emphasised how his experience provided the family an opportunity to spend quality time together without distractions.

> *Family D – Father: "About spending time with the family so it was, um, you know, going out for kind of value walks where you know you didn't have phones, you were chatting, you were spending time together" (p. 1)*

Family D – Son, additionally, explained that the by having the opportunity to have more time with his family, it strengthened their bond. He highlighted how they transitioned certain individual activities into shared family experiences. He also expressed how whenever they had the opportunity, they would make the most of it by spending it together as a family.

> *Family D – Son: "I'd say closer. Look at we-- we spent a lot more time than we normally would with each other. And we did a lot of stuff that normally we just sort of go and do on our own, but because we only had an hour a day, we all did it together." (p. 7)*

In a similar vein, Family D – Daughter explained how she and her family would engage in activities over digital platforms to maintain social connections.

> *Family D – Daughter: " We did [connect] over Zoom trivia with and a lot of them just had just come out of shower towels on their heads. We had a very interesting range of over Zoom trivia for the family." (p.30)*

Family C

Despite the COVID-19 restrictions, Family C – Mother sought alternative ways to maintain a social life, as during the interview, she emphasised the importance not taking everyday social interactions for granted.

> *Family C – Mother: "I'm trying to like basically break the, what have happened and during the lockdown so going therapy trying to have a bit more social life not take the everyday thing for granted anymore." (p. 12)*

Family C – Mother discussed how external agencies provided her support to alleviate some of her struggles she had when her family support was disrupted. She highlighted:

> *Family C – Mother: "I did got some support from-- from […] social services, so they gave us a care package so we could have a carer that will come to the house and take [care] Family C – Son for like 3 hours during the day, 15 hours a week, and just so that I can have that break." (p. 6)*

However, she did explain that at first, the support from social services she received was a struggle, as the carer was not aware of the difficulties of children with autism. Thereafter, the social services offered her a different program which allowed her to pick her own carer, which provided her with much relief. This is evident in Family C – Mother's extract below:

> *Family C – Mother: "So, my sister became his carer, for 15 hours. So, she would come and take him outside and he was a lot happier because it wasn't someone new, it wasn't someone, and yeah, it was my sister and she would be in her car, which he knows and, yeah. And I and I felt so much relief. I wasn't worrying for three hours in a day 'cause he was with my sister. So yeah." (p.13)*

Family H

Family H – Mother's narrative suggested that having Family H – Son 2's other siblings at home during the lockdown played a crucial role in supporting Family H – Son 2 during this period. Family H – Mother noted that his brother engaged in activities with him, ensuring that Family H – Son 2 had company.

> *Family H – Mother: "And you know his brother stays at home and plays with him and they play together, time passed quicker." (p. 4)*

In addition, Family H – Mother explained that her family lived in the same household, which aided in social contact and mitigated the pandemic's disruption to their social life.

> *Family H – Mother: “Social life, umm, it was not affected at all, alhamdulillah. On the contrary, I mean like I didn’t feel like there was a difference […] there are several other ways of contacting each other, like mobile phones, and things like that, that’s why I felt like our social lives was not affected.” (p.3)*
>
> *Family H – Mother: “Well to be honest, our social life, we actually didn’t feel like it was affected at all to be honest. Maybe because I live in a villa with my family, my whole family we are next to each other, my mom, my brothers, maybe that’s why I didn’t feel like anything changed, like I didn’t feel like there were any issues in our social life. You know like my whole family is here with me to be honest” (p.5)*

Family G

Family G – Mother’s narrative highlighted the importance of family members engaging with each other. She pointed out how the lockdown restrictions allowed the family members to bond and spend quality time with each other as a family:

> *Family G – Mother: "Being able to spend quality time with each other, being able to do things that improve our understanding of each other, umm and to make that bond grow, make that love grow." (p. 3)*
>
> *Family G – Mother: " Spending more time with each other just, may just become more close I think. And, yeah, getting to spend more time with each other. I think that was a plus. That was a good thing. You know, spending a lot of time in the garden. We did quite a lot." (p. 14)*

Family B

Family B – Mother pointed out that being at home provided an opportunity for family bonding to increase, especially with her son Family B – Son 1:

> *Family B – Mother: "Yeah, yeah, cause we were all at home, and yeah, that did help, he got to spend a lot of time with all of us, so yeah." (p. 5)*

Family E

The confinement at home and the lockdown restrictions provided Family E – Mother with a significant opportunity to bond with her daughter. Family E – Mother stated that the sudden changes in her working life led to positive outcomes, such as spending time with her daughter:

> *Family E – Mother: Positives was where I was very lucky. I was able to spend time with her working from home, and that was quite a positive, just break. (p. 2)*

Subtheme: Psychological Domain

Family I

Family I – Daughter 1 highlighted her personal growth with regards to her physical health, academics, and mental health during the pandemic.

> *Family I – Daughter 1: Even for me, I feel like my quality of life got way better [...] Yes, exactly, I became an adult, more mature. I changed [...] Like without COVID, I wouldn't have been the person I am today." (p. 5)*

> *Family I – Daughter 1: "So, as my mum mentioned during the lockdown, it was a changing state of my life. I was going through growing mentally, physically, academically [...] mentally, I grew a lot [...] That made me grow mentally and become a better version of myself." (p. 6)*

On another note, Family I – Daughter 2, emphasised that the family became aware of each other's emotional states during the lockdown:

> *Family I – Daughter 2: "We became socially aware of each other's traits [...] I learned a few things about them, and we became more socially aware of each other." (p.6)*

> *Family I – Daughter 2: "Psychologically? I mean, like I don't know what the change is exactly, but I feel like we started seeing, for example, like when my brother comes down, we'd notice that he's in a bad mood. It's like we started knowing and noticing each other more." (p. 6)*

In addition, Family I – Daughter 2 expressed that the pandemic allowed her to find solace within herself.

> *Family I – Daughter 2: " I made peace with myself I mean." (p. 5)*

Family J

Family J discussed the psychological impact that the pandemic had on them. Family J – Father stressed on the importance of his sons' safety and the comfort of knowing that they were at home and safe:

> *Family J – Father: "The feeling that your kids are at home. It's like, you know, safe and comfort idea. When the pandemic was-- yeah, yeah-- yeah. Literally. Literally. I'm saying, you know,*

> *when usually when they go to regular school at regular days, they have the flu, the stomach bug and everything, you know. Believe it or not, for the-- for the two years they are sitting at home, alhamdulilah they did not even get the flu." (p. 32)*

Family D

During the focus group interview, Family D discussed how the pandemic's impact made them realise the meaning of quality living:

> *Family D – Mother: "It's simplified our life, so it made you realise what mattered in quality of life, actually." (Family D Family interview, p. 3)*
>
> *Family D – Daughter: "Also, quite positive impact in a lot of mental health [aspects] because you weren't going out and doing as many large social gatherings and stressful things." (Family D Family interview, p.4).*

Family D – Mother emphasised that the impact of the pandemic made her aware of the importance of community and psychological well-being:

> *Family D – Mother: "Actually, it made you remember what was important, like being out in nature in the walks. Actually chatting, having long chats with the kids while we were on long walks coming together as a community and ordering food together and helping each other." (p. 3)*
>
> *Family D – Mother: " And you know, we did like a little newsletter to keep [up] everyone's spirits. Our neighbour did one to keep everyone spirits up. We all checked on each other all the time and it made you remember what was important in life actually. So that you know, for me, some real positives came out of that in terms of really noticing everyone's mental health. And being aware." (Family D Family interview, p.3)*

In addition, Family D – Daughter and Family D – Father discussed how the pandemic allowed them to recognise their strength and ability to overcome challenges and struggles.

> *Family D – Daughter: "And so now that we're out of the pandemic, I feel like my mental health is a lot better because I've kind of seen it as it's highest in anxiety and it's lowest in happiness" (p.5)*

> *Family D – Father: "I think as soon as we found a routine of the new, the new normal, I think. Mentally, I was much stronger and I think you could kind of deal with anything." (p.2)*

Family H

Despite the setbacks the pandemic presented, Family H - Mother highlighted Family H – Son 2's adjustment to the new lifestyle and pointed out that he adapted well when transitioning back to school, particularly after lockdown measures were removed:

> *Family H - Mother: "Well to be honest he really transitioned well, he accepted it, and he was excited because he loves going out." (p. 10)*

Family E

Family E – Mother's account describes how both her and her daughter responded positively to the transition to the lockdown restriction, at the onset of the pandemic. She explains:

> Family E – Mother*: "Positives was where I was very lucky. I was able to spend time with her working from home, and that was quite a positive, just break. Umm, but when she went back to school and she was taught by dinner lady, the quality of life was going down." (p. 2)*

> *Family E – Mother: "First lockdown it was good. I'm going to be honest with you. During that, it helped me to see her progress and it was great. It was wonderful. Umm. Yeah, I really liked it" (p.9)*

Family C

Family C - Mother found solace when she focused on her son, as a coping mechanism. This provided her a distraction to the struggles and the emotional toll she experienced. She said:

> *Family C - Mother: "Focusing my time and my attention on my child, umm, it was, it was the only way I survived." (p. 21)*

Theme 2: Negative Impacts

Contrastingly, the second theme focuses on the negative impacts that families faced during the pandemic. This theme discusses the disruptions, challenges, and struggles encountered by families across the domains of FQoL. Similarly to the Theme 1, the subthemes include, the Academic Domain, Physical Domain, the Social Domain and the Psychological Domain.

Subtheme: Academic Domain

Family A

In Family A – Mother's extract below, it is evident how her children's school made efforts to support their online learning. However, she did emphasise how she and her husband faced challenges in managing their children's education while also balancing their work-life.

> *Family A – Mother: "I mean, I think the school was very good. They did try to do online learning, but it was very difficult. I mean, it was just impossible. I mean, I was working from home. My husband was trying to do his job. And then we had two children that we were trying to educate. And it was just impossible. It was just too much." (p. 8)*

To be more precise, Family A – Mother was explicit in explaining the work she engaged with her children's education. However, she highlighted how the support was there, but it was still considerably difficult for her to manage.

> *Family A – Mother: "I mean, I tried to do some stuff with them. I tried to do some reading and some writing and some maths and things. But it was just very difficult. It was very hard. And I think the school did try to support, but it was just very difficult." (p. 9)*

Family A – Son 2 also mentioned that his mother took on the role to assist him with online schoolwork, however it was evident from the extract below that he missed the traditional school environment.

> *Family A – Son 2: "Mum helped me with my work. We did some reading and maths. It was okay, but I missed school." (p. 4)*

Family I

Family I – Daughter 1's experience during the lockdown demonstrated how it marked a significant transition for her as a senior, however this transition came as a shock for her -- she found it particularly challenging.

> *Family I – Daughter 1: "When the lockdown ended and I went to school, I was a senior, so it was kind of a shock for me because everything I already went through, it was online, as if it wasn't trained [...] I was a sophomore and then changing pointset junior and everything was online, so that was also kind of challenging." (p. 6)*

Family I – Daughter 2's experience was different from her younger sister. She found online learning to be relatively smooth compared to her sister, however she faced certain difficulties with her presentations. Family I – Daughter 2 is accustomed to presenting while standing or walking, as it aided in alleviating her stress. Consequently, transitioning to online presentations was a struggle for her.

> *Family I – Daughter 2: "Maybe if anything that came on my mind, or anything that bothered me, would be the presentations for university, for example [...] I am the type of person, if I want to talk and not feel stressed, I have to walk. I have to keep on walking to be able to talk." (p. 5)*

On the other hand, in terms of their brother Family I – Son 1, both sisters mentioned that Family I – Son 1 did not progress academically during the lockdown.

> *Family I – Daughter 1: "And academically he wasn't learning anything." (p. 6)*
> *Family I – Daughter 2: "Now, he doesn't go to anything except to camp. Everyday. Before he used to go [to school]." (p. 8)*

Family J

One of Family J – Father's main concerns revolved around the rapid change in his children's lifestyle and academic routine. He expressed that the pandemic severely disrupted their schedule and the plans Family J – Father had prepared for them.

> *Family J – Father: " And imagine. These two kids are locked [in] the apartment. Just knowing what they're supposed to do. Eat, sleep. Even school now become like a pain for them. Like they just got used to being lazy, just like Family J – Son 2 said, because during this time like they could, or like it's a pandemic, before the pandemic I put for them a schedule that was way different and they join different activities, go to the gym, all of that disappeared, all the plans that I had in my head was gone." (p. 7)*

Family G

Family G – Mother's account demonstrated how the sudden disruption to her children's school routine impacted their lives. She described how they became accustomed to being at home, which gradually became their new daily routine. However, when the lockdown restrictions were lifted, the children had to transition back to school, which had a significant impact on them.

> *Family G – Mother: "I think once they were at home and they spent so much time at home going back to school and going back to the routine, that was what had affected them the most." (p. 9)*

Similarly, due to the school closers, Family G – Mother explained how she struggled with online learning. She found herself taking in several roles, especially as a teacher, to support her children. She expressed how she found it challenging to keep them motivated and engaged in their studies.

> *Family G – Mother: "It was very challenging. It was very hard to keep them motivated, to keep them interested in doing the work." (p. 7)*

Family B

Family B – Mother's narrative explained that the school closure disrupted Family B – Son 1's routine, which he relied on. For example, in her extract below, Family B – Mother emphasised the challenges he faced while adjusting to the dramatic changes COVID-19 had on them:

> *Family B – Mother: "That was hard with Family B – Son 1, because he likes his routine, was a massive struggle [...]. He was really hitting himself, you know, getting aggressive, and he just wasn't coping [...] soon as the lockdown happened he was like everything for him was just up here [Hand gesture], meltdowns more, he just wasn't himself, basically." (p. 2)*

Additionally, Family B – Mother noted that she struggled to take on the role of a teacher, and to keep Family B – Son 1 engaged in his schoolwork. She expressed that the pandemic impact decreased her son's academic levels.

> *Family B – Mother: "School sent work for him to do, umm, but it's hard because he's a different child in school, he's a different child at home and to get his attention. So, we tried our best, umm just do what he did and whenever we could. It wasn't like I've made sure he did it every day, no I didn't. If he was in the mood and wanted to do it, I'd do it with him. I wasn't forcing him 'cause I knew it wasn't gonna work, but yeah, we did manage to get some work done." (p. 4)*

> *Family B – Mother: "I think it declined" (p.4)*

Family F

Family F – Mother discussed how the sudden school closures disrupted the daily routines that her son, Family F – Son 1, relied upon. She emphasised his depression and struggles with communication:

> *Family F – Mother: "Like I feel like 100% he was depressed too, just like his brother, but his brother is able to communicate, and he can't, but I feel like he felt the exact same way. Like "mama we are bored, what will we do?", so like they feel the same." (p. 5)*

In addition, Family F – Mother pointed out that she did not notice any changes in her son's academic outcome during the pandemic.

> *Family F – Mother: "Like I didn't see a difference to be honest, it's the same, like I didn't see any change." (p. 9)*

She also noted that she attempted to help Family F – Son 1 at home, during the lockdown, however she struggled to keep her Family F – Son 1 engaged.

> *Family F – Mother: "And I gave him some academic stuff to teach him, too. Because Family F – Son 1 listens to his teacher more than me. (p. 8)*

Family E

Family E – Mother's narrative vividly described how the immediate closure of schools disrupted her family's routine, particularly the routine that her daughter relied upon. She explained that upon returning to school, when the restrictions were lifted, her daughter's quality of life declined, consequently affecting Family E – Mother's quality of life as well.

> *Family E – Mother: "Umm, but when she went back to school and she was taught by [the] dinner lady, the quality of life was going down. That's when everything was spiralled, and that's when I had to stop taking [her] to school. Then it took my life back down." (p. 2)*

Family C

Family C – Mother's account described how the closure of the schools impacted her son's academic life.

> *Family C – Mother: "I think he regressed really badly during the lockdown. He was already behind having a neurological condition that affects every aspect of his life, and then now not having any specialist support. It's just he regressed really badly during the lockdown." (p. 10)*

Family C – Mother's explained that due to her son's needs, his school did not offer online learning, and there was no expectation for him to complete the work.

> *Family C – Mother: "So because for him, for he goes to a special school, there was no remote learning, they-- they will not join on Zoom and expect these children to sit down. […] They didn't even, the school was not even doing that." (p. 11)*

In addition, she described her struggles in assuming the role of the teacher as the school did not provide assistance on how to complete the work with her son.

> *Family C – Mother: "And it's difficult because like, you're not, it's not being modelled to you as a parent and how you teach your special needs child. It's not the same thing, you know, no one prepared us for it." (p. 11)*

Subtheme: Physical Domain

Family A

Family A – Mother expressed in her narrative that she and her family engaged in several outdoor activities, however, when lockdown came, she missed some of her regular physical activities that she was no longer allowed to do in a public space, specifically swimming.

> *Family A – Mother: "I mean, I loved the no car noise. You know, that was just so amazing. And I'd love to have that back[...]. But I you know, I would, I missed like going swimming, you know, things like that, that I miss." (p. 12)*

In particular, Family A – Mother explained how the lack of physical activity has significant effects on her children's swimming skills.

> *Family A – Mother: "I think, [it] was interesting 'cause we got swimming, […] you know, they had years of swimming lessons. And, before COVID and then because they didn't, couldn't swim over time. Neither of them can remember how to swim. Very shocking. Like literally we went swimming and Family A –Son 1 could swim really well, and then we went swimming after COVID. [He] hadn't been swimming for two years, turned around and he just dropped like a stone, completely forgotten. Which is interesting, you know." (p. 1)*

Family D

Family D – Son was very expressive in explaining how the pandemic put a stop to his participation in physical activities. He divulged his intentions to join several sporting activities, however, the lockdown restrictions disrupted those plans.

> *Family D – Son: "The only thing I was annoyed about is we did martial arts for a long time before that we did […] we were thinking of quite a few that we were looking at, but they all just got completely shut down over lockdown. And it was sort of the sports stuff I like doing, just going out and playing sports. But you couldn't do any of that in lockdown." (p. 6)*

Family I

Family I – Daughter 1 explained a shift in Family I – Son1's physical activity during the pandemic.

> *Family I – Daughter 1: "So, during the lockdown, the changes that I saw on Family I – Son 1 from a […] physical perspective, it's got less." (p. 5)*

It was evident from Family I – Mother and Family I – Daughter 2’s interview that their physical activity levels were affected due to the pandemic. Family I – Mother expressed how she did not engage in any sort of physical activity. Family I – Daughter 2, on the other hand, mentioned that she did make an effort in incorporating some form of physical activity during the day, however, it was less than usual.

> *Family I – Mother: "To be honest, other than the 10 minutes you heard about, no not at all." (p. 9)*

> *Family I – Daughter 2: "To be honest, I tried, I’m not going to tell you I was consistent with exercising, but I did try to exercise, not 100% of the time, but at least let’s say 70% of the time." (p. 9)*

Family J

Family J – Father’s narrative demonstrated the impact the restrictions had on his family due to the reduction of outdoor activities. He explained how it disrupted their outdoor routines and physical education classes, and how it caused concern that individuals were prone to a sedentary lifestyle.

> *Family J – Father: "We used to go to places like AL Shaheed Park. We used to love to go to many places. Yes, but since COVID started, nothing was to be done." (Family J Family interview, p. 16)*

> *Family J – Father: " There is no school, there is no PE.” (Family J – Father, p. 11)*

> *Family J – Father: " The online life made the society lazy and have a sedentary lifestyle.” (Family J – Father, p. 11)*

Family H

Family H – Mother’s interview demonstrated that the lockdown restrictions affected the family’s ability to engage in physical activities. She emphasised that her children did not participate in any physical activities.

> *Family H – Mother: " Yes, of course yes, because he [Family H – Son 2] didn’t have any sports or physical activity that he used to have before COVID. (p. 8)*

> *Family H – Mother: "Like physical health, no not at all. They did not manage to keep active at all. Especially the older one [Family H – Son 3], not at all." (p.15)*

Family E

Family E - Mother expressed that the lockdown restrictions affected Family E – Daughter's physical well-being, as Family E – Daughter's QoL is connected to her ability in engaging in outdoor activities.

> *Family E – Mother: "For Family E – Daughter, quality of life is bizarre, as too enjoy her life more not being cooped up inside as it at home and she can go out" (p.2)*

> *Family E – Mother: "Physical quality of life, it did [go down] quite a bit." (p. 7)*

Family C

Family C – Mother's interview underscored the frustration she and her son experienced during the lockdown, which affected her ability to find ways to engage him in physical activities.

> *Family C – Mother: "But because there was nothing that we could do physically, other than going for a walk, and ridiculously driving every day, there was nothing like that kind of stimulating physical activity that he could do". (p.5)*

Subtheme: Social Domain

Family A

Family A – Mother expressed how the lockdown had a significant impact to her family's regular social activities. From the extract below, Family A – Mother expressed that it was isolating, specifically for her children who missed their regular activities and friends:

> *Family A – Mother: "It was very isolating. The kids missed their friends. We missed our usual social gatherings. Everything just came to a halt." (p. 6)*

This was also evident in Family A – Son 2's interview.

> *Family A – Son 2: "Umm 'cause I never saw my friends. You know, I've got two friends. What one is called [...] and one is […] another boy. Is called It--it is called […]." (p. 8)*

In addition, Family A – Mother noted how the pandemic impacted her and her husband.

> *Family A – Mother: " Uh, socially. I think it's impacted a lot on myself and my husband." (p. 1)*

Family A – Mother attempted to explore alternative methods to socialise, such as video calls. However, she emphasised how these methods did not feel the same essence as in-person interactions.

> *Family A – Mother: "We tried to do video calls with family and friends. It helped a bit, but it's not the same as in-person interactions." (p. 10)*

Family I

Family I – Daughter 2's interview demonstrated how the lack of socialising during the lockdown made her appreciate her time, however, it did also affect her by causing her to be less interactive.

> *Family I – Daughter 2: "Social life, umm, it made me less interactive, I mean like there is quality, like I appreciate the time out, a lot, a lot a lot." (p. 9)*

Family I – Daughter 2 mentioned how her brother, Family I – Son 1, suffered from the lack of social interaction as it was challenging for him to accept the restrictions:

> *Family I – Daughter 2: "For example, from the social aspect, like he accepted the fact, that there is no car, and you can't go out. This is your space. Deal with it and accept the people around you. Like at the start, he was frustrated and angry most of the time." (p. 4)*

Family J

Family J – Father's narrative demonstrated that there was a sudden shift in his social life due to the pandemic. He explained that his ability to engage in social gatherings was disrupted significantly, particularly because of his job description.

> *Family J – Father: "Well, it was affected. Dramatically. You know, I stopped seeing people. I stopped going to gathering stuff like duwainiyas [Arabic term for social gatherings] and everything. Of course, the gyms were locked." (p. 3)*

> *Family J – Father: "Because like I told you, we have a small family, and I didn't go to many gatherings anyways, I cut myself off because I used to constantly work in the hospital, so, for me, yes, my social life was affected, like I rarely went out and saw people" (Family J family interview, p.23)*

In addition, Family J – Father expressed concern regarding his sons, as he noted that their pandemic experience involved a lot of confinement, particularly his son Family J – Son 1, which resulted in him becoming more antisocial.

> *Family J – Father: " And Family J – Son 1 become. Very, very, I'm not sure how to say it. He became more antisocial. Family J – Son 1, we don't see him, only during lunch time or dinner time." (p. 5)*

> *Family J – Father: "But like if there was no COVID, their social life and mental life will be much better by doing more activities which was cancelled" (p.7)*

Family J – Son 1 explained that he and his brother rarely socialised during their time at home. He noted that there were some occasional moments where he would assist Family J – Son 2 in a game, but their interactions were not frequent.

> *Family J – Son 1: "I think it's just only like very rare moment where I have to [help him] about some game, you know." (p. 2)*

Family G

Family G – Mother's interview outlined how the pandemic resulted in reducing her family's regular social activities. She explained:

> *Family G – Mother: " The boys, I think it's made them more recluse. The little bit of social interaction that they used to have when we used to go to our families and stuff like that, we used to go out and outings, although the middle one is not so bad, he still has his moments where I don't wanna go. I don't wanna go anywhere. I don't wanna do anything. My oldest is. I don't want to do anything I don't want to go anywhere at all. Spends a lot of time in his room. So, they've become, I think, even less social than they were before." (p. 5)*

Family B

Family B – Mother's narrative below noted that the lockdown restrictions significantly reduced the family's social interactions. She highlighted:

> *Family B – Mother: "There was no social life, it was just literally looking after Family B – Son 1, making sure he was okay, looking after the family. There was no social life at all." (p.2)*

In addition, she explained that restrictions impacted her daughter, Family B – Daughter, and her son, Family B – Son 2's social life, as the school closures limited their social interactions.

> *Family B – Mother:: "Yeah I think it did, my daughter's quite, she was, she was already shy, and as I said, it was during the pandemic when she started secondary school, and she doesn't know anybody at secondary school, so that really affected her, she is, she's quite shy as it is and she*

> *finds it hard to make friends, and she was having a bit of a difficulty in school, umm, so yeah it did affect her quite a bit. (p.9)*
>
> *Family B – Mother: "I think they did miss out on like socialising, seeing their friends, going to school, that aspect of it." (p.9)*

Family E

Family E – Mother's extract below described how the pandemic significantly impacted her and her daughter's social activities. She explained how her life prior to the pandemic was very active, but due to the restrictions, she no longer engaged in the same level of activity.

> *Family E – Mother: "Ohh a lot. I'm gonna be honest with you. Before pandemic, I used to go once out once a month, out with my friends for a coffee or used to go out and about myself just to have some free time or have a facial." (p.3)*
>
> *Family E – Mother: "I went to used to grab parties with my daughter. I used to. We did travel a bit. We went to museums. And then afterwards it's just gone, gone completely 0." (p.5)*

Family C

Family C – Mother expressed that even prior to the lockdown, her social life was non-existent. However, she explained that the lockdown restrictions caused her to feel isolated by restricting her ability to socialise. The inability to socialise with family or go outdoors lead to the feeling of isolation, which significantly impacted her mental health.

> *Family C – Mother: "I mean, so my social life, in general was-- was not existent before uh, but it was just that every day, normal things, you know, just being able to go to the park, being able to just do, like, go to the play centres, have play dates, it was just normal everyday thing that you don't think about, that since somehow you kind of take for granted that was just taken away from you, you're not allowed to do that and you just realise how isolating you know it was."(p.3)*
>
> *Family C – Mother: "I can't just, you know, go on a drive and go to my mother's house or go to my grandma's house, umm, so it was like that pure isolation, umm It really did, it really did took a toll on my mental health." (p. 3)*

In addition, Family C – Mother's interview suggested that she relied a lot on her family for extra support. It was seen that the extra support and socialising with family did affect the entire family's social and mental health. Family C – Mother described this feeling by stating that there was an element of guilt and worry from her family they played a crucial role in providing support, and the pandemic disrupted that support:

> *Family C – Mother: "Yes, normally my sister helps me, and she she's got a child as well, so my niece, at the time was two years old and she works so normally it's like I'd either go to her house and she's got a garden and a big space so we can do that […] so we couldn't come together." (p. 6)*

> *Family C – Mother: "In some ways I think there was that element of guilt from my grandmother because she couldn't support us as much, so she would check in and I-- I think it did bother her a lot, because, you know, she's my grandmother and she tends to worry […] there was that element of guilt from everybody, anyways, everybody just kind of was worried about me." (p.6)*

Family F

In the interview, Family F – Mother pointed out that the lockdown restrictions significantly affected the family's social life.

> *Family F – Mother: "Yes yes, it was affected. A lot, it made a difference, a lot." (p. 6)*

Subtheme: Psychological Domain

Family A

In Family A – Son 1's interview it was evident that he had feelings of nervousness caused by the sudden closure of his school. He was particularly concerned about how the sudden closure of the school required his parents to educate him and his twin brother, while managing their own work at home.

> *Family A – Son 1: "Well, it's a little bit nervous about it, because-- we will-- well, we currently have--have to leave school." (p. 1)*

> *Family A – Son 1: "Well, I was a bit nervous at first, because, well, our parents had to teach us, but they also had work to do. They barely get enough time to work." (p. 2)*

In addition, Family A – Son 1 expressed how anxious he was about COVID-19 and the implications of falling sick:

> *Family A – Son 1: "Ohh. I was actually quite anxious. I hate getting poorly." (p. 2)*

> *Family A – Son 1: "Being poorly means no school, no hanging out, no exploring, no nothing." (p. 2)*

Similarly, Family A – Son 2 expressed that the lockdown restrictions brought feelings of anxiety.

> *Family A – Son 2: A bit--a-- a bit anxious." (p. 9)*

Specifically for Family A – Mother, working felt like a respite, allowing her to have a break from the challenges she faced, and it provided her with time for herself. The lockdown restrictions disrupted her routine. In addition, Family A – Mother explained that because of these restrictions, she and her family were confined to their home, unable to interact with anyone, thus adding to her emotional strain and feelings of isolation:

> *Family A – Mother: "It did because I wasn't able to go to work and work for me, going to work is like, I guess, uh, a respite, really […] it's time for myself […], it is my own time and I don't have any of my own time normally. So for me it's a rest and I didn't get to do that." (p. 2)*
>
> *Family A – Mother: "Umm, the emotion was really to do with being isolated, and not seeing people, and-- and it becomes like an echo chamber, your house […] And there was nowhere to go, or no one to talk to about it." (p. 2)*
>
> *Family A – Mother: "Yeah, because […] there was no way to, I mean, you're only escape was to go for a walk at night on your own. That's my only getting out of the situation. And sometimes, yeah, it was very hard." (p. 13)*

In terms of her twin sons, Family A – Mother emphasised the challenges she faced while managing their meltdowns. She explained that they could not handle being confined at home, and eventually she had to transition back to traditional schooling.

> *Family A – Mother: "And the meltdowns are so bad in the end I had to send them to school." (p. 7)*

Family D

Family D – Father explained how exhausting it was to constantly hear negative news about the virus; that the continuous need to reassure himself that things were not as bad as the news made it seem, was difficult for him.

> *Family D – Father: "Yeah, I think it made me quite tired, because you're constantly thinking, um, you know, is the news as bad as it [seems] As it is, and you, you're reassuring yourself that it isn't that, [and] that just doesn't come naturally." (p. 1)*

Family D – Daughter expressed that her QoL during the pandemic was significantly lower compared to her post-pandemic QoL. She explained that she experienced her highest level of anxiety and lowest level of happiness during the lockdown, as she was confined to the home and unable to socialise.

> *Family D – Daughter: "Umm, it definitely-- quality of life feels like it was a lot lower because it's a couple of years of your life where you just couldn't go out anywhere. But it also did show you what the important things are. And so now that we're out of the pandemic, I feel like my mental health is a lot better because I've kind of seen it as its highest in anxiety, and its lowest in happiness, not able to go out and see anybody." (p. 5)*

Family I

Family I – Mother expressed the strain she felt due to the constant need to monitor her children, particularly her son Family I – Son 1, which resulted in sleep disruptions:

> *Family I – Mother: "I don't sleep until the sun rises. If I heard the door open, I'd wake up and leave Family I – Son 1's room and see what is going on." (p. 7)*

To elaborate further, Family I – Mother explained the necessity of seeing a doctor due to her inability to sleep, which led to the doctor to observing the significant weight loss she experienced. Thereafter, the doctor diagnosed her with several health issues and severe depression.

> *Family I – Mother: "He asked me "why are you so thin?", I told him because I don't eat. Like I don't feel hungry. I feel like the food doesn't even go down." (p. 7)*

> *Family I – Mother: "After that, he told me that I am going through severe depression. He did so many tests, and then diagnosed me with depression and low on iron and so many other things." (p. 7)*

Family I – Daughter 1 also expressed her fear of uncertainty regarding the pandemic. Additionally, she elaborated how once she adjusted to pandemic's restrictions, she then began to feel frustrated and bored of being confined at home.

> *Family I – Daughter 1: "At the start I was scared, very scared. Didn't know what's going to happen, what are we going to do. Also, school, it shifted, and it became online, so this was all new to me, I didn't know what to do, I didn't know if I will accept it. And then after, way after,*

> *when we adjusted and accepted it, I started getting bored of it all, frustrated too, and even when I started feeling this way, I couldn't go out. So, we all had to stay at home, live with each other and just live with it." (p. 3)*

Regarding her son Family I – Son 1, Family I – Mother explained how he used to go out every day prior to the pandemic, however, during the pandemic, he was not allowed. In addition, post-pandemic, she remained concerned about his safety, limited his outings, and to ensure his safety, she would take extra precautions.

> *Family I – Mother: "Of course, yes. Because he used to go out every single day, literally every day. So, like, even when the lockdown was over, he didn't go out much, I was worried, so I didn't let him go out much." (p. 3)*

> *Family I – Mother: "I'd always make sure with the driver, please wash your hands, please sanitise the car, please help him when he is out. When he comes back home, we make sure he is clean and sanitised." (p. 3)*

Family I – Daughter 1 conveyed that she felt that Family I – Son 1 did not fully comprehend the severity of the pandemic or the restrictions. She explained that he would also experience feelings of boredom and frustration, often screaming and attempting to open the door to go outside.

> *Family I – Daughter 1: "So obviously he, he doesn't and he's not able to understand and acknowledge what's happening [...] some days he would just get too frustrated and too bored [...] He wants to go out so he might start screaming and like trying to open the door." (p. 5)*

Family J

Initially, Family J – Son 1 did not expect that the pandemic would last as long as it did. However, as the situation progressed, he began to feel shaken up.

> *Family J – Son 1: "Sounds like a, oh-- okay, okay. I just did not know much about the-- about the virus at first, but as soon as [it] just start[ed] spreading more and more wide, [it began] turning into a pandemic. That kind of got me a bit shook up." (p. 1)*

> *Family J – Son 1: "Yeah, it's basically like a really dangerous virus at this point." (p. 1)*

Both sons expressed concerns about their father's health, given his career as a physician. His father's job role increased Family J – Son 1's anxiety, and Family J – Son 2's worry, as his exposure to patients with COVID-19 posed to be a major risk to his health.

> *Family J – Son 1: "I think you're see, the how my dad, as a physician, as he, as he's going to the hospital with, you know. You know, helping, helping people. Of course, of course. I had that small anxiety in my mind where, where, other either he's gonna get sick, sick or not from the coronavirus. So, I was just praying that he'll, he'll be good." (p. 1)*

> *Family J – Son 2: "Yes, definitely. Honestly, it has been on my mind for a long time. I was like, I was afraid because you know him being a physician and, you know, being around people with COVID made me afraid he would come home with the virus." (p. 1, Family J – Son 2)*

In addition, Family J – Son 2 highlighted a particular concern about the possibility of losing his loss of smell and taste due to COVID-19’s symptoms.

> *Family J – Son 2: "What I was most worried about [with] COVID is the fear, the losing of your sense of smell and taste. That was what I was afraid of-- that." (p. 1)*

Family J – Father reported on a surprising behaviour in his son Family J – Son 2; he mentioned that when he would go out, Family J – Son 2 would call him and ask about his whereabouts. Family J – Son 2 expressed that his father leaving the house caused feelings of concern and worry as he feared something might happen to his father.

> *Family J – Father: "Surprisingly. Family J – Son 2, when I go out without telling him, I want to go out, he calls me. And he says,” where are you” […] He still do it." (p. 3)*

> *Family J – Son 2: "And I call you because I keep having these dark thoughts [in] my mind. Oh shit. Something happened what if something happened." (Family J Family Interview, p. 3)*

Family J – Father was very explicit in his interview about his quality of life. He expressed that he experienced depression during the pandemic and the level of his mental health still remains uncertain. He mentioned that there is a lingering fear inside him. In addition, he noted how his disastrous his sleeping patterns were.

> *Family J – Father: "Mental health … Honestly, I had a period of depression. More than one year. Now I'm just adjusting. Just keeping my mental health clear as much as possible. But, like you know, I still sometimes feel, like ever since COVID, up until now, I think my mental health is still unsecured. I think there is something wrong with [me], as I told you, the fear inside me, there is still something." (p. 4)*

> *Family J – Father: "Sleeping well. Sleeping was a disaster." (p. 2)*

Furthermore, Family J – Father noted his concern and fear for his children. He expressed that he was apprehensive about being able to provide for his family during the pandemic, which was significantly difficult for him.

> *Family J – Father: "Emotionally… Well, I remember that time, emotionally I was concerned and like [a] little afraid. Let's say, uh, in general, I was half concerned and afraid, Okay? So, I'll focus on afraid. You will ask me. "You're afraid of what?" I'll tell you. Afraid of what? As a father, [it] was a full-time job. During a period that most of the people didn't go to work, okay. Uh, I had a difficult time, okay? And very concerned about, you know, about providing the basic needs for my children, for my family, like food, stuff, and something like this, you know, because, whenever you are, let's say in the-- put example, okay, if you wanna go to the supermarket, okay, there was a time you had to take an appointment." (p. 2)*

Family H

Family H – Mother emphasised her concern about her son Family H – Son 2's psychological well-being. She explained how he consistently felt upset and eventually reached a point where he couldn't bear the lockdown restrictions anymore.

> *Family H – Mother: "His psychological health yes, very much yes [...] he was always not in a good mood and he's the type that does not like to use or play with electronics, he always wants to go out [...] he was not doing well psychologically. He showed that he reached to a point of […] [having] enough." (p. 4)*

Family G

Family G – Mother expressed her concern for her son Family G – Son 1, explaining that as a result of the lower social interaction that he experienced during the lockdown, he began preferring his own company, resulting in him intentionally isolating himself in his bedroom.

> *Family G – Mother: "I think it's like I said, it's made him going [go] to his shell more. He's actually adapted to being even more unsociable or, suppose, um, he prefers his own company, prefers to stay in his room all day." (p. 12)*

In addition, she discussed how her quality of life is low due to her health concerns. She explained that due to the lockdown, she struggled with hospital visits and hospital cancellations.

> Family G – Mother*: "My quality of life at the moment is not very good because of my health." (p. 3)*

> Family G – Mother*: "My mental health has always been bad, but I think it probably-- it probably was a lot more because, I was due to have a hysterectomy before the the […] I've planned all these things and then for it to turn to cancelled it did […] make a big impact on. My mental health, I was already taking antidepressants." (p.9)*

Family B

Family B – Mother's interview highlighted the considerable negative effects that the lockdown restrictions had on her son Family B – Son 1. She explained that the sudden disruption to his routine led to aggression, self-harm and meltdowns:

> *Family B – Mother: "That was hard with Family B – Son 1, because he likes his routine, was a massive struggle... He was really hitting himself, you know getting aggressive, and he just wasn't coping [...] soon as the lockdown happened he was like everything for him was just up here [Hand gesture], meltdowns more, he just wasn't himself basically." (p. 2)*

In addition, Family B – Mother expressed her concern for Family B – Son 1's quality of life. From her extract below, it is evident that Family B – Son 1 was regressing, however, she explains that once the restrictions were lifted and he was back at school, his meltdowns were less.

> *Family B – Mother: "For me, it was Family B – Son 1 basically, because he's, him regressing him getting more angry because we were at that stage where he was enjoying school, he was enjoying [his] routine and his meltdowns were, he was still having them, but they weren't as much as they used to be." (p. 2)*

Family F

Family F – Mother felt concerned while observing the psychological toll the pandemic had on her children. She explained that the sudden change in their life led to feelings of depression.

> *Family F – Mother: "Like I feel like 100% he was depressed too, just like his brother, but his brother is able to communicate, and he can't, but I feel like he felt the exact same way. Like "mama we are bored, what will we do?", so like they feel the same." (p. 5)*

Family C

Family C – Mother discussed her pre-existing struggles with depression and anxiety prior to the lockdown. However, her narrative demonstrated how the pandemic triggered her, increasing her depression and anxiety, leading her to binge-eat to cope.

> *Family C – Mother: "For someone who struggles with depression and anxiety [...] it really did took a toll on my mental health." (p. 3)*

> *Family C – Mother: "It triggered, it triggered a lot of binge-eating, which I'm still finding it hard to break that habit because that was all I could do, you know, there was like, not really much. So, I would eat my feelings away and I did start a lot of binge-eating habits that I have not yet broken. So, it did, it really did, did took a massive effect." (p. 4)*

Family E

Family E – Mother's account describes how she was significantly concerned for her daughter due to the rapid change in their lifestyle during the pandemic.

> *Family E – Mother: "My main concern was "what's gonna happen to Family E – Daughter? Who's gonna look after Family E – Daughter, because will I be able to work full time? Will it be, if I'm not working from home?" That was my main concern and, you know, what will happen Family E – Daughter being in lockdown. You know her health, coronavirus and everything. That was my main concern." (p. 2)*

To be more precise, she expressed her struggle to contact people and ask for help, mentioning feelings of embarrassment.

> *Family E – Mother: "I had nobody to contact. I couldn't even talk to my colleagues because I feel embarrassed and [I'd worry] they got upset, that why didn't I tell them." (p.11)*

6.3 Cross-cutting Themes and Patterns

6.3.1 Overview

In the midst of the COVID-19 pandemic, the family quality of life for families with children diagnosed with ASD experienced substantial changes. This section provides the reader with a cross-case analysis of the intricate experiences of diverse families, each presenting a distinct narrative, yet they are bound by similar challenges and coping mechanisms. Family B – Mother's account highlights the emotional chaos, describing her time as "a nightmare, I never want that to happen again", emphasising the importance of maintaining a routine for her child (Family B – Mother, p.1). Similarly, Family F – Mother's narrative vividly portrays the challenges she encountered, particularly in attending her son's needs (Family F – Mother, p.5), echoed by her son's feelings that the restrictions caused boredom (Family F – Mother, p.4). Family J, on the other hand, faced the social ramifications of the pandemic, with social gatherings and plans being cancelled, a sentiment reiterated by Family J – Father's yearning for social gatherings (Family J – Father, p.3). Family A – Mother faced challenges with online learning, explaining the technological difficulties of accessing the material, as well as her sons' difficulty with concentrating and refusal to sit and study (Family A – Mother, p.7). Family I – Mother's narrative emphasised the significance of family unity, an outlook echoed by her daughters as they faced the challenges amidst the COVID period (Family I – Daughter 2, p.4; Family I – Daughter 1, p.2). Lastly, Family C – Mother's interview offers insight into the challenges she encountered, particularly regarding her son's routines (Family C – Mother, p.2) and the lack of external support (Family C – Mother, p.3). As this cross-case analysis progresses, it aims to intertwine the family member's narratives, providing a comprehensive understanding of the shared and unique experiences of these families during the global pandemic.

6.3.2 Academic Domain

Subtheme: Unfamiliar academic methods

The Academic Domain during the global pandemic endured a drastic transformation, especially for families of children diagnosed with ASD. As educational institutions transitioned to online learning due to the lockdown restrictions, families found themselves in the midst of a significant change. Throughout the interviews conducted, a shared narrative between the families emerged. These narratives emphasised the difficulties the family members encountered when adopting unfamiliar academic methods. These difficulties included a lack of traditional school environment, lack of support from school, adapting to online learning and balancing work and school.

Family members had to adapt to new roles that they did not anticipate. Beyond being caregivers or siblings, they became teachers and supporters of each other. Family A – Mother's account described the struggles she and her husband encountered as they tried to manage their work life and their sons' education "They did try to do online learning, but it was very difficult. I mean, it was just impossible. I mean, I was working from home. My husband was trying to do his job." (Family A – Mother, p.8). This resonated with a couple of families who experienced the unprecedented territory of navigating their own work commitments and managing their children's education. Alongside this, while some families transitioned seamlessly to digital platforms for educational resources, others faced technological challenges and barriers, and were unable to adapt to new methods of learning. Family A – Mother mentioned her sons' inability to sit and engage with the online curriculum, thus leading her to create her own curriculum. Their home, traditionally a place for relaxation and comfort, was transformed to both a living area and a learning environment. Family D – Mother's narrative of trying to provide an adequate environment at home for her children's education (Family D Family interview, p.46) highlighted the various challenges families faced. The role of a parent changed from a supporter to an active participant in their child's educational life. In addition, certain schools opted to not provide online learning, due to the awareness that some children may struggle to engage with the digital platforms and online material. Alternatively, schools distributed educational packets to families, allowing the children to learn from home, and the parents assumed the role of the educator during the pandemic. However, Family C – Mother's narrative clarified their school did not put pressure on families to complete the educational packets. She mentions that "there was no pressure to do schoolwork because it was not like, or it's marked or it's it's like it's monitored." (Family C – Mother, p.11). Her narrative highlighted her difficulties in educating her son, as she felt unprepared to assume the responsibilities of a teacher.

Subtheme: Disruptions to social life

The setbacks were not just associated with the technological and curriculum aspect, though. The Social and Psychological domains were also impacted by the pandemic on the Academic Domain. An evident example is Family A – Mother's son, Family A – Son 2 (Family A – Son 2, p.7). For Family A – Son 2, the academic aspect was not solely about education; it also was a place intended to foster social interactions and relationships. His statement, "'Cause I never saw my friends. You know I've got two friends." (Family A – Son 2, p.7), clearly identified the role a traditional schooling system has on a child's life, outside of academics. This viewpoint was shared by some families who highlighted the vital role that the academic domain serves in a child's social life, along with educational learning. To be more specific, Family J – Father's narrative painted a vivid image of the drawbacks of online learning. His account, "They become more bored. More bored, [but] not because they don't like school, Family J – Son 2 and Family J – Son 1 love to go to school and see their friends." This highlighted that his sons preferred a traditional learning environment and social interaction with their peers.

Subtheme: Parental involvement and adaptability

Despite these challenges, there were positive impacts. Family E – Mother's account of providing more quality time assisting her daughter with her academics (Family E – Mother, p. 1 - 2) highlighted the opportunities for significant parental involvement and bonding time. Some families also demonstrated adaptability, by creating educational environments at home and implementing routines to reflect the traditional learning environment that their children were accustomed to. This was evident in Family A – Mother's narrative (Family A – Mother, p.3). For Family A – Mother, adapting to the school's curriculum was challenging for her family. Therefore, she accessed her brother-in-law's online math tutoring classes and worked closely with her children. Her account "So I started to do tutoring that online, one to one, tutoring in maths. And, he went from, umm, no maths, to a reasonable math skill, during that time" (Family A – Mother, p. 3). This statement highlighted that working closely, and becoming more involved in her children's education, led to an improvement in the academic domain.

When comparing the family's perspectives from their interviews, it has become evident that the academic domain had the most significant ramifications of the COVID-19 pandemic. Families had to confront a complex array of challenges and were required to be adaptable and flexible, highlighting the resilience of some family members and the role of the education within their lives.

6.3.3 Physical Domain

Subtheme: Disruptions to Routine

A noteworthy concern for families during the pandemic was the Physical Domain, which includes physical health, consistent daily routines, and day-to-day outdoor activities. There was a consistent pattern between families that emerged of disrupted daily routines and the significant efforts to establish a new normalcy. Family C – Mother's emphasis on the significance of having a routine for herself and her son, stating "I prefer [a] life where we have routine." (Family C – Mother, p. 12), resonated with many families who also found solace in routines during times of struggle. This emphasis was not exclusive to school routines but also included encompassed traditional day-to-day outdoor activities. Family H – Mother pointed out how her son's physical health was affected during the lockdown, as his usual daily routine of outdoor activities was abruptly halted (Family H – Mother, p.8). Due to social distancing restrictions, families were mandated to be at home; Family H – Mother noted that being outdoors generated excitement and motivation for her son to be physically active, which their home environment lacked (Family H – Mother, p.8). Similarly, Family E – Mother explained that the restrictions impacted her daughter's physical well-being, as her daughter's QoL was closely connected to her participation in outdoor activities (Family E – Mother p.3). Therefore, for these families, when the restrictions were put in place, the QoL and physical activity of the families were affected simultaneously.

Subtheme: Low levels of Physical Activity and Sedentary lifestyle

The lockdown restrictions not only led to school closures, they also instigated a transition for families to work from home. This often resulted in a blending of the Physical and Academic domain for the children. Family D – Mother pointed out that online learning required creating spaces at their home dedicated to learning and adapting to the new norm (Family D Family interview, p.4). These setbacks were not exclusive to the Academic Domain. Family J – Father noted that the lockdown led to the absence of PE classes causing a major concern, as he reflected that this led to a sedentary lifestyle for his sons (Family J – Father, p.5). Family I – Mother narrative further demonstrated the complex essence of the Physical and Psychological Domains, as she spoke of sleep deprivation and its consequential impact on her emotional well-being (Family I – Mother, p.7). This complex essence was further proven as some families struggled to maintain physical activity during the pandemic. The lack of outdoor activity emphasised in Family E – Mother's interview regarding her daughter, demonstrated the palpable physical pressure the pandemic led to (Family E – Mother, p.7). Another example of this essence would be when Family C – Mother spoke of the absence of daily activities, underscoring how the lockdown directly triggered her physical and psychological well-being (Family C – Mother, p.3).

Subtheme: Adapting to Restrictions

A pattern of adaptability, creativity and resilience was established while analysing the insights provided by some families. Some families manoeuvred the extremely disrupted routines and challenges brought by the pandemic with adaptability, creativity, and dedication to ensure a healthy physical and mental well-being. Family I – Daughter 1 and Family I – Daughter 2's account of partaking in regular physical activity and TikTok dances (Family I – Daughter 1, p.3 and Family I – Daughter 2, p.2) emphasised the prioritisation of physical activity, preventing physical health from being overlooked. In addition, this was further demonstrated by the how Family F – Mother navigated the disruption of routines by uprooting her family to her mother's house (Family F – Mother, p.3). This approach allowed Family F – Mother to feel less concerned about her children, and they would establish a structured routine and engage in physical activities with their cousins.

When analysing the families' insight, the Physical domain is evidently the most challenging domain that required the most adaption. Families faced the disruptive brunt of the pandemic with unprecedented methods, demonstrating creativity, adaptability and dedication to ensure physical health.

6.3.4 Social Domain

Subtheme: Restricted Social Interactions

During the pandemic, the Social Domain emerged as one of the most impacted quality of life domains, particularly due to the enforced social restriction measures that fundamentally restructured the nature of socialising. It was evident that families experienced a sense of loss and a desire for the social interactions that had defined their daily life prior to the pandemic. Family C – Mother's narrative, "it was just that every day, normal things, you know, just being able to go to the park, being able to just do, like, go to the play centres, have play dates" (Family C – Mother, p.3), resonated with other families, as it echoed feelings of oppression within social contexts. This restriction was particularly perceived by the children, who are normally in the midst of social interaction via school, outdoor activities and play dates. Family A – Son 2's phrase, "'Cause I never saw my friends. You know I've got two friends” (Family A – Son 2, p. 8), highlighted the longing of social interaction and the impact of the void in the social domain.

Subtheme: Adaptability and Acceptance

When analysing the family members’ insights, the social domain during the COVID-19 pandemic emerges as an insightful illustration of an individual’s desire for human interaction. While the pandemic presented uncommon measures, families navigated these unprecedented territories with acceptance, adaptability and commitment to preserve essential social bonds. Despite the restrictions, a couple of families have shown resilience and acceptance in the face of the pandemic’s hardship. Family J – Son 1’s narrative of virtual social interaction (Family J – Son 1, p.2) and Family D – Mother’s approach of participating in virtual quiz nights between family members (Family D Family Transcript, p.4) demonstrated the innovative techniques families sought to ease the struggles caused by the lockdown restrictions. These restrictions, in a way, accelerated the path to a virtual social innovation, with family members shifting to virtual interaction to compensate for the lack of traditional socialisation. In addition, members of several families aimed to recreate innovative forms of social interactions within the confines of the pandemic’s restrictions. Family A – Mother’s approach in partaking in long outdoor family walks (Family A – Mother, p.8), and Family I – Daughter 1’s approach in participating in virtual applications to socialising with friends, as well as hosting movie nights with her sister and mother (Family I – Daughter 1, p. 3 - 5), demonstrated the ability to find joy, family bonding and connections amidst the challenges brought by the pandemic.

Subtheme: Developmental setbacks

This domain was particularly challenging for the children, both typically developing and autistic. The sudden closure of schools, leisure centres, outdoor activities and playdates, led to an abrupt separation from the children’s social circles. Family B – Mother’s narrative about her daughter, “it was during the pandemic when she started secondary school, and she doesn’t know anybody at secondary school, so that really affected her” (Family B – Mother, p.9), highlighted the sense of disconnection her daughter felt from her peers as she transitioned back to school as a secondary student. This was not just an account of children missing friends, it was about the absence of a crucial phase of the children’s social development. This development phase encompassed the children’s loss of opportunity to learn how to build interpersonal relationships, rapport and to share memories.

Subtheme: Social isolation

The Social Domain experienced profound transformations during the pandemic, which revealed vulnerability within social relationships. The social distancing restrictions inflicted significant impacts on the families of children with ASD. Family F – Mother's depiction of her struggles, not only with the isolation but also with observing her sons' social life diminish (Family F – Mother, p. 4 – 5), distinctly demonstrated the multifaceted challenges experienced in the social domain. This, in turn, concocted emotional and psychological challenges as a result of social isolation. Family C – Mother's comments, "being a parent who's got a child with special needs can be a very lonely way of parenting because your child doesn't talk to you, so, I'm a single mom and the only other person in the house is a child who doesn't talk to me, and the world is in a lockdown. I can't just, you know, go on a drive and go to my mother's house or go to my grandma's house, umm, so it was like that pure isolation" (Family C – Mother, p.3), highlighted the distinct absence of connections and support systems – when these were gone, she was very much affected by the lack of community. This was also evident in Family A – Mother's narrative. Family A – Mother's account of "I struggled, um, with loneliness" (Family A – Mother, p.5) demonstrated the impact of self-isolation.

Based on the families' accounts, the social domain during the pandemic narrates a story of repression, acceptance, adaptation and flexibility. It emphasises the intrinsic human desire of connection and the lengths families took to maintain their social connections, despite the unprecedented restrictions they encountered.

6.3.5 Psychological Domain

Subtheme: Emotional disturbance

The psychological impact of the pandemic was apparent across all families, which created a perplexing narrative of emotional and psychological distress, acceptance and resilience. In Family B – Mother's account of the COVID-19 period, she said "it was a nightmare, I never want that to happen again. It [has] been a real struggle, especially with Family B – Son 1. It was like the worst nightmare ever" (Family B – Mother, p.1), honestly expressed the feeling of emotional distress, a sentiment that was collectively shared between all families. This emotional disturbance was not only exclusive to the parents, the children were also made to adapt to the sudden change and the impediment that came alongside it. Family I – Daughter 2 and Family I – Daughter 1's account of their strengthened bond, between them and their family members during the lockdowns (Family I – Daughter 2, p,4; Family I – Daughter 1, p.5), highlights the emotional disturbance families endured, particularly when Family I – Daughter 1's narrative explained "Getting closer to my siblings […] It became a coping mechanism" (Family I – Daughter 1, p.2). The challenge of maintaining emotional well-being was multifaceted and difficult. Families were presented with unprecedented challenges and struggles. This was illustrated with Family J – Father's narrative who grappled with the struggles of cancelled plans and commitments for his sons' routines and the consequential emotions of disappointment (Family J – Father, p.7), while Family I – Mother's diagnosis of "severe depression" (Family I – Mother, p.7) clearly emphasised the significant impact the pandemic had on families and their mental well-being. The strength of familial bond was tested throughout the challenging period brought by the pandemic. Family F – Mother's narrative during the interview emphasised how crucial family support is in her life, specifically in maintaining both of her sons' needs (Family F – Mother, p.2), and Family D – Mother's confirmation of the benefits of "coming together" (Family D – Mother, p.3) highlighted the importance of family as an anchor during challenging times. Essentially, the psychological well-being of the families were demonstrated though an array of challenges and coping mechanisms, following by strong familial bonds, inspiring hope and strength.

Subtheme: Challenges During School Closures

As the lockdown measures were introduced, families were made aware that schools were transitioning to online learning; this shift presented a disruption for families to adapt to. At the core of these disruptions were psychological impacts; impacts that were shared between families. Family A – Mother's description of the challenges she faced with the closure of schools, "the meltdowns are so bad [that] in the end I had to send them to school" (Family A – Mother, p.7), did not reflect her own views. This was also evident in Family B – Mother's narrative, where she expressed feelings struggle, "He was really hitting himself, you know, getting aggressive, and he just wasn't coping" (Family B – Mother, p.2), emphasising the emotional turbulence the families experienced as a result of the closure of schools during the pandemic. This sentiment was also shared with Family A – Mother's son's report on his view on school closures. He reflected nervousness, "Well, I was a bit nervous at first, because well, our parents had to teach us, but they also had work to do. They barely get enough time to work." (Family A – Son 1, p.2), expressing concern on his parents' ability to educate him and his twin brother. Yet, for Family J, the pandemic's restrictions created a sense of relief for Family J – Son 2, he expressed "I was happy because, you know, first they said alright, no school for two weeks, then [it] kinda escalated. Then we basically had no school for like the year, and that was amazing." (Family J – Son 2, p. 7).

Subtheme: Parental Job Roles and the Family's Concerns

One apparent impact was also shared in children's narratives of their concern regarding their parents' job roles during the pandemic. Family J – Son 1 and Family J – Son 2 reflected concerns about their father, as he was a physician. The description of anxiousness and concern was additionally demonstrated in Family I – Daughter 1's account, reiterating concern "because he's a doctor" (Family I – Daughter 1, p.8), adding further stress to the psychological impact of the pandemic. This was also demonstrated in Family F – Mother's narrative regarding her job role. She reflected "I go to work, I come back home, I'm scared, I stay away from my kids" (Family F – Mother, p.2), expressing feelings of fear and anxiety compelling her to maintain distance from her children to minimise the risk of potential virus transmission.

When analysing these key insights, it's evident that the pandemic brought significant emotional setbacks for families. Despite these setbacks, families demonstrated strength and resilience, and received support from their loved ones. The psychological impact was faced with strength, hopelessness was countered with faith and confinement led to strengthening familial bonds.

6.4 Synthesis

The extensive impact of the COVID-19 pandemic, as shown in the narratives of the families, provides a profound exploration into the shared effects that the pandemic had on individuals and families. This included the challenges they came across, the ways they adapted to new circumstances and the resilience in overcoming hardship. A unanimous expression of a disrupted life was resonated across all families. Family C – Mother's poignant observation, "he was really in need of some routine and there was nothing I could do about that" (Family C – Mother, p.4), encapsulated the shared feelings of disruption, a sentiment echoed by Family A – Son 1's lamentation of the pandemic's disruption: "Being poorly means no school, no hanging out, no exploring, no nothing" (Family A – Son 1, p.7). These statements suggest that despite the challenging families faced, the shared experience of disturbance fostered a collective sense of understanding and empathy among the families.

Yet, as families navigated through this challenging time, it became evident that the different quality of life domains discussed were closely intertwined. Family I – Mother's narrative highlighted this connection, where sleep destitution not only impacted her physical health but also affected her psychologically, leading to a diagnosis of depression (Family I – Mother, p.7). Similarly, Family A – Son 2's yearning for school highlighted that traditional school was not exclusively a centre of education, but also a focal point for social interactions, as he expressed, "'Cause I never saw my friends" (Family A – Son 2, p.8).

Amidst the challenges, the families' resilience and adaptability was demonstrated. Family E – Mother's innovative efforts to engage with her daughter in indoor activities (Family E – Mother, p.6), Family D – Mother's embrace of virtual quiz nights (Family D Family interview, p.4), and Family I – Mother's movie night with her daughters (Family I – Daughter 1, p.5), stood as examples of how some families had the ability to adapt and find happiness during difficult times. Additionally, this period led to families strengthening their bonds together. While the pandemic restricted their social interactions, families were accustomed to spending more quality time together, deepening their relationships and creating more memories.

The pandemic also revealed socioeconomic disparities among families. While some families were able to transition to online platforms without much difficulty, others encountered challenges due to technological challenges or external support constraints. This disparity sheds light on a wider societal implication of the COVID-19 pandemic. Yet, despite encountering significant challenges, some families expressed a sense of optimism. They recognised the difficulties they faced but also spoke about the positive aspects, highlighting lessons learned and strengths discovered, hoping for a better future post-pandemic.

When examining the families' narratives, common themes emerged. The core narrative displayed is one of shared challenges, unified resilience and maintaining a sense of hope. Despite each family's unique experience, their narratives are interconnected and offer insights into a broader societal experience during the pandemic.

6.5 Negative Cases and Anomalies

This section will provide the reader an exploration of the instances where the impact of the pandemic on the FQoL domains diverges from the predicted patterns observed in the main results. Despite the overarching themes identified above, the cases below will highlight the unexpected outcomes and provide clarity and valuable insights into the varied experiences of the families during the COVID-19 pandemic.

6.5.1 Case 1: Varied Experiences among Higher-Functioning Families

Based on the results above, it has been observed that some families with higher-functioning autistic children shared experiences that diverged from the predominant finding observed. Despite acknowledging struggles and low levels of FQoL, these families demonstrated significant adaptability and ease compared to experiences of families with lower-functioning children. During the interviews, parents of higher-functioning autistic children and their children noted they were coping significantly better with the transition to online learning. Family J – Father explained "I think the online thing, yes, it was good for them for a reason. They used to type and chat, you know, on the laptop and the iPads. So, the typing thing was easy for them to solve." (Family J Family Interview, p.25). Similarly, Family D – Daughter noted that "the pandemic did very negative things to him

[Family D – Son] in school but did very positive things when he left because it was also one of the primary reasons [that] he left school.” (Family D – Daughter, p.6). Compared to families with lower-functioning autistic children, higher-functioning children exhibited a notable ability to adjust to the changes and disruptions to their routines brought by the pandemic’s lockdowns. In addition, the social experiences that the higher-functioning families encountered differed from the lower-functioning families. Their ability to communicate their experiences in the interviews allowed for a more distinctive understanding of the impact that the pandemic had on the social domain. While the lockdown restrictions have limited their social interactions, the families expressed a preference of abiding at home and reported lesser stress levels than when socialising. This was evident in Family D – Father’s narrative, as he explained “I think socially as a family group we, you know, we were really strong, and it was, it was really nice as a family. But the wider social group, I think we've, we’re, so you know, we're so kind of insular. Anyway, it didn't make much of a difference” (Family D – Father, p.2). Similarly, Family J – Son 2 pointed out “Honestly, when they said there will be a lockdown like, okay, I like being introverted anyway.” (Family J – Son 2, p.1). It was made apparent that their familiarity with digital platforms and their preference with solitary activities diminished the impact of the social domain on their QoL.

The contrasting encounters of families with higher-functioning children provides insight into the intricate impact of the COVID-19 pandemic on their FQoL. Despite facing difficult challenges and noting low levels of QoL, the contrasting encounters demonstrated that the severity of these challenges seemed to be diminished by factors such as the autistic’s child’s level of functionality. In addition, the absence of aggressive behaviours or evident disruptions to the drastic changes in the children’s daily routines, suggests a level of versatility and resilience that may not be noticeable among the lower-functioning autistic children. This anomaly highlights the significance of considering levels of functionality and individual differences among autistic individuals when exploring the impact of the pandemic on FQoL.

The significance of these results prevails in their capability to dispute assumptions regarding the homogeneity of experiences among autistic children during the pandemic. By recognising the contrasting encounter of the families, this allows for further understanding of the dynamics between levels of functionality, impact of the pandemic and the FQoL. Various factors could have come into play for the relatively smoother experience observed among the families with higher-functioning autistic children. This could have been access to additional support or resources, pre-existing coping strategies, and access to early intervention. These tactics could have contributed to ease the children’s experiences with the challenges brought by the pandemic. In addition, the child’s diagnoses, and their level of functionality could have had an influence on their response to the lockdown restrictions.

6.5.2 Case 2: Struggles and Resilience among Single Parents

Single parents of children with autism encountered unprecedent challenged during the pandemic, significantly impacting their FQoL. Unlike households of two parents, single parents often assume the sole responsibility of taking care of their children’s well-being, leading to specific challenges. During the interviews, single parents noted high stress levels, depression and exhaustion compared to the other families interviewed. More specifically, some single parents were required to work outside of their homes, due to their job roles, as they did not have the option to work remotely. The combination of single parenting and their job roles contributed to a sense of overwhelm and low levels of QoL. This was evident in Family F – Mother’s narrative, as she noted “I was so upset, like seeing people not wanting to talk to me or come close to me, just because I had to go to work. Like, what can I do, I had to go. Like it, affected me badly” (Family F – Mother, p.5). In addition, Family C – Mother explains “being a parent who's got a child with special needs can be a very lonely way of parenting because your child doesn't talk to you, so, I'm a single mom and the only other person in the house is a child who doesn't talk to me” (Family C – Mother, p.3).

Despite these struggles, single parents demonstrated noticeable determination and adaptation during the pandemic. In their narratives, the single parents managed to seek external support, prioritised their children’s needs and demonstrated strength and resilience during the pandemic. More specifically, Family E – Mother’s narrative elucidated that the lockdown allowed her to work more closely with her daughter, which she noted was beneficial for the both of them. She explains, “I used that opportunity to do speech therapy and occupational therapy, and it was great” (Family E – Mother, p.13).

The narratives demonstrated in the interviews highlight the intertwined challenges of parenting and employment during the pandemic, with the implications to the FQoL. Balancing work and single parenting duties imposed considerable strain, resulting to high levels of stress and low levels of FQoL. In addition, the absence of a two-parent support system meant that single parents did not have the emotional support provided in a two-parent household. Their narratives highlighted the importance of social support and community in mitigating the impact of the pandemic on FQoL. However, the resilience demonstrated by the parents underscores their ability to adapt during challenging times. Despite the hurdles they faced, the single parents' narratives showcased their commitment to their children's QoL as well as willingness to seek resources and external support to address their children's needs.

6.6 Conclusion

This chapter delved into multifaceted impact the pandemic had on the quality of life of families of children with autism spectrum disorder. Chapter 6 included a thematic analysis, cross-cutting themes and negative cases and anomalies. The analysis unveiled an intense tapestry of distinct yet similar journeys, highlighting the various ways in which families adapted and navigated through the struggles and challenges brought by the lockdown restrictions. The thematic analysis demonstrated two overarching themes exploring the pandemic's impact, encompassing the Academic, Physical, Social and Psychological domains of the FQoL.

Within the Academic domain, families encountered the abrupt shift to online learning, with varying levels triumph and adjustment. Some families faced barriers in adjusting to online learning, while others used this experience to work more closely with their children. The Physical domain revealed challenges ranging from sedentary behaviours and limited outdoor activities to opportunities for prioritising health and creative solutions to maintain physical activity in outdoor activities and family bonding. Within the Social domain family members encountered social isolation and disruptions to social gatherings and routines. However, most families, amidst the barriers, found comfort in socialising within their family and strengthening their bond. Lastly, the Psychological domain elucidated the emotional toll that the families faced, with heightened stress levels, concern levels and depression, reported by the families. Families were confronted with sentiments of isolation and uncertainty, with some family members experiencing significant changes to emotional health and coping strategies. The identification of negative cases provided further insight into the distinct experiences families encountered during the pandemic. Case 1 indicated the varied report among families of higher-functioning autistic members, underscoring the emphasis on levels of functionality and adaptability in responding to the disruptions brought by the pandemic, to their FQoL. Case 2 demonstrated the challenges and struggles encountered by single parents, highlighting the intertwined pressures of parenting and employment amidst the pandemic.

To conclude, this chapter offers a detailed analysis of the impact of the pandemic on QoL of families of children with ASD, revealing the challenges and resilience in navigating through a pandemic.

6.6.1 Limitations

Despite the insights this study provided on the impact of the pandemic on FQoL, some limitations are acknowledged below.

Limited Interviews with Lower-Functioning Autistic children

An evident limitation of this study is the small number of interviews conducted with children diagnosed with autism, particularly lower-functioning autistic children. The effort was made to include a diverse range of families, however, difficulties in communication and concentration of the children limited the depth of insights gained from the participants. Future research should consider the inclusion of lower-functioning autistic children to allow for a further thorough understanding of the families’ experiences during the COVID -19 pandemic.

Limited Interviews of Other Family Members (Fathers)

Another evident limitation of this study is the underrepresentation of interviews conducted with other family members, specifically fathers. The interviews provided a focus primarily on maternal perspectives, yet, the inclusion of fathers or other family members could provide invaluable insights into diverse experiences in FQoL within the family. Future research should consider the inclusion of other family members to allow for a broader range of experiences and perspectives during the COVID-19 pandemic.

CHAPTER SEVEN: DISCUSSION

Chapter Seven will demonstrate the discussion of this research study, which aimed to explore the impact of the COVID-19 pandemic on the FQoL of families of children diagnosed with ASD. This chapter aims to delve into the results provided by Chapter six, providing a detailed discussion and interpretation of each theme identified, relating it to the existing literature and theoretical framework, as demonstrated in previous chapters. Through investigating the positive and negative impacts of the pandemic within the context of the relevant existing literature, this chapter aspires to expand the reader's knowledge of the multifaceted dynamics involved. This discussion will be presented according to the themes identified in the Results chapter.

7.1 Introduction

This research study aims to explore the impact of the COVID-19 pandemic on the quality of life of families with children diagnosed with autism spectrum disorder.
More specifically, the breakdown of the aims are as follows:

a) To explore the impact of COVID-19 on the quality of life (within the psychological, social, physical and academic domains) of families with children with autism.

b) To explore the impact of COVID-19 on the quality of life (within the psychological, social, physical, and academic domains) of children with autism.

A qualitative descriptive approach was adopted to explore the research aims outlined above. Focus group interviews and one-on-one interviews were conducted with families of children with autism. This research study is one of the first studies to employ a qualitative research approach to gather comprehensive and reliable data on the impact of the COVID-19 pandemic across different domains of FQoL for families of children with autism. Notably, it is among the first to explore specific QoL domains, including the academic domain, to assess how the pandemic had an impact on the overall QoL of families who have children with ASD.

The previous chapter, Chapter Six, presented the analysis gathered for this study, delving into the multifaceted impact of the pandemic on families of children with autism. The results showcased two overarching themes encompassing the Academic, Physical, Social and Psychological domains of the FQoL. The Academic Domain endured an abrupt transformation into digital learning. This transition forced families to navigate an unfamiliar, which brought significant changes to their daily routines and challenges. Throughout the interviews, some families struggled in adapting to the new learning methods, while others viewed the lockdown restrictions as an opportunity to actively engage in their children’s education. The Physical domain revealed the struggles families encountered that were brought by the lockdown restrictions. Families expressed concerns regarding the impact on aspects such as physical health, consistent routines and engaging in outdoor activities. There was a consistent pattern between some families’ physical health, as they found themselves leading sedentary lifestyles, while others discovered creative ways to prioritise physical health. The Social domain underwent a complete transformation due to the social restriction measures. Some families expressed sentiments of isolation and refrained from socialising. However, most families utilised different approaches to maintain their social connections and found solace in spending quality time with their families. The Psychological domain showcased an impact that was apparent across all families. Families experienced an emotional toll that included heightened stress levels, concern, and depression. However, families confronted the experience with strength, resilience, acceptance, and coping strategies. When analysing the families’ accounts, the core narrative demonstrated shared challenges, collective resilience, and hope. Each family had their own unique experience, yet their accounts are interconnected and present a broader understanding of how society as whole experienced the lockdown restrictions during the pandemic.

7.2 Family Quality of Life: Integration with Literature on COVID-19 and Autism Spectrum Disorder

The pandemic has indisputably posed significant disruptions for families with autistic children, impacting various domains of their QoL. Several studies found that for families with autistic children, the COVID-19 pandemic exacerbated the families’ existing challenges and brought forward additional layers of complexity to their daily lives (Meral 2021; Neece et al., 2020; Fontanesi et al., 2020; Masters et al., 2020). Chapter Six’s findings demonstrated that throughout the lockdown restrictions, families of children with autism reported that they faced unprecedented challenges in accessing crucial support systems and services. The closure of schools disrupted the families’ day-to-day routines that were crucial for their health and well-being and the development of their children. These challenges and disruptions to routines align with recent research that has highlighted the significance of structure and consistency for families with autistic children (Stankovic et al., 2020; Yahya and Khawaja, 2020). Research from Windarwati et al. (2024) supports this by showing that HRQoL for autistic children declined significantly during lockdowns, largely due to the loss of educational and family support systems. Similarly, Furar et al. (2022) found that parents reported loss of access to healthcare services, further intensifying family stress levels and exposing the fragility of support during crises.

Previous studies have linked disruptions to routine with increased behavioural challenges and emotional distress (Stankovic et al., 2020; Yahya and Khawaja, 2020; White et al., 2021; Tokatly Latzer et al., 2021; Pecor et al., 2021). The findings of this study reinforce those claims and offer deeper insight into the specific emotional and academic demands placed on families. One of the most immediate impacts of the pandemic was the sudden shift to remote learning. While this abrupt transition presented obstacles for most families, families with autistic children faced unique and complex challenges. As identified in this study, families were required to navigate an unfamiliar realm, which brought significant challenges to the children in adapting to the new learning methods, emphasising the importance of routine and traditional learning environments for autistic children. These findings build on previous research documenting the negative impact of school closures on the QoL of autistic children (Eshraghi et al., 2020; Fontanesi et al., 2020), and are further supported by more recent literature showing that such disruptions had long-term implications for family emotional well-being (Kaur et al., 2024).

This unprecedented pandemic has not only affected the children but also imposed significant strain on the parents, who had to rapidly adjust to the lockdown restrictions and increased caregiving responsibilities. Parents expressed struggles in maintaining their mental health, balancing work with childcare and accessing services for their children. The data also highlighted how disruptions to social interactions and routines heightened stress levels and contributed to feelings of isolation. The abrupt closure of schools and therapeutic services deprived families of crucial support systems and services, leaving parents struggling to assume several roles to accommodate their children’s needs. These findings extend earlier research suggesting that the pandemic significantly contributed to increased stress, social isolation and burnout among parents of autistic children, ultimately resulting in poorer overall FQoL compared to families of neurotypical children. These parallels are consistent with Janssen et al. (2020) and Vanderhout et al. (2020), who found that parental psychological distress increased as a direct result of balancing parental responsibility with professional and emotional demands. Furar et al. (2022) add to this by showing that a lack of institutional guidance left many families overwhelmed, unsure how to support their child academically and emotionally. These patterns are further reflected in Bowen’s concept of emotional fusion (Brown, 1999), in which stress experienced by one family member transmits through the entire system, intensifying collective emotional strain. Furthermore, social distancing measures restricted families’ ability to socialise, disrupting supporting networks, social gatherings and routines, which contributed to feelings of isolation and loneliness. The current findings echo the work of Ravens-Sieberer et al, (2020) who emphasised that social support is a crucial factor for parental health and well-being, particularly for parents raising children with ASD. More recent studies by Kotera et al. (2021) and

Araz et al. (2024) suggest that informal social and spiritual networks played a vital role in mitigating stress for families who lacked access to formal therapeutic supports.

Nevertheless, amidst these challenges, the findings of this study also revealed that families demonstrated resilience and creative ways of adapting to the challenges and disruptions caused by the COVID-19 pandemic. Some families reported improvements in domains of their QoL. This reflects emerging research by Tokatly Latzer et al. (2021) and Ng et al. (2025), who reported that families used the lockdown period to strengthen relationships, build routines that suited their child's sensory needs, and rediscovered shared time. These adaptive responses were not only practical but emotionally significant, reinforcing Bowen's concept of family systems as dynamic and interconnected (Brown, 1999). In some cases, the struggles associated with the pandemic unexpectedly sparked innovation, including new approaches to home learning, flexible routines, and deeper family cohesion. These findings also align with Meral (2021) who found that some parents reported strengthened familial bonds during the pandemic. Reduced external stressors and increased time together contributed to more emotionally mindful interactions, offering moments of stability amid the broader uncertainty. This suggests that, while the pandemic introduced multiple layers of difficulty, it also opened pathways for reflection, reconnection and resilience.

The following sections will examine the findings made during the data collection and compare it against previous literature that will underscore the positive impact the unprecedented pandemic had on families with children on the autism spectrum. These findings will be presented according to each FQoL domain, as demonstrated in Chapter Six.

7.3 Discussion of Theme 1: Positive Impact of the Pandemic

In this study, one of the overarching themes identified was the positive impact the pandemic had on the QoL of families of children with ASD. This finding was unexpected as it contrasts with the existing literature which generally focuses on the negative impact that the pandemic had on autistic individuals and their families. However, the findings of this present study show that some families reported positive changes to their FQoL during the pandemic.

7.3.1 Academic Domain

Within the academic domain, some family members narrated positive changes to either their or their children's educational experiences during the COVID-19 pandemic. Some families observed that their autistic child benefited from the one-on-one attention and instruction provided by parents, a dynamic made possible by remote learning and lockdown restrictions. These findings extend existing research that emphasises the value of personalised, child-centered approaches, particularly for autistic children who often require tailored support to thrive (Guldberg et al., 2011). In addition, some autistic children in this study reported that the pandemic did not impact them negatively. Instead, the closure of their school reduced their stress levels and created a more calming learning environment. This observation builds on findings by Fumegalli et al. (2021), who reported that some autistic children welcomed the break from the sensory overload and social pressures typically associated with traditional school environments. The reduction in exposure to environmental triggers, such as crowds or sensory overload, contributed to enhance QoL domains for children with ASD (Fumegalli et al., 2021). These accounts are further supported by Spain et al. (2018), who identified a decrease in anxiety levels among autistic children who function more successfully within structured home routines, reducing social interaction. Similarly, Pennefather et al. (2018) suggested that remote learning, when well-structured, could foster consistency and reduce stress for children with ASD. These perspectives are reinforced by more recent research: Ng et al. (2025) noted that for a notable portion of families, remote learning offered stability and increased control, especially for children sensitive to sensory input. Likewise, Windarwati et al. (2024) found that children with ASD in quieter home environments demonstrated more controlled behaviour and emotional responses.

Furthermore, these findings suggest that the academic challenges posed by the pandemic were not all negative. Some families in this study revealed that the shift to remote learning, while initially overwhelming, eventually created conditions that allowed for better focus and lower stress levels in some autistic children. This adds to research by Furar et al. (2022), who emphasised the potential of remote or hybrid learning formats to accommodate ASD needs when supported effectively. The implications of these findings suggest a need to rethink educational delivery for children with ASD beyond crisis periods. The reported benefits of reduced sensory stimulation, one-to-one teaching, and flexible learning spaces point to the potential of hybrid educational models that combine structured in-person support with remote learning opportunities. Such an approach could cater more effectively to the varied learning preferences and emotional needs of autistic children, ultimately contributing to improved educational experiences and outcomes.

7.3.2 Physical Domain

Within the physical domain, this study demonstrated that some family members reported positive improvements to their physical well-being during the lockdown restrictions. Some families noted that the restrictions provided parents with the opportunity to work closely with their children and engage in outdoor activities and exercise, activities that contributed to a sense of routine, shared bonding, and improved physical health. These findings expand upon previous research highlighting the importance of physical activity participation in enhancing the physical and psychological well-being of autistic children (Arim at al., 2012). Notably, some parents demonstrated adaptability and creativity in ensuring their child's, and their own physical and mental well-being. Families described participating in outdoor walks, exercise routines, and even virtual physical activities through digital platforms. These strategies reflect an ability to repurpose constrained environments into health-promoting spaces, reinforcing the idea that supportive environments can be shaped through intentional family practices. This adaptive behaviour resonates with the broader theme of resilience noted in the study and is echoed in more recent literature. Kaur et al. (2024), for example, identified that some families used local outdoor spaces and home-based activities to maintain wellness during the height of lockdowns, despite limitations in support services. However, it is important to acknowledge that while some literature recognises the benefits of increased family-led physical activity during the pandemic, studies specifically documenting sustained positive impacts on physical well-being remain limited. Furar et al. (2022) also caution that access to safe outdoor spaces and resources was not equitable across families, and in some contexts, restrictions reduced opportunities for movement altogether. Therefore, while the findings of this study reflect positive examples of adaptation, they also raise questions about disparities in access and the sustainability of such routines post-pandemic.

Overall, these findings underscore that physical well-being within families of autistic children was not solely shaped by the pandemic itself, but by how families responded to and restructured their environments. This reflects Bowen's concept of family units functioning as adaptive emotional systems — where collective choices can buffer external stressors and support both mental and physical resilience.

7.3.3 Social Domain

Within the Social Domain, some family members stated that the lockdown restrictions had unexpectedly positive impacts on their social life. These participants noted that reduced social activities and interactions led to a less overwhelming environment, particularly for those with autism, who often experience heightened stress in socially demanding or unpredictable contexts. This finding builds on evidence from Ayed et al. (2021), which highlights the sensory and emotional challenges autistic individuals often face in social settings, while also underscoring the benefits of controlled and predictable environments. For many families, the pandemic created an opportunity to establish consistent routines that supported social development at home. Parents described how their children were more comfortable practising social interactions within the familiar and emotionally safe context of the family. This observation expands on findings by Hidayat et al. (2020) who noted that structured environments can facilitate improved social functioning in autistic children. Moreover, this aligns with recent work by Ng et al. (2025), who found that families reported enhanced emotional connection and social growth during lockdown periods, despite external restrictions. A common theme across the families in this study was the strengthening of familial bonds. Many participants shared that they spent more quality time together and experienced deeper emotional connection during the pandemic. This sense of unity provided critical emotional support, mitigating stress and contributing to a sense of collective resilience. These findings further develop insights from Kotera et al. (2021), who emphasised that stronger intra-family relationships served as protective factors against psychological strain during periods of social disruption. Likewise, Araz et al. (2024) reported that emotionally connected families were more likely to cope with uncertainty by drawing on internal support systems.

Overall, these findings reinforce the idea that social wellbeing for families with autistic children can be strengthened when external pressures are reduced and intra-family communication is nurtured. These outcomes reflect Bowen's emphasis on the importance of family cohesion and emotional connectedness in promoting stability during stressful circumstances.

7.3.4 Psychological Domain

Although the pandemic undeniably impacted the psychological welfare of families in complex ways, this study also revealed that some families experienced unexpected psychological benefits. Several families indicated that the restrictions increased their awareness of their own mental health and well-being, offering them with the opportunity to pause, reflect and prioritise their psychological health. The reduction in social demands and external pressures enabled families to focus on spending quality time together and engaging in intentional self-care. These findings build upon insights from Kotera et al. (2021), who emphasised the importance of mental health awareness and self-care practices for families raising autistic children, particularly during times of crisis. Families in this study described moments of emotional clarity and reconnection, which contributed to a sense of psychological balance despite the broader challenges of the pandemic. This is further supported by more recent research by Araz et al. (2024), who found that caregivers of autistic children reported moderate QoL but demonstrated increased use of personal and spiritual coping mechanisms to protect their psychological wellbeing. Similarly, Ng et al. (2025) reported that some families viewed the deceleration of daily life as beneficial for managing stress and reconnecting emotionally.

These findings suggest that psychological wellbeing during crisis periods may not be solely defined by the presence or absence of external stressors, but rather by how families adapt their routines, perceptions, and coping strategies. This reinforces Bowen’s emphasis on the emotional system of the family, where individual wellbeing is shaped by collective emotional dynamics, and where increased self-awareness can foster resilience and relational stability (Brown, 1999).

7.4 Discussion of Theme 2: Negative Impact of the Pandemic

The second overarching theme identified was the negative impact the pandemic had on the QoL of families of children with ASD. This theme was anticipated as previous existing literature extensively described the negative impact the pandemic had on autistic people and their families. The findings revealed various negative impacts the lockdown restrictions had on the families. This will be demonstrated below.

7.4.1 Academic Domain

This study found that the pandemic had a substantial negative impact on the academic domain of families with autistic children. The findings revealed that this negative impact on academic progress can be attributed to multiple interrelated factors, including the disruption to daily routines, and the loss of essential support services and therapies. Parents highlighted that for their autistic children, routine and consistency are essential in managing behaviour and sustaining engagement. The lockdown led to the sudden closure of schools and services, which significantly impacted the autistic children’s lives and halted progress. These findings reinforce earlier work by Pellecchia et al. (2020) who argue that remote learning may not be effective for many children with autism, particularly those who benefit more from a traditional learning environment. The disruption to routine also supports previous research highlighting the difficulty autistic children face when adapting to change (Stankovic et al., 2020; Yahya and Khawaja, 2020). One significant contributor to this disruption was the abrupt shift to remote learning, which many families in this study described as unsuitable for their children’s learning needs. Autistic children often benefit from in-person interaction, consistent therapeutic engagement, and hands-on support. The removal of these elements intensified the educational challenges families faced. The lack of access to educational specialists, structured classroom settings, and professional therapies made it difficult for parents to maintain learning progress, especially for children with more complex needs. These findings are echoed in more recent research. Furar et al. (2022) found that parents struggled to support their children’s learning at home due to limited professional guidance and the demands of full-time parenting. Similarly, Windarwati et al. (2024) reported that the absence of educational support negatively affected both academic development and broader QoL for children with ASD, particularly in resource-limited contexts.

The long-term implications of this academic disruption are also significant. As noted by several parents in this study, delays in educational progress may reduce future opportunities for academic independence and success. Beyond academics, a lack of access to structured learning and professional rehabilitation may also impact broader developmental outcomes, including social communication and emotional regulation. The present findings are consistent with studies documenting the emotional and behavioural challenges experienced by autistic children during the pandemic (Stankovic et al., 2020; Yahya & Khawaja, 2020; White et al., 2021; Tokatly Latzer et al., 2021; Pecor et al., 2021). Many families observed that the lack of predictability and support led to increased distress, disengagement, and regression in academic functioning.

However, it is also important to acknowledge the diversity of experience within this domain. While many families reported considerable academic strain, others recognised the transition to remote learning as an opportunity to become more involved in their children's education. This suggests that when remote learning is supported with flexible and individualised approaches, it may hold promise for certain students. These findings align with emerging literature on parent-mediated interventions and home-based learning models, reinforcing the need for more adaptable and inclusive educational strategies for children with ASD in future planning.

7.4.2 Physical Domain

Consistent with previous research, the findings of this study revealed that, due to the restrictions, most families spent significantly less time outdoors. Parents reported that this reduction in outdoor activities limited both social interaction and physical exercise for their children, thereby negatively affecting the physical domain, particularly in the autistic children. The lack of physical activity contributed to an increase emotional and behavioural challenge, which families found difficult to manage with the constraints of home environments. These findings reinforce those of Pecor et al. (2021) who emphasised the importance of outdoor play for autistic children, noting that it fosters essential sensory stimulation, physical exercise and social interaction. The current data further highlight how limitations in this area intersected with challenges across other domains, demonstrating the interconnectedness of the physical, social, and psychological aspects of family quality of life. Several parents described how their autistic child exhibited more aggressive behaviour during the lockdown period. Without access to school, therapeutic support, or outdoor outlets for physical release, families reported feeling overwhelmed and unprepared to manage the resulting behavioural escalations. These experiences are in line with prior research linking elevated anxiety to increased behavioural difficulties in children with autism (Pecor et al., 2021), and they also align with Bowen's notion that unresolved emotional tension in one family member can reverberate throughout the system, amplifying stress for the entire household. The impact of reduced physical activity extended beyond the child to affect the family unit. Vasilopoulou and Nisbet (2016) reported that declines in physical activity can significantly lower overall QoL for both children and their caregivers, contributing to increased stress, reduced coping capacity, and emotional fatigue. The findings of this study build upon that evidence, showing how disruptions to outdoor activity created cascading challenges that affected daily functioning, mood regulation, and family dynamics. More recent research supports these concerns. Winderwati et al. (2024) observed that in low income environments, physical restrictions during the pandemic exacerbated well-being gaps for families of autistic children, particularly when safe outdoor spaces were inaccessible. Kaur et al. (2024) similarly highlighted that the inability to engage in routine physical or social activities contributed to deteriorating mental and physical health in both children and parents.

These findings suggest that access to physical space, movement, and structured routines is not merely a lifestyle preference but a foundational element of FQoL. They highlight the need for future emergency response strategies to account for the physical needs of autistic individuals and their families, particularly in ensuring that safe, inclusive, and adaptable activity opportunities are made available during periods of crisis.

7.4.3 Social Domain

A collective finding that emerged from this study related to the social domain; the implementation of social distancing measures resulted in a significant reduction in social opportunities for all family members, including the autistic children. Families commonly reported feelings of isolation and loneliness, which, in turn, negatively affected their overall well-being. These findings build upon earlier research by Prime et al. (2020), who found that the pandemic-related social restrictions disrupted family routines, gatherings and sources of community support, contributing to elevated stress levels across family systems. This correlation between the social and psychological domains was clearly evident in the participant narratives. As family members struggled with prolonged isolation and the absence of in-person social support, their stress levels and sense of disconnection intensified. These observations are further supported by Kaur et al. (2024), who reported that reduced access to community and peer networks significantly exacerbated emotional strain in families of children with autism. Similarly, Ng et al. (2025) observed that the lack of informal and formal social contact during lockdown was a key factor in declining FQoL among families. The findings of this study also indicate that the loss of outdoor play and school-based interaction had a detrimental effect on children's social development. Many parents expressed concerns regarding their children's social skills deteriorating during the lockdown period, opportunities to engage in peer relationships and learn social norms in traditional school settings were severely limited. These findings extend the work of Fegert et al. (2020) and Xie et al. (2020), who noted that school environments play a crucial role in children's development of interpersonal skills and emotional regulation. Children with autism already experience challenges in social communication due to the core characteristics of ASD (DSM-V, 2014), and the added constraints of lockdown further compounded these difficulties. The absence of social learning opportunities placed some children at greater risk of regression. Ravens-Sieberer et al. (2020) similarly warned that social restrictions increased the likelihood of long-term developmental delays for children with additional needs.

While it is important to recognise that some autistic children may have experienced temporary relief from social demands during lockdown, the broader findings underscore the potential long-term repercussions of extended school absence, particularly in relation to social confidence, relationship-building, and community integration. These insights highlight the importance of viewing social development not as isolated from other domains but as deeply interconnected with emotional wellbeing, educational engagement, and family support structures. Bowen's theory offers a useful lens here, as the withdrawal of external relational systems placed increased emotional weight on the nuclear family unit, which in some cases led to increased internal strain (Brown, 1999).

7.4.4 Psychological Domain

One of the most prominent findings to emerge from this study is the significant negative impact of the pandemic on the psychological domain of families with autistic children. The abrupt global lockdown and the resulting disruption to daily routines were universally highlighted by parents as major stressors, a recurring theme that intersected with all other domains of FQoL. As discussed in the literature review, Meral (2021) emphasises that raising autistic children, typically requires consistent access to external professional support across psychological, social, educational and physical dimensions. When these structures were removed, families were left to navigate complex emotional and behavioural challenges with little formal assistance.

Parents in this study consistently stressed the importance of structure and routine in maintaining their children's psychological wellbeing. For many, routine meant more than scheduled tasks, it represented a foundation for stability, including school attendance and outdoor engagement, which were vital to both their children's regulation and their own emotional stability. The sudden removal of these routines during lockdown contributed to feelings of helplessness, emotional exhaustion, and in some cases, depression, for both children and parents. Some parents described their children as withdrawn or noticeably distressed, even if they could not articulate it due to communication challenges. This reflects findings from Shek (2021), who observed that confined living conditions and lack of personal space strained familial mental health. Similarly, Ravens-Sieberer et al. (2020) reported elevated rates of depression and anxiety in children and adolescents during lockdowns, particularly among those with existing vulnerabilities.

Emotional and behavioural difficulties were also heightened. Families reported experiences of temper tantrums, anxiety, fear, crying, and emotional dysregulation among their autistic children. These findings are strongly supported by a range of studies (Stankovic et al., 2020; Yahya & Khawaja, 2020; White et al., 2021; Tokatly Latzer et al., 2021; Pecor et al., 2021), which have shown that children with ASD are especially susceptible to behavioural distress during periods of uncertainty and change. The emotional turmoil triggered by the lockdown restrictions, such as disrupted routines, social isolation, and loss of support, appears to have compounded pre-existing challenges and placed greater psychological pressure on both the child and the family unit.

Many parents in this study shared their own emotional responses, which included frustration, guilt, and a desire to return to traditional schooling as quickly as possible. The cumulative burden of caregiving, working from home, and attempting to facilitate their children's learning created an unsustainable environment for many. Some opted to step back entirely from formal schooling, while others took leaves of absence from work to focus on caregiving full-time. These findings expand on those of Eshraghi et al. (2020) and Fontanesi et al. (2020), who reported that the pandemic placed significant emotional and practical strain on parents of children with ASD. Moreover, Isensee et al. (2022) and Tokatly Latzer et al. (2021) confirmed that the increased caregiving burden often led to parental burnout, emotional fatigue, and breakdowns in family resilience.

More recent studies provide additional insight into how these stressors unfolded across different sociocultural contexts. Araz et al. (2024) observed that parents of children with autism reported moderate QoL during the pandemic but faced significant psychological burdens, particularly when institutional supports were absent. Likewise, Furar et al. (2022) found that lack of accessible therapeutic guidance during school closures led to increased parental stress and uncertainty, especially when behavioural difficulties intensified.

Taken together, the findings of this study underscore the significant and multifaceted impact of the pandemic on the psychological wellbeing of families with autistic children. While moments of adaptability and resilience were present, they did not negate the considerable emotional toll experienced by parents and children alike. Routine disruption, social withdrawal, and the absence of specialised services exacerbated behavioural challenges, leaving families to navigate heightened anxiety, stress, isolation, and emotional exhaustion. These experiences reflect not only individual psychological struggles but broader systemic breakdowns in support, further affirming the interconnectedness of family wellbeing and societal infrastructure.

7.5 Summary

The COVID-19 pandemic has had a profound impact on the QoL of families with autistic children across the globe. It introduced both positive and negative consequences. On the positive side, while lockdown restrictions abruptly disrupted daily life, many family members, both children and adults, reported an increased awareness of psychological wellbeing, physical health, and the importance of self-care. Families also highlighted that the confinement at home provided opportunities to strengthen familial bonds, spend more quality time together, and find innovative ways to connect with friends and extended family members remotely. Conversely, the negative effects were significant. Social isolation, disruption to daily routines, and limited access to essential services and support systems exacerbated the emotional and behavioural difficulties of autistic children. Parents reported that these challenges, compounded by the pressures of caregiving, led to heightened levels of anxiety, stress, and emotional strain. As expected, most families reflected that their overall FQoL was substantially diminished, particularly during the early stages of the global pandemic.

CHAPTER EIGHT: CONCLUSION

This study explored the multifaceted impact of the COVID-19 pandemic on the FQoL of families with children diagnosed with Autism Spectrum Disorder. In examining the nuances of this pandemic, it is clear that the pandemic posed significant challenges for families with autistic children, impacting their QoL across all domains. Notably, children demonstrated increased aggressive behaviours and difficulties adapting to the change their in routines. Socially, the physical distancing measures led to reduced social interactions, and exacerbated feelings of isolation and loneliness. Psychologically, both parents and children experienced heightened emotional distress, with parents reporting significant stress and burden in caring for their children whilst balancing work during the lockdown restrictions. Yet, amidst the challenges, families demonstrated resilience and adaptability. While the pandemic restricted their social interactions, families spent more quality time together and strengthened their bonds. Additionally, despite encountering significant challenges, some families recognised the difficulties they faced but also spoke about optimism, and positive aspects, highlighting the strengths discovered between family members. This revealed significant implications for a better understanding of the psychosocial dynamics within families of children with ASD during crisis periods. Taken as a whole, this study underscored the necessity of adopting a holistic and personalised approach to supporting and understanding families of children with ASD during crisis periods, such as the pandemic.

8.1 Strengths

Despite the challenges families faced during the pandemic, this research study displayed various strengths that greatly contribute to current research on QoL for families with autistic children. The findings offer a robust understanding and valuable insights into the families' experiences during the crisis period. As a starting point, this study involves a varied sample of families from different backgrounds and family structures. This varied sample aids in adding depth and thoroughness to the findings, which enables a more detailed understanding into the impact the pandemic had on diverse populations within the autistic community. In addition, the findings aid in sparking a wider conversation around mental health, encouraging a greater level of understanding and empathy towards children with special educational needs. Secondly, this study is one of the few research studies that examine how the COVID-19 pandemic affected families of children with autism. It addresses a gap in the literature regarding the unique challenges encountered by vulnerable population during a global crisis. In addition, addressing this will aid in understanding the psychosocial dynamics of families during crisis periods, as well as adding valuable knowledge in the field of ASD research. Lastly, the methodology adopted to collect and analyse the data was modern and innovative. Employing online platforms as a data collection method allowed for easier and convenient participation, ensuring a broader, diverse audience.

8.2 Limitations

Within the context of this research study, it is essential to acknowledge the limitations (Busse and August, 2020). The limitations may arise from several factors, which include the sample size, methodology adopted, data collection process, and external validity (Morgado et al., 2017; Ross and Zaidi, 2019). The sample size of this study could be considered small as it was limited to 10 families. This small sample size could limit the generalisability of the findings to a broader population (Flight and Julious, 2015). The data collection process in this study relied significantly on the participants' subjective responses. The reliance on the methodology adopted in this study could affect the reliability and accuracy of the findings as the participants' responses are based on their perceptions and opinions (Leung, 2015). In addition, due to the structure of this study, the cause-and-effect relationships between the findings cannot be determined. In terms of external validity, this study was conducted within specific geographic regions, which may not reflect populations of other geographies accurately. In addition, as this study was conducted during the pandemic, the lockdown restrictions limited the researcher's ability to collect the data more comprehensively, particularly given the variations in the type and duration of COVID-19 lockdowns implemented across the three countries involved. The UK, Kuwait, and Saudi Arabia each adopted specific public health strategies at different points in time during the pandemic, ranging from full curfews to phased restrictions and tiered systems. These national differences likely influenced families' access to education, healthcare, and social support, as well as their psychological well-being and daily routines. Consequently, differing lockdown measures may have contributed to differences in FQoL across the cases. While the study explored these environmental factors in Chapter Two, the extent to which lockdown duration and severity shaped participants' lived experiences remains a limitation when interpreting and comparing the findings. These differences are discussed in more detail in Chapter Two, which outlines the comparative national lockdown strategies and their potential influence on family dynamics. These limitations indicate that readers should be cautious when generalising the findings and applying them to different populations.

8.3 Application / Future Direction

Within the context of this research study, the recommendations in this section are grounded in an interpretivist qualitative approach, which emphasises the lived experiences of families and the contextual meanings they attach to them. This approach recognises that autism, often framed within a medical model, is better understood through a biopsychosocial lens, particularly during crisis periods such as the COVID-19 pandemic. The study initially addressed Autism Spectrum Disorder as a diagnostic category, however, what emerged from the participants' narratives did not indicate the search for medical treatments, but rather a need for structural, emotional, and environmental support for the family unit as a whole. Therefore, these recommendations are designed not to address deficits within autistic individuals but to improve the systems and contexts in which families live and function.

8.3.1 Recommendations for Families

At the outset, the findings highlighted that families benefited most when they were able to establish flexible yet consistent daily routines during the pandemic. Going forward, it is recommended that families prioritise structure in their day-to-day lives, while allowing room for adaptability during crisis periods. These routines helped reduce uncertainty and were associated with greater emotional stability and a stronger sense of control. Following this, the findings demonstrated the significance of support networks and of strengthening familial bonds for the families interviewed. Peer support networks emerged as a valuable resource for families who felt isolated during lockdowns. Facilitating opportunities for families to connect with others facing similar challenges, whether through virtual platforms, community groups, or school-led programs, can provide emotional support and practical advice during disruptive periods, thus alleviating feelings of isolation. The study underscored the significance of providing parents with effective interventions and support to aid in managing the behavioural and emotional challenges their children encounter. Thus, families would benefit from having access to simple, accessible resources tailored to home environments. This includes guidance on supporting children's learning, emotional regulation, and daily living activities. Educational materials about mental health and development that are culturally appropriate and sensitive to family circumstances can encourage parents to feel more confident in their caregiving roles. Furthermore, future research should also consider investigating the unique experiences of single-parent families with autistic children during the pandemic. By adopting this approach to understand single parent experiences, professionals will be able to develop specialised interventions that address the unique challenges single-parents face. This could be more effective as the interventions will be aimed at social support, stress management and work-life balance among single-parent families, with a focus on promoting health and well-being.

8.3.2 Recommendations for Families with Children with Autism

For families of autistic children, recommendations must be based on approaches that are tailored to individual needs and context-sensitive. Rather than relying on standardised programmes, services should develop flexible intervention plans that reflect the specific needs of the autistic child within the broader family system. This helps ease the pressure on parents to conform to fixed therapeutic frameworks during periods of uncertainty. The pandemic highlighted the importance of remote or hybrid approaches to delivering services remotely, which accommodated children's sensory needs and allowed families to access support from home. Future services should build on these approaches by offering continued flexibility in how therapy, education, and social engagement are delivered, ensuring that children and families remain connected even during crisis periods. This could include offering remote therapy sessions, guidance on coping strategies, techniques to avoid stress and guaranteeing parents have access to resources to support their children's needs remotely. Parents and caregivers also require access to training that is aligned with the values of neurodiversity and cultural relevance. Support programs that focus on stress reduction, empowerment, and strengthen parental confidence are crucial to improving both family and child outcomes. It is essential to recognise the family as a whole, not just the child, as the primary unit of support. This research demonstrated that the well-being of children was intricately linked to the mental health, emotional stability, and resource availability within their family. Therefore, recommendations must go beyond the child and include comprehensive support for caregivers and siblings as well.

8.3.3 Recommendations for Future Pandemics and Crises

A family systems perspective should inform both emergency planning and public policy to ensure that the needs of all family members are addressed holistically. During the COVID-19 pandemic, many services focused narrowly on individuals, leaving families without the necessary structural support. Future recommendations should include provisions for all members of the family, including caregivers and autistic children, with an emphasis on holistic well-being. Systems must also be designed to ensure that families of children with special educational needs are not excluded from essential services due to strict eligibility criteria. Greater flexibility in accessing education, health, and social care can prevent vulnerable families from being overlooked or unsupported during times of crisis. Furthermore, digital platforms developed for education, therapy, and social interaction must be designed to be inclusive and adaptable to meet the diverse needs of autistic individuals. To ensure accessibility and relevance, these digital platforms should be designed with input from both autistic individuals and their families. Lastly, it is crucial to ensure investment in local and community-based mental health and educational services that can operate during lockdowns or other emergency conditions. These services provide ongoing support and can significantly reduce the negative impact of social isolation and disrupted routines on families.

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APPENDICES

Appendix A

Family Focus Group Interview Questions

Research Study Title: Quality of life of children from a family's perspective during the COVID – 19 pandemic: A comparative case study

1. Can you tell me how do you all feel about the pandemic?
2. Can you tell me what does the quality of life mean to you as a family?
    a. Could you elaborate more on that?
3. Can you tell me what it was like for you as a family when they first announced that there would be a lockdown?
    a. How did it affect you as a family?
        i. Probe for Quality-of-life aspects.
    b. What were your concerns when they announced that there will be a nationwide lockdown?
4. Can you tell me a little bit about how did it affect your family emotionally?
    a. Did you have any concerns about your family's mental health?
5. Can you tell me about how your family's daily structure has been affected?
    a. Was your routine disrupted?
        i. If yes, how was it disrupted and how did you handle it?
6. Was your family able to keep active?
    a. Did you have any sort of physical activity?
7. Was there in impact on your family's social life?
    a. How did you feel about these changes?
    b. Can you elaborate more on that?
8. Did you have the school's support and extra therapeutic input during lockdown period?
    a. How did the school support your family?
        i. Did they provide any support from a social, psychological and physical aspect?
9. How did your child and your family cope with remote learning (if you had any)?
    a. How was your child taught through remote learning?
    b. How did you find the online resources?
10. How well do you feel the school is managing your child's education during the pandemic?
    a. Did you have any other support from your community?
11. When lockdown was over, how did your family manage the transition back to regular life?
    a. How did your family manage the transition back into schools?
12. Can you tell me about some of the positives your children and you as a family took from lockdown?
        i. How was your family's social life impacted?
        ii. Did it affect your mental health?
        iii. Was there any positives in your family's physical activity?
13. Looking now to the future what advice would you give to other families about how they can better their home environments during the pandemic?
    a. What advice would you give to schools and to teachers about how they can create better learning environments for children on the autism spectrum?

This is the end of the interview.

Appendix B

Parents Interview Questions

Research Study Title: Quality of life in families of children with Autism during the COVID – 19 pandemic: A comparative case study

1. How do you currently feel about the COVID – 19 pandemic?
2. As a parent, how did you feel when they announced the nationwide lockdown?
    a. Did you have any concerns?
3. Can you tell me what does the quality of life means to you?
    a. Could you elaborate more on that?
4. Can you tell me a little bit about the emotional tole the nationwide lockdown took on you?
    i. How was your social life affected?
    ii. Did it affect your mental health?
5. Can you tell me a little bit about some of the difficulties your child had during lockdown?
    i. How was their social life affected?
    ii. Did it affect their mental health?
6. Why do you think these changes affected your child's behaviour?
    a. Could you elaborate more on that?
7. How did your family cope with these difficulties?
    i. How was your family's social life affected?
    ii. Did it affect their mental health?
8. Did you use any strategies to manage difficult behaviours, especially behaviours during these times?
    a. What are some tips to help manage behaviour?
9. What are some of the challenges your child faced during social distancing orders?
    a. Can you tell me which challenges affected your child's quality of life (Social, psychological, physical and academic)
10. Has your child's sedentary lifestyle changed during this pandemic?
    a. Can you elaborate more about that?
11. Were you able to keep active?
    a. Other than the lockdown rules, did you face any sort of difficulties to be active?
12. Did you child manage to keep active?
    a. Was their physical activity impacted?
13. What are some of the positives your child gained during this pandemic?
    a. Can you tell me how it benefited your child's quality of life (Social, psychological, physical and academic)
14. Did any of you have to take over jobs of your child's teacher, therapist and so on?
    a. Which roles did you have to take over?
15. On average, ever since schools have closed, how long has your child been spending on remote learning?
    a. Do you think your child's academic outcome has improved through remote learning?
    b. If yes, can you tell me how has it improved? If no, can you elaborate why.
16. How well do you feel the school is managing your child's education during the pandemic?
17. Did you think the pandemic would last this long?
    a. Please share what this experience has been like for you as a parent.

This is the end of the interview.

Appendix C

Sibling Interview Questions

Research Study Title: Quality of life in families of children with Autism during the COVID – 19 pandemic: A comparative case study

1. How do you currently feel about the COVID – 19 pandemic?
2. How did you feel when they announced the nationwide lockdown?
    a. What were your concerns as a sibling when the news was announced?
3. Can you tell me what does the quality of life mean to you?
    a. Could you elaborate more on that?
4. Can you tell me a little bit about the emotional tole this on you?
5. How did you cope during the lockdowns?
    i. How was your social life affected?
    ii. Did it affect your mental health?
6. How did your family cope during the lockdowns?
    i. How was your family's social life affected?
    ii. Did it affect their mental health?
7. What strategies or methods did you and your family use to reduce any anxiety that you and your sibling were feeling?
8. As a sibling, what roles did you have to take over to support the family?
    a. Did you have to help by being a teacher, therapist and so on?
9. Did you have to study through remote learning?
    a. If yes, how did you manage to keep up with your education?
    b. Did it make a difference to you if you had to study online, or face to face?
10. Did your sibling have to study through remote learning too?
    a. If yes, how was it?
    b. Did you have extra support?
11. How did your lifestyle change during the pandemic?
    a. Can you elaborate more on their quality of life (Social, psychological, and academic)
12. Other than the lockdown rules, did you face any sort of difficulties to be active?
    a. Were you able to keep active?
13. How did your sibling's lifestyle change during the pandemic?
14. Has your child's sedentary lifestyle changed during this pandemic?
    a. Can you elaborate more about that?
15. Was your sibling able to keep active?
    a. Did you face any sort of difficulties to help them be active?
16. How did your relationship change with your family and sibling during the nationwide lockdown?
    a. Can you elaborate more on that?
17. What are some of the quality life changes did you see on your sibling? (Social, psychological, physical and academic)
    a. Towards you?

    b. Towards your family?
18. Did you have any support from your family and community?
19. Did you think the pandemic would last this long?
    a. Please share what this experience has been like for you as a sibling.
20. What advice or tips would you give to other families on how they can structure and manage their life during the pandemic?

This is the end of the interview.

Appendix D

Higher-Functioning Autism Interview Questions

Research Study Title: **Quality of life in families of children with Autism during the COVID – 19 pandemic: A comparative case study**

1. Do you know what the CoronaVirus is?
2. How did you feel when you found out about the CoronaVirus?
3. Did it upset you when you found out that there will be a lockdown?
    a. If yes, can you explain how did you feel?
    b. If no, can you tell me why?
4. When there was a lockdown, did you got to school to study? Or did you stay at home?
    a. If you studied at school, how did you feel when you went to school?
    b. If you studied online, did you like studying online?
5. Did you go out for walks or do any type of exercising?
    a. If yes, did you like it?
    b. If no, why did you not exercise?
6. Did you enjoy staying at home during the lockdown?

This is the end of the interview.

Appendix E

Participant Information Sheet for Adults

The title of the research study

Quality of life of children with Autism from a family's perspective during the COVID – 19 pandemic: A comparative case study.

Invitation paragraph

You are being invited to take part in a PhD research study exploring the impact of the COVID – 19 pandemic on the family quality of life families of children with Autism Spectrum Disorder. Before you decide to take part in this study, it is important for you to understand why this research is being done, and what will it involve. Please take time to read the information below carefully. Feel free to discuss it with others, or contact us should you have any questions or, would like to know more information. You will have one week to decide whether or not you wish to partake in this research study.

What is the purpose of the study?

The primary focus of the research study is to explore the impact of the COVID – 19 pandemic on children with autism from the perspective of their family. More specifically, it aims to investigate the impact of the global pandemic on the family quality of life of children with autism from a family's perspective. The domains of family quality of life that this study will be looking at includes the psychological, social, physical and academic domain. The research study requires the involvement of children with autism aged from 7-14 years old, and their family members, including parents and siblings. The duration of the study will be from June 2022 until August 2022.

Why have I been chosen?

You have been chosen to participate in this research because you are a parent or sibling of a child with autism, and you have shown an interest in taking part in in this study. The aim will be to recruit a total number of 8 - 10 families who have a child with autism.

Do I have to take part?

The decision of whether or not you would like to take part in this study is completely up to you. There will be no penalty or loss of benefits if you refuse to participate in this research, nor will there be any payment made for participation. If you decide to partake in this research study, you will be given this information sheet to keep, and will be asked to sign a consent form. You can withdraw from this study at any time during data collection, without giving any reason, and all your data will be removed. Once the data has been generated and data analysis has begun, and the research study has been submitted, your data can not be removed, however, the data will still be anonymised for potential publishing.

What do I have to do?

If you choose to participate, you will be required to partake in a family focus group interview. Each focus group will include all family members. Thereafter, a follow up individual interview will be undertaken with each family member. If the individual interview was with a minor, the researcher will request for a parent/minor to be in the room. The interviews will be scheduled at your convenience. Firstly, you will be interviewed with the whole family, then you will be interviewed alone. The approximate duration of the family interview will be 45 mins to 1 hour, and the individual interview will be 30 – 45 minutes. The individual interview with children will last 20 – 30 minutes.

Minors will not be interviewed alone, a family member will be asked to be present. The interview style will be semi-structured. There will be open-ended and closed questions. They will allow you to communicate your opinion on how the pandemic has impacted the autistic child and your family.

The research study will last two months. You will be responsible for attending your interview and partaking in answering the interview questions. The interview will be scheduled at your convenience and once you have attended the interviews, your participation in the study will be over.

Your personal information will not be viewed, or released to anyone other than the researcher, and the research team. All data will be anonymous. Your participation is voluntary, and you can withdraw at any time. However, once the data has been published, it is impossible to withdraw your data, but your data will still remain anonymous.

What are the possible disadvantages and risks of taking part?

Taking part in this research study involves minimal risks, thus all appropriate risk assessments and measurements will be taken to avoid any foreseeable discomforts. A potential risk would be that a participant may discuss a topic that could upset or discomfort them, and in this case, the researcher will make sure that they do not have to answer any questions that could potentially make them feel upset.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for taking part in this study, the outcomes will potentially emphasise how this pandemic has had an impact on individuals with autism. This could potentially demonstrate the importance of interventions for practitioners to improve the overall quality of life of children with autism, and their family during this pandemic.

Use, dissemination and storage of research data

All of the research data will be anonymized and pooled together for analysis. The results of the research study will be shared with conference presentations, internal reports and will be send to peer-reviewed journals for publications. None of the data shared will show any of your un-anonymized personal information. No data will be shared without written consent.

Please read the Privacy Notice for Research which is provided alongside this Participant Information Sheet for further information.

What will happen to my personal information?

The researcher and the researcher's supervisors will be the only ones who have access to the research study and the data generated from the research. In order to ensure confidentiality, the participants will be assigned pseudonyms, and no names will be mentioned. All of your data will be anonymised and will not be identifiable. The recorded interviews will be transcribed, and downloaded onto a password-protected laptop. The original recording will be deleted from the recording device.

What will happen to the results of the research study?

All of the participants' contact information that is collected during the course of research, will be anonymised and stored separately from the research data. Steps will be taken wherever possible to anonymise the research data so that the participant's contact information will not be identifiable in any publications or reports. Full anonymity cannot be guaranteed during data collection as the method used for this study will be a family focus group interview.

Due to the nature of the data collection, confidentiality may not be possible if the participant disclosed information that could be harmful to themselves or others. If this were the case, the researcher would act accordingly and report the disclosed information to the appropriate authorities.

The data collected and the results of the research study might be used for subsequent and or additional research. None of the data shared will show any of your un-anonymized personal information and no data will be shared without written consent.

What type of information will be sought from me and why is the collection of this information relevant for achieving the research study's objectives?

The information sought from you will be regarding your perspective on COVID - 19 and it's impact on your child or sibling. Moreover, the questions will ask about your opinion on the COVID – 19 pandemic. This information will help the researcher decide whether you are a suitable participant for the research study.

Will I be recorded, and how will the recorded media be used?

You will be audio and video recorded during both interviews. The recordings will only be used for data analysis, and for illustration in conference presentations and lectures. No other use of the recordings will be made without your written consent, and no one outside this research will be allowed to access the recordings. If the recordings were to be used in a publication, broadcast or deposited in an archive, it would not be released without your written consent.

Who is organising the research?

Dr. Andrea Utley, and Dr. Shaunna Burke, along with the Faculty of Biological Sciences in the University of Leeds are organising this research study.

Contact for further information

If you would like any more information or have any questions about the research study, please feel free to contact us:

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Thank you for taking the time to read this information sheet. A copy of this information sheet, and, if appropriate, a signed consent form will be given to you to take home.

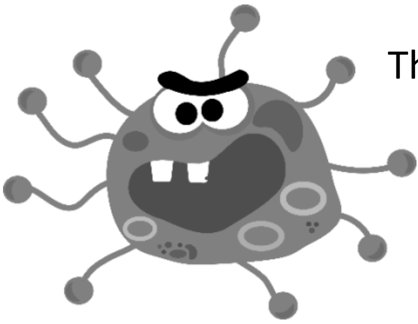
Study title	*Document type*	*Version #*	*Date*
Quality of life of children with Autism from a family's perspective during the COVID – 19 pandemic: A comparative case study.	Adults - Participant Information sheet		

Appendix F

Information Sheet for Younger Children

This project is about families of children with autism and CoronaVirus.

What is this project about?



This project is about finding out if the CoronaVirus changed your life and your family's life.

What is CoronaVirus?

CoronaVirus is a new virus that make you feel sick and stay at home.

If you get Coronavirus you had to stay at home and wear masks when you go out.

Why do I want you to do this project?

I am asking you to do this because you can help me find answers to my questions.

Do you have to do this?

No, you do not have to do this. It is up to you. If you say yes, I will ask you to sign a sheet that will tell me that you know what this project is about and you want to do it

What will happen if I join?

You will have to do two online interviews with me. First one will be with your family. Second one will be your parent and me.

Will joining be good or bad for me?

Joining will not be bad for you. You will talk about CoronaVirus. This may make you feel bad, and if you feel bad you can tell me or your family and we will help you. This project will not be good for you now, but answering the questions will help you in the future.

What if I change my mind?

It is okay to change your mind. You can tell me or your family that you changed your mind and you do not have to tell us why. It is okay.

Thank you!

Contact Information

ed16saa@leeds.ac.uk

School of Biomedical Sciences
Irene Manton,
Office 6.72,
University of Leeds,

Appendix G

Adult Participant Consent Form

Consent to take part in 'Quality of life of children from a family's perspective during the COVID – 19 pandemic: A comparative case study'	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw anytime without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. Feel free to contact us regarding any questions: ed16saa@leeds.ac.uk If you wish to withdraw from the study, after participation, the data of the participant will be excluded from the analysis.	
I understand that members of the research team may have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my personal information will be kept confidential and separate from my responses, and pseudonyms will be assigned.	
I understand that the data collected from me may be stored and used in relevant future research in an anonymised form.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Appendix H

Child Participant Consent Form

Quality of life of children with Autism from a family's perspective during the COVID – 19 pandemic: A comparative case study

Please tick the box to answer these questions about what you will be doing.

If you don't understand something, please ask me or someone close to you to explain.

	Yes	**No**
Do you understand what you will be doing?	☺	☹
Were you able to ask questions about it?	☺	☹
Do you know that you can stop taking part if you change your mind?	☺	☹
Do you know that you don't have to answer any question if you don't want to?	☺	☹
Do you want to take part?	☺	☹

Please write your name:

Please write today's date:

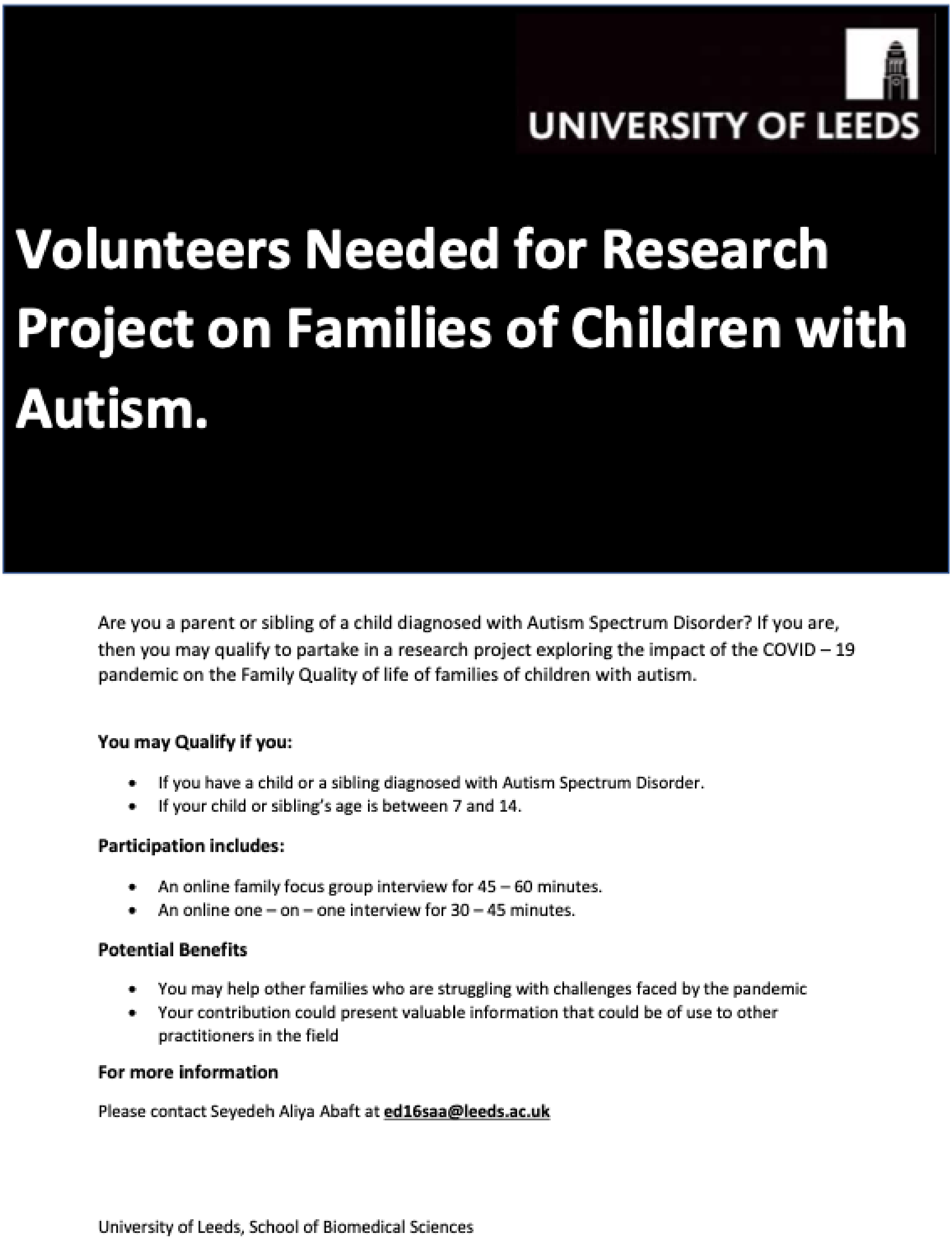
Please sign here:

Thank you!

ed16saa@leeds.ac.uk

School of Biomedical Sciences
Irene Manton,
Office 6.72,
University of Leeds,
LS2 9NH, United Kingdom

Appendix I



UNIVERSITY OF LEEDS

Volunteers Needed for Research Project on Families of Children with Autism.

Are you a parent or sibling of a child diagnosed with Autism Spectrum Disorder? If you are, then you may qualify to partake in a research project exploring the impact of the COVID – 19 pandemic on the Family Quality of life of families of children with autism.

You may Qualify if you:

- If you have a child or a sibling diagnosed with Autism Spectrum Disorder.
- If your child or sibling's age is between 7 and 14.

Participation includes:

- An online family focus group interview for 45 – 60 minutes.
- An online one – on – one interview for 30 – 45 minutes.

Potential Benefits

- You may help other families who are struggling with challenges faced by the pandemic
- Your contribution could present valuable information that could be of use to other practitioners in the field

For more information

Please contact Seyedeh Aliya Abaft at **ed16saa@leeds.ac.uk**

University of Leeds, School of Biomedical Sciences