How do Autistic Young People use Social Media: A Qualitative Study of Online Social Networking Site Usage.

Prakriti Gupta-Stelk

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: [redacted]

Name: Prakriti Gupta-Stelk

Date: 30th August 2020

Overview

Autism is currently conceptualised by problems with social interaction and communication. However, the accounts of autistic people and qualitative research in the field indicate that autistic people desire social connections, friendships, and relationships. Transitions between different stages of development are often linked to an increase in mental health conditions for autistic people. Social interactions are key to master the tasks set for each stage of development and buffer from the stresses related to failure. Researchers have found that though some autistic people may struggle with face-to-face interaction in neurotypical contexts, they show strengths in screen-based technologies. This thesis therefore sought to explore the role of social media (SM) for autistic people.

Part 1 comprises of a narrative synthesis and review of current literature of SM use by autistic people. A total of twenty-seven studies were identified; to conduct the narrative synthesis the papers were divided in three broad categories based on their focus areas: (1) Features of SM and their relevance to autistic people, (2) Virtual communities for social Support, self-expression, and autistic identity, and (3) Video games for socialising. The results indicated that there are both benefits and risks associated with the use of SM by autistic people. However, further research is needed to access its full impact on the lives of autistic people.

Part 2 comprises of the empirical study that explores the role of SM in a sample of autistic young people (18-25 years) from the United Kingdom. Here, attention was paid to the risks and benefits highlighted by the participants that may include the use and role of SM. For this study a qualitative grounded theory approach (Charmaz.2006), based on semi-structured interviews, was used. The findings highlighted that there are both risks and benefits associated with SM use for autistic young people. However, the risks lead to the development and adaptation of coping strategies that enhance the net benefits of SM use.

Part 3 is a critical review of issues that were pertinent during the process of the thesis, with the focus on the empirical study. The topics explored within the review include personal assumptions and qualitative research, reflection on results and importance of co-production.

Impact Statement

The present thesis has added to the literature on SM use by autistic people and the findings have significant implications for clinical practice, research, and academia. The study has generated new insights on the development and adaptation of coping strategies that facilitate SM use by autistic young people. The research has highlighted that professionals, family members and individuals can help make SM use more beneficial and safer by supporting the use and development of coping strategies.

A review of previous literature indicated the need for more theoretical models or conceptual framework to investigate the risks and benefits associated with SM use for autistic people. Using Constructivist Grounded Theory (Charmaz, 2006) in the empirical paper led to the development of a model that can be used for future research and helps make the dissemination of the results and findings easily accessible. The framework can also be used within therapeutic settings by psychologists for 1-2-1 sessions, within organisations like schools or the NHS as a tool to facilitate conversations about both the benefits and risks of SM use or increase training to be able to respond to the impact of the risks associated with the use of SM.

The present study has also contributed to the limited research on the use of SM by autistic people and generated new insights about the use and adaptation of coping strategies to enhance the benefits of SM use. Though some of these strategies may have short term positive impacts but long-term negative impacts, the analysis of these strategies with the individuals may help make them safer to use. The present study has also brought to light the transitional nature of online learning and how SM can be used to learn skills and increase knowledge about the external social world. This finding can enable the use of SM within therapeutic, organisational, and school settings as an option to help autistic people learn skills in a safe and known environment that can then be transferred into the real world

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List of Abbreviations

Dorota Ali (D.A.)

Prakriti Gupta-Stelk (P.G.S)

Social Media (SM)

Autism Spectrum Disorders (ASD)

Grounded Theory (GT)

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Part 1: Literature Review

How do Autistic People Use Social Media: A Narrative Synthesis and Review.

Abstract

Introduction: Autism is currently characterised by differences in social interaction and communication and restrictive and repetitive behaviours. Though some autistic people may struggle with communication in neurotypical contexts, research has found that they show strengths in screen-based media. There are bound to be risks and benefits associated with social media use by autistic people. The current review and narrative synthesis assess the nature and extent of research out there on SM use by autistic people to highlight the gaps that may exist in the current literature to be able to make recommendations for future research.

Method: Following database searches 62 references were identified, of these 27 full text publications from 7 countries were included in the review. The literature was synthesised and categories into three focus areas- 1) Features of social media and their relevance to autistic people, (2) Virtual communities for social Support, self-expression, and autistic identity, and (3) Video games for socialising.

Results and Conclusion: The current literature suggests that there are both benefits and risks associated the use of SM for autistic people. However, due to the limited nature of the research there is a limited understanding of the impact of these risks and benefits. The review also highlighted other gaps within the literature, like the need for further research to be able to draw age and gender related conclusions that can then inform future research and practical implications.

1. Introduction

Social media (SM) use has become commonplace and has permeated many areas of society over the last 15 years. The number and types of SM platforms have increased rapidly over the last two decades (Perrin, 2015). With the advent of SM there has been a debate over both the opportunities as well as the risks associated with the use of SM in relation to wellbeing and mental health (Ahmed et al., 2019). Some researchers have focussed on how helpful SM can be, allowing networking opportunities and providing access to information about a wide range of people (Kraut, Kiesler, Boneva, Cummings, Helgeson, et al., 2002; Skues et al., 2016), while others have focused on the potential drawbacks of SM usage on a regular basis. People who use SM sites in their daily lives run the risk of being overexposed to upward social comparison information, which can have a harmful impact on their mental health (Forest & Wood, 2012; Jan et al., 2017). There have been indications that for certain populations, like autistic people, internet use is extensive and that there are both positive and negative factors associated with it (Ahmed et al., 2019; Benford & Standen, 2009; Newton et al., 2009; Saha & Agarwal, 2015a, 2015b; Sallafranque-St-Louis & Normand, 2017; Deborah M Ward et al., 2018; Zhao et al., 2019). However, since SM is new and research on it is a relatively recent area of focus, it is important to be able to get an overview of the studies that have investigated the use of SM by autistic people, to gain a better understanding of its impact on them. Though in the past decades several literature reviews have been carried out focusing on different aspects of SM use within the autistic population, the present researcher was not aware of a review covering the most recent relevant research.

1.1 Defining SM

There are multiple different definitions of what SM is and its functionality, however, at its core, SM can be defined as any web-based site or platform that allows people (though it may not always be another human- they could be Bots) from all over to connect with each other, create and share content and form communities (Meng et al., 2017). Though SM has many definitions, for the purpose of this review SM is defined as communities with content such as microblogs (Twitter) or blogs, social networking sites (Facebook, Instagram among others) and virtual worlds used for social communication (video games). Any studies that included instant messaging (texts, WhatsApp) or real-time face-to-face exchanges (teams, zoom, skype) were excluded (Kaplan & Haenlein, 2010) as they did not enable their users to create content or share it with a larger audience.

1.2 SM and Autistic people[1]

Autism spectrum disorder (ASD) is currently conceptualized by: (a) social communication differences and (b) restricted and repetitive patterns of behaviour, interests, and activities (APA, 2013). About 60% of adults with ASD have at least one psychiatric condition (Taylor, Smith, & Mailick, 2014). Although decreased interest in social interactions was thought to be a common characteristic of ASD, a developing body of research implies that many autistic people desire friendships (Bauminger & Kasari, 2000; Carrington et al., 2003; White et al., 2007). Face-to-face social interactions may be challenging for some autistic people because they may struggle with ambiguous nonverbal communication, thoughts and feelings, as well as with the speed of live engagement (Petrina et al., 2016).

While autistic people may face social and emotional challenges in largely neurotypical contexts, some may show strengths and interest in screen-based technologies (Benford & Standen, 2009; D. M. Ward et al., 2018). Researchers studying SM use by autistic people suggest that there are positive impacts of SM use, some of which may work into and affect their offline social interactions as well (Benford, 2008; De Sausmarez, 2018) . It has also been speculated that autistic people may be at higher risk for the negative factors associated with

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[1] There are several research papers on preferred terms that indicate that autistic people themselves largely prefer identity first language (Dunn and Andrews, 2015; Kenny et al., 2015; Robison, 2019), I do believe that the language used in the paper and the study are important, therefore the present study will use identity first language throughout.

internet use, such as isolation, addiction, and cyber-bullying (Burke et al., 2010; Mazurek & Engelhardt, 2013; Schroeder et al., 2014; D. M. Ward et al., 2018).

The current scoping review will aim to provide an understanding of the research on the field of SM use by autistic people as well as the type of data sources and research mediums used so far. The review will also aim to highlight the gaps that may exist in the current literature. Though in the last couple decades that have been several studies focussing on different aspects of SM use and autistic people, the current researcher was not aware of a broad-scoping review covering the research in this area. The three previous reviews have studied the use of screen-based media by children and youth. Stiller and Möble (2018) focused on the used of media by autistic children and youth including but not limited to SM (Stiller & Mößle, 2018). While two of the reviews focussed on the impact of use of media on autistic children (Lane & Radesky, 2019) and the impact of the early use of media on autistic children (Slobodin et al., 2019). Therefore the present scoping review aims to give an overview of scope and nature of current research on SM use by autistic people to (1) synthesise the current knowledge in the field; (2) Identify key gaps in the literature.

2. Methods

2.1. Literature Search

A systematic review of literature was conducted in consultation with a subject liaison librarian for psychology in August 2020. A second search was carried out in November 2020 before analysis began. Newly published, grey and pre-published studies were retrieved for inclusion. The searches were conducted in the Psych Info., Medline, SCOPUS and Web of Science databases, using a combination of the search terms in Table 1.1. The reference lists of the selected articles were then manually examined for further citations that had been overlooked in the initial database searches.

Table 1.1 Search terms for database searches

Primary Search Terms	Filtered By (and)	Other Filters
Autistic (and)	Social media	English
ASD	Social network	Full text
Autism	Social networking	
Asperger's	Facebook	
Autism spectrum disorder	Twitter	
Asperger's syndrome	snapchat	
Autistic spectrum	Instagram	
autistic	Social web	
Autistic spectrum disorders	Social networking media	
Learning disabilities	My space	
Pervasive Developmental Disorder	Tik tok	
	virtual	
	internet	
	Video games	
	Social networks	
	Computer mediated communication	

2.2 Eligibility Criteria

Studies that adhered to the following eligibility criteria were included in the review:

a) Full text articles reporting primary empirical data relating to the use of SM by autistic* people (children, adolescents, and adults) (* studies that reported using a sample of autistic people were taken on face value as having a sample of people with autism spectrum condition as described in the DSM-IV (studies prior to 2013) or DSM-5 or ICD-10).

b) All studies whether qualitative or quantitative that reported including 1 or more individuals with Asperger's, high functioning autism, ASD, pervasive development disorder, presenting qualitative or quantitative data relating to SM use or studies presenting qualitative or quantitative relating to SM use by autistic people (analysis of blogs, online messages etc.).

c) Articles available in English.

The exclusion criteria included studies that focused only on video game use (no social aspect, like video game addiction), screen-based media use only (e.g., television, phones), studies including participants with autistic traits, studies addressing virtual reality and computer-based programs for educational purposes.

2.3 Screening and Selection

The primary search of the databases generated a total of 534 records; ten additional records were identified through hand and bibliography searching. A total of 361 records were left after the removal of duplicates; the titles and abstracts of these records were then screened manually. Book chapters, records on autism not mentioning SM, records on SM use by non-autistic samples or press releases were excluded at this stage. Then, full text journal articles were accessed for the abstracts that passed the initial screening (n=62). These articles were read and screened against the eligibility criteria (see Figure 1.1). The reliability of the process was assessed by giving a sample of 13 of the 62 articles to an independent rater (D.A.) to appraise against the inclusion criteria. There was agreement between these two raters on 92% (12 of 13) of these papers. The discrepancy was discussed by the raters, and a consensus was reached.

3. Results

3.1 Description of the studies included

The comprehensive search across a range of databases along with hand searching, led to the identification of 27 studies for inclusion in the review. The majority of these described studies conducted in the USA (59.2%, n =16), 22.2 % (n =6) were from Europe and the UK, with the remaining 18.5% (n =5) from Canada (Davidson, 2008; Sallafranque-St-Louis & Normand, 2017), China (Zhao et al., 2019), Australia (Abel et al., 2019) and Saudi Arabia (Mashat et al., 2016).

Of the 27 studies, 77 % (n= 21) had participants while 23% (n=6) analysed online content. Of the 21 studies that had participants, the participants' ages ranged from 10-64 years, 57.1% (n=12) of the studies sampled adults over the age of 18. 71% (n=15) of the studies with participants had only autistic samples, of these13.3% (n=2) had autistic controls who did not use SM. 19% (n=4) of the 21 studies with participants had neurotypical control groups while 4% (n=1) had neurodiverse controls.

To conduct a narrative synthesis of papers identified by the search, the articles were categorised into three different narrative categories areas after reading the literature based on their focus and findings: (1) Features of social media and their relevance to autistic people (n=12), (2) Virtual communities for social support, self-expression, and autistic identity (n= 11), and (3) Video games for socialising (n=4). The first rater (P.G.S) completed the procedure separately, and the second rater (D.A.) classified a sample of seven publications individually. The agreement between the two raters was six of seven (85.7%) papers. Any inconsistencies discovered throughout the process were discussed and an agreement was reached. Details of all articles reviewed are in Tables 1.2, 1.3 and 1.4; the narrative categories are also discussed separately in the results section.

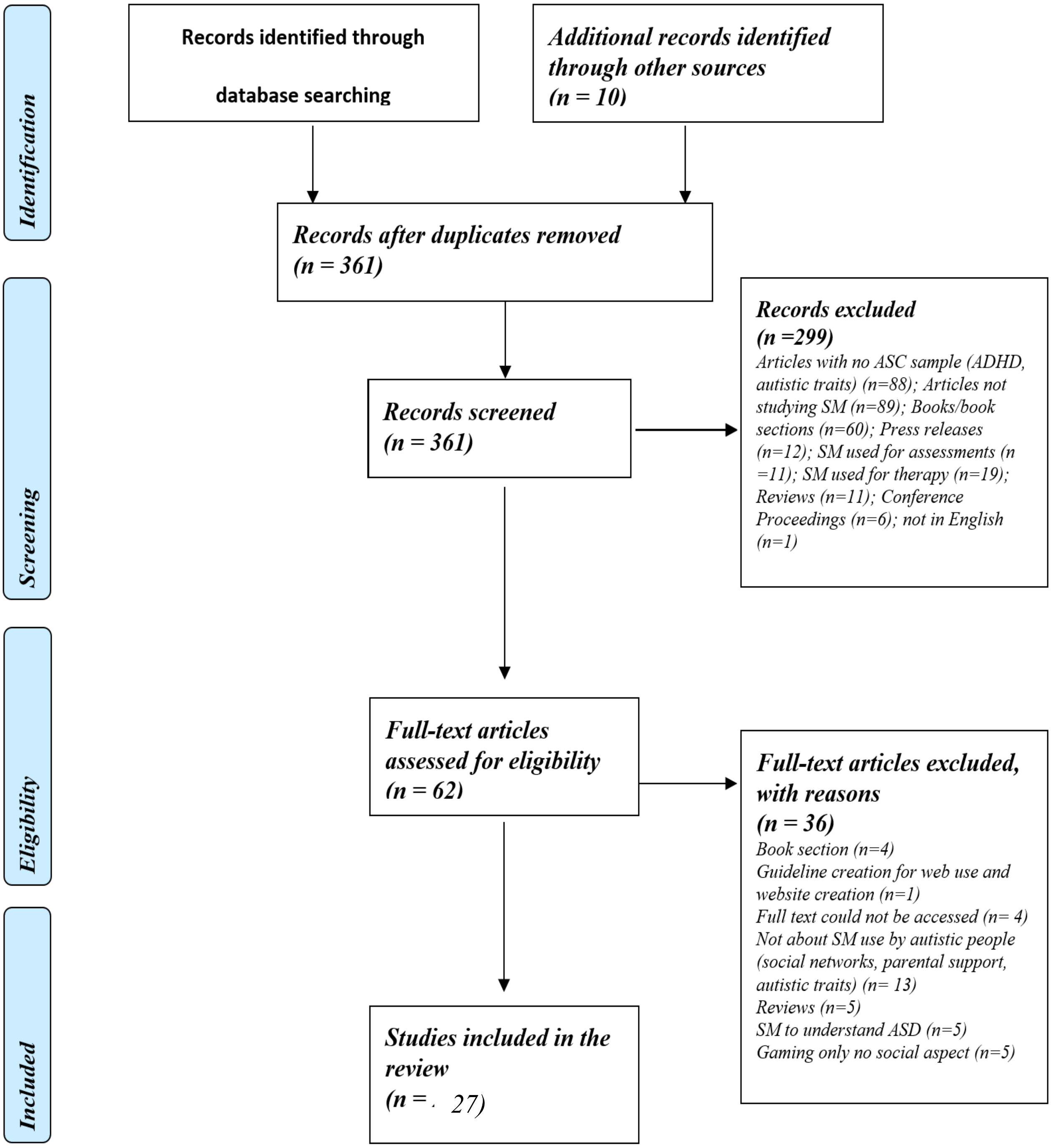

Figure 1.1 Flow Diagram of reviewed studies

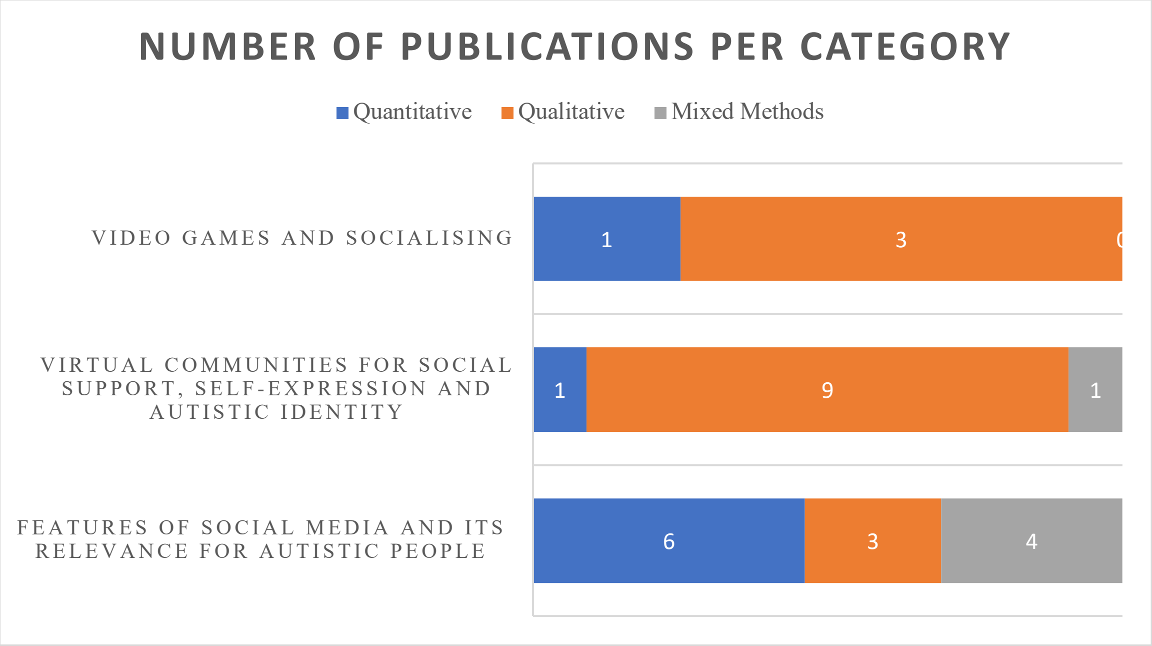

Fig 1.2. Methodology of publications per category

3.2 Features of SM and their relevance for autistic people

12 studies fit this category, of these, six were qualitative, three were quantitative and four were mixed-method studies (See Table 1.2). One of the studies analysed data from blogs, comparing linguistic similarities and differences between typically developing and autistic bloggers (Newton et al., 2009). The age range in the 11 studies that included participants was 12-64 years.

In summarising the literature within this category, I tentatively argue that, since screen-based media may be a preferred way to spend time for some autistic children and young people (Mazurek et al., 2012; Mazurek & Wenstrup, 2013; van der Aa et al., 2016), SM could be an easier way to access socialising for some autistic people. There may also be aspects of SM that make it attractive for some autistic people like- more control over their environment (Durkin, 2010), reduced social and emotional communication stresses (Benford & Standen, 2009), better defined social norms in groups and chats (Burke et al., 2010), ability to connect with people with similar interests who they may otherwise not have met and being able to engage in specific interests (van der Aa et al., 2016; van Schalkwyk et al., 2017). Taking this into account, the following section focuses on SM benefits and risks potentially specific to autistic people.

3.2.1 Beneficial features of SM use

Nine of the 12 studies found perceived benefits of SM use for autistic people. All nine studies reported that SM had potential (social) benefits, such as closer relationships with pre-existing friends, contacting new people, seeking romantic relationships, experiencing a better quality of friendship, meeting similar people and finding typing easier than spoken conversations (Benford, 2008; Benford & Standen, 2009; Engelhardt & Mazurek, 2013; Kuo et al., 2014; Massier, 2017; Mazurek, 2013; Sallafranque-St-Louis & Normand, 2017; van der Aa et al., 2016; D. M. Ward et al., 2018). Two studies reported SM use may have mental health benefits, Ward et al. (2018) through an online survey found increased levels of happiness in autistic adults who used SM, while Newton et al. (2019), through the analysis of 40 blogs found that learning and talking about autism increased the sense of being accepted.

Seven studies reported other benefits of SM. Firstly, four studies using different methods of analysis (quantitative, mixed and qualitative) found that SM could provide some autistic people with more control over their social interactions, in terms of response time, clarity of communication, ability to re-read conversations and pre-defined social norms in online communities and groups (Benford, 2008; Benford & Standen, 2009; Burke et al., 2010; Massier, 2017; van der Aa et al., 2016). Secondly, Mazurek (2013) and Van der Aa et al. (2016) s through the quantitative analysis of online surveys found that autistic people using SM reported having more secure friendships and being satisfied with their online social life as compared to a neurotypical control group (Mazurek, 2013; van der Aa et al., 2016), however, it is also possible that more engaged autistic people respond to and take part in research studies about SM. Lastly, Newton et al. (2009), through analysis and comparison of blogs of autistic and typically developing people, found there was a negligible difference in the word usage and linguistic patterns of online communication. They hypothesised that the removal of face-to-face communication stresses might be a moderating factor.

3.2.2 Risk features of SM

Despite the above-mentioned potential benefits of SM, it is crucial to note that the online social context may not promote net advances in social and emotional wellness for autistic people. Overall, six of the 12 studies reported potential risks of SM for autistic people. The main themes in the reported risks included difficulties figuring out who to trust online, misinterpretation of communication, people being unkind, reduced privacy, solicitation and no reduction in perception of loneliness (Benford, 2008; Benford & Standen, 2009; Massier, 2017; Mazurek, 2013; Sallafranque-St-Louis & Normand, 2017; van der Aa et al., 2016).

Van der Aa, et al. (2016) using self-report measures found that though the autistic people who used SM reported satisfaction with their online social lives, the use of SM was also negatively correlated with life satisfaction in the same group. It could be hypothesised that this could be due to the increased time online and decreased time engaging in face-to-face interactions, as Benford and Standen (2009) found that online interactions were not a replacement for in person social connections. However, it could also be that autistic people who are generally less satisfied with their lives tend to use SM more.

Burke et al. (2010) using grounded theory found that, as beneficial as SM was in helping individuals get in touch with many people and maintain relationships, using SM brought out some challenges, including difficulty in knowing whom to trust in purely online relationships and not knowing how much to disclose or share. Similarly, Massier (2017) reported that people found it difficult to maintain privacy amongst their SM friends, as they struggled to determine what should and should not be private. The same two studies reported that autistic participants also struggled with the norms of online communication, since it was different from the social norms of face-to-face contact. Not being able to work this out meant autistic participants often found it difficult to maintain the relationships and this led to feelings of loneliness *(Burke et al., 2010; Massier, 2017).*

Table 1.2 Summary of articles relating to features of SM and its relevance for autistic people

Sno.	Author, Year, Country	Title	Aim	Methodology and sample	Results
1	Benford and Penny Standen; 2009; UK	The internet: a comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)?	To see how online communication was helpful or unhelpful to HFA adult's method of communication	Grounded theory, semi structured interviews via email and mail. 23 Autistic Adults over 16.	- Internet reduced the social, emotional and time related pressure of communication. - online relationships not a substitute for offline relationships. - Internet provided more opportunities to interact. - forum rules and moderation could provide structure and guidance for interaction.
2	Kuo, Orsmond, Coster and Cohn; 2014; USA	Media Use among Adolescents with Autism Spectrum Disorder	(a) Describe how adolescents with ASD use media, in terms of the frequency, amount of time, and media content. (b) identify the companions with whom they spent time using media. © examine the factors (e.g., severity of symptoms) associated with their media use; (d) examine the associations between media use family relationships and friendships.	Quantitative analysis of survey results. 91 adolescent aged 12-18 and their parents.	- 98% spent over 5 hours a day on media/technology. - Used computer more than TV. - Activities ranged from video games, SM, chat to iming. - those who received emails and used SM with friends had more secure friendships.
3	Mazurek, Shattuck, Wagner, Cooper, Benjamin; 2012; USA	Prevalence and Correlates of Screen-Based Media Use Among Youths with Autism Spectrum Disorders	What is the prevalence of use of various types of screen-based media among youths with ASD? b) How does screen-based media use among youths with ASD compare with that among youths with other disabilities? c) Among youths with ASD, what are the correlates of screen-based media use?	Computer assisted telephone interviews, parents and caregivers, quantitative. Youth 13-16 years, stratified random sampling (n-11000)	- 64.2% used media but not all used SM (46.6%). 41.4% played video games. - Age, functioning and access to computers at home were factors that predicted the use of SM.

4	Newton. Krammer and Mcintosh; 2009; USA	Autism Online: A Comparison of Word Usage in Bloggers With and Without Autism Spectrum Disorders	To compare neurotypical (NT)and autistic participants in a distal communication situation. They hypothesised that this may diminish the communication differences between NT and Autistic Participants	40 blogs by individuals who identified Autistic, were analysed using Linguistic Inquiry and Word Count and TAWC word counting programming. These mimicked the conditions of the NT sample.	- The effects size of NT vs AUTISTIC bloggers was smaller than one would expect based on Autism symptom criteria. - The sociability factor (use of social words) from the five factors showed the biggest difference compared to NT bloggers. - blogs were used to explain and talk about Autism.
5	Mazurek, 2013, USA	SM use among adults with autism spectrum disorders	The aims of the study were to (1) describe the patterns and identified purposes of SM use for adults with ASD, (2) determine whether SM was associated with increased quality or quantity of friendships among adults with ASD, and (3) to determine whether SM use was associated with decreased loneliness in this population	Survey, open ended questions and questionnaire. 108 adults with ASD (18-64), ASD PDD, aspergers.	- 79.8% used SM for at least 3. 2 hours. - Reasons ranged from social connection (64.9%), Entertainment and getting information about specific interests (22.1%). - Autistic people using SM more like to have close friendships than those not using it and reported greater closeness. - social network use was not a predictor of loneliness
6	Burke, Kraut, Williams; 2010, USA	Social Use of Computer-Mediated Communication by Adults on the Autism Spectrum	The aims were- 1) What are the current social communication needs of adults with ASD, (2) How well does existing CMC technology address those needs, and (3) What opportunities exist for improving CMC experiences, including tools or training?	Grounded theory analysis of qualitative interviews and observations of 16 HFA with ASD (18-37)	- Communicating online seems to have both pros and cons. - It enabled people to connect with others as it reduced stress of non-verbal communication, provided tips for interaction that were pre-defined, helped find people with similar interests. - The main cons were maintaining relationships that were started online, as people found it difficult to figure out who to trust people online, how much to disclose and online communication norms.
7	Benford,2008, UK	The use of Internet-based communication by people with autism	The purpose of this study was to explore how people with HFA or AS experience the Internet as a communication medium.	Mixed methods, survey from 138 participants and 19 email interviews for grounded theory analysis. 3 nonusers also interviewed. 16-69 years of age. 72% men	- 95% (n=138) used computers, 83% used SM, 61% were a part of groups. Participants who had less f-2-f contact used SM sites for communication and online groups more. - People joined online groups to discuss shared hobbies. - Participants engage in communication online as it provides them with control over the communication. the internet has a liberating effect by allowing autistic people to communicate and get social connection.

8	Massier,2017, USA	Computer-Mediated Communication Usage and Perceptions Amongst Young Adults with Autism Spectrum Disorder	This study was conducted to determine what young adults with ASD perceive as the benefits and challenges of using CMC, and the supports needed to access CMC not currently being utilized	Mixed methods design. Online survey (n=21) followed by a grounded theory analysis of interviews (n=2) of young adults aged 18-30.	- Participants used SM for emails, social networks and joining groups for special interests. - SMS are used to mostly interact with people they know (45%), few use it to meet new people (29%) - Participants saw more benefits than drawbacks of online communication- include- responding in own time, not imposing, not having to read facial cues, no body language, typing easier than talking, easier social rules, friends from lots of countries and advocacy. - drawbacks include- privacy, misinterpretation- people saying unkind things easily. - They wouldn't mind support in the form of trusted websites and bloggers.
9	Sallafranque-St-Louis and Normand; 2017, Canada	From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the internet	1- How do young people with intellectual disabilities or ASDs use the Internet? and 2- Have they experienced online sexual solicitation?	Mixed methods design, a questionnaire followed by an interview and content analysis for the qualitative data. 8 participants from a care home, 3 were autistic.	- All participants used the computer to connect with other people and for a community. - 62% of the 8 participants used SM to meet people and potential partners. SM enabled them to meet other people with and without disabilities. - People used the internet to keep in touch with others and talk to many people at once. - 6 of the 8 participants reported sexual solicitation online. - being alone was perceived to be worse than sexual solicitation.
10	Van Der Aa, Pollman, Platt, vVndergag, Jan; 2016; Netherlands	Computer-mediated communication in adults with high-functioning autism spectrum disorders and controls	To compare CMC use in autistic adults and Non autistic adults	Quantitative analysis of questionnaires of 113 autistic adults and 73 non autistic adults (mean age 40).	- Autistic participants spent more time online as compared to non-autistic. - both groups reported advantages of CMC, though autistic people focused more on the positive aspects of communication online (no non-verbal communication, time binding, facial expressions). - Autistic people make more friends online compared to non-autistic. - Autistic people reported a satisfactory social life online.
11	Ward, Dill-Shackleford and Mazurek;2018; USA	SM Use and Happiness in Adults with Autism Spectrum Disorder	To explore the relationship between SM use and happiness in a population of adults with self-disclosed ASD	Quantitative analysis of an online survey for autistic adults- mean age ranged from 26-28	- Autistic adults who used SM were happier than those who did not. - Perception of a large audience was found to be gratifying.

					- Autistic people found it difficult to figure out who to trust. - Use of Facebook increased trust as it enabled the participants to learn more about the people they were interacting with. - SM was used for sharing information with a large audience and social communication
12	Van Schalkwyk et al. 2017, USA	Social Media Use, Friendship Quality, and the Moderating Role of Anxiety in Adolescents with Autism Spectrum Disorder	To explore the patterns of social media use, quality of friendship and level of anxiety in adolescents with ASD. They aimed to explore whether the relationship between friendship quality and social media use for adolescents with ASD was moderated by anxiety.	Quantitative analysis of questionnaires collected from a sample of 100 adolescents. 44 with ASD and 56 controls. Mean Age ranged from 12-19.	- Results suggested that the use of social media was related to better quality of friendships in adolescents with ASD. - This association was not seen in the control group. - A moderating role of anxiety was found between friendship quality and social media use for adolescents with ASD, using the parent report measures of anxiety. - Friendship quality was correlated with the amount of time spent on social media and the utility of social media. Anxiety was only a moderator for social media utility and friendship quality.

3.3 Virtual communities for social support, self-expression, and autistic identity

11 studies fit this group. Of these, nine were qualitative, one quantitative, and one a mixed-methods study (See Table 1.3). Seven studies analysed data that was posted online and one analysed “Social Circles” (a SM app). The participants ranged from parents of autistic people, autistic people, their friends to immediate family. The ages of the autistic participants ranged from 16-84 years of age; for the seven studies that analysed data posted online, the age of the participants is unknown.

In summarising this literature, I argue that SM can provide a comfortable platform for autistic people enabling them to engage with others, find and retain social connections and communicate in a comfortable way (Mazurek, 2013). It is through connection with others, self-disclosure and support that people form relationships, learn about themselves and deal with the stress associated with the day to day life (LaRose et al., 2001; Radmacher & Azmitia, 2006). Given the importance of social support for development, the current section will focus on SM and its role in social support, self-expression, and autistic identity.

3.3.1 Identity

Four of the 11 studies suggest that being a part of a community provided participants with a sense of empowerment, support and a safe space to engage, develop and explore their identities (Bordignon et al., 2015; Gillespie-Lynch et al., 2014; Stendal & Balandin, 2015; Zhao et al., 2019**.**

Through the analysis of 40 autobiographies of autistic people online, Davidson (2008) suggests that there is an emergence of an ‘autistic culture’. He further postulates it is this formation of an autistic culture that enables people to explore how they may want to present themselves in a world filled with neurotypical people. Though none of the other researchers have alluded to the presence of an autistic culture, it can be hypothesised that the presence of communities and support groups have facilitated identity formation, and, like any other community, it helps with inclusion in the social world and demands that diversity is valued.

Sousmarez (2018) found that 57% of autistic participants had both an autistic and non-autistic identity, giving individuals the opportunity to explore different aspects of their identity. Large and Serrano (2018), through their analysis of posts on two online groups (AspiesCentral and AsperClick), found that, as supportive and helpful as online communities can be to identity development, they may also lead to threats (stereotyping, stigma among others) to the development of an autistic identity. These can threaten an individual’s self-esteem and sense of control. However, they also found that, through these identity threats, autistic people developed coping strategies: acceptance of diagnosis, viewing their difference in a positive light and the developments of autistic and non-autistic identities and fantasies. Through a single case study, Stendal and Baladin (2015) through a case study found that virtual worlds facilitate coping through fantasy. The virtual world helped people make friends, connect with themselves and feel a sense of control (Stendal & Balandin, 2015). This led to the development of identity through communication and learning about what they liked and did not like about themselves and others.

However, the research in this field is still sparse, Though these preliminary findings are promising and may be an indicator of the presence of autistic culture and the impact SM has on the development of both an autistic and non-autistic identity, further research is needed to understand the true nature of this.

3.3.2 Community and support

SM connects autistic people who may not have otherwise met, via Facebook groups (Abel et al., 2019; Zhao et al., 2019**)**, autism blogs **(Saha & Agarwal, 2015a)**, virtual worlds e.g. ‘Second Life’ (Stendal & Balandin, 2015), and other SM sites (Ahmed et al., 2019; Gillespie-Lynch et al., 2014). Abel, Machin, and Brownlow (2019) through content analysis aimed to characterise the purpose of Facebook autism social groups, finding they helped connect people from different countries; provided support, friendship, coping strategies, information that facilitated identity development and a space to vent and advocate. These findings are similar to those of Ahmed et al. (2019) who through the content analysis of reddits and subreddits suggest that while these members of online communities may not know each other in the non-virtual world, they form a community through their interactions on SM; these communities provide support and perform important functions that promote wellbeing and acceptance (Ahmed et al., 2019)**.**

Two studies also suggested SM can help connect (distant) family members and friends **(Hong et al., 2013; Saha & Agarwal, 2015a)**. Hong et al. (2013) used an app called 'Circles' to connect an autistic person with a small group of individuals consisting of parents, close friends, and siblings for social and day-to-day support. Through thematic analysis, they found that small groups on SM helped strengthen bonds with pre-existing support networks and reduced the reliance of autistic people on their parents. Saha and Aggarwal (2015) through a word count program analysed 40 autism bloggers, finding that online blogs helped family members connect with each other and others with autistic family members. This suggests that SM can be used to strengthen relationships that may exist outside the virtual world. Thus, non-virtual communities can also help strengthen their bonds and get more support using SM. However, the findings do not consider any other reasons that could lead to the strengthening of the bonds outside the virtual world. They also found that, though useful, online communication did not seem to replace face-to-face communication and social support.

Though these findings appear to be encouraging, there is a need for further research focussing on the importance and function of support groups, communities, virtual worlds, and circles on SM.

Table 1.3- Summary of articles relating to virtual communities for social support, self-expression, and autistic identity

Sno.	Author, Year, Country	Title	Aim	Methodology and sample	Results
1	Zhao, Zhang, Wu, 2019, usa and china	Finding Users' Voice on SM: An Investigation of Online Support Groups for Autism-Affected Users on Facebook	To investigate the topics that are discussed in online support groups for autistic people.	analysis of topics on groups for autistic people that had more than 50 members and were in English. Latent Dirichlet allocation was used to derive topics.	- Social support groups were used to get social support for problems people were facing - Groups were also used to get information about autism - membership in the groups led to the development of coping strategies for the group and individuals. - Groups were used for venting.
2	Hong, Yarosh, Kim, Abowd and Arriaga.2013, USA	Investigating the Use of Circles in Social Networks to Support Independence of Individuals with Autism	To understand how autistic people may reach out to members of a circle (small set of people) for advice.	3 participants with Asperger's with 5-7 members in their circle 3 autistic people were aged 16-28. descriptive analysis of questionnaires and a thematic analysis of the texts and interviews were done.	- Social network support groups reduced reliance on parents and primary care givers - The circles were only used for conversations around leisure and social topics not on more personal topics. - They helped promote closeness to others.
3	Saha and Agarwal, 2015, USA	Demonstrating Social Support from Autism Bloggers Community on Twitter	This study examines the social support via sentiments expressed in information exchange and interactions among members of autism bloggers community.	40 Autism bloggers were selected based on being the most popular bloggers in 2013 according to autism speaks. The blogs were written by parents, autistic people as a group and individual autistic people. The data collected was analysed using Linguistic Inquiry and Word Count (LIWC) program.	- Members of autistic communities are easy to reach. - bloggers provide both support via information sharing and emotional support. - Mother bloggers provided the most support in terms of advice support. - Blogging helped garner support in the larger community by dissemination of information.
4	Stendal and Balandin; 2015, Norway	Virtual worlds for people with autism spectrum disorder: a case study in Second Life	To explore the use of social worlds specifically second life by autistic people.	A case of a single participant in an online world called second life. The data was analysed using content analysis.	- the participant used the virtual world to meet people and make friends. - The online community provided the participant with a sense of control, support and empowerment.

					- The virtual world provides a venue for social inclusion and community involvement that the participant lacked in the physical world.
5	Davidson, J.; 2008, Canada	Autistic culture online: virtual communication and cultural expression on the spectrum	To explore the development of an autistic culture online.	Qualitative study of online posts and messages.	- The researcher suggests that there is an emergence of an autistic culture online, this is supported by specific features of SM like finding like-minded people, absence of demands to read non-verbal cues and the ability to respond at one's preferred pace of communication. - the emergence of the autistic culture also lends itself to the development of the autistic identity through social support and belongingness.
6	De Sausmarez, 2018, UK	An investigation into the views of young people with Autism Spectrum Condition (ASC) (aged 14-19) on their use of SM	This research explored young people (aged 14-19) with ASCs' digital identity and how they feel it relates to; relationships, psychological well-being and life outcomes.	Mixed methods, questionnaires, case study and thematic analysis of online forums. 85 participants for the quantitative analysis, 41f, 36, m, 8 others. 6 participants for thematic analysis and 2 for case study.	- 57% had both an autistic and non-autistic identity online. - people who use SM show more interest in friendship. The relationship between self-esteem and SM sites depend on how SM cites were used. - online communities and friendships were viewed as a safe space to develop their identity
7	Gillespie-Lynch, Kapp, Shane-Simpson, Smith, Hutman; 2014; USA	Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication	To understand the functions for which autistic adults use SM as compared to non-autistic adults.	291 autistic participants and 311 non-autistic participants aged 18-84 were included in the study. Quantitative analysis of an online survey, looking at online and offline socialization, communication benefits of the internet and preferred functions of the internet.	- Autistic participants were less likely to report that the internet does not help them communicate - Autistic participants liked to use the internet to connect with people with the same interests compared to non-autistic people. - Autistic participants found the internet helpful to be able show their true selves and engage with individuals with similar interests.
8	Mashat, Wald, and Parsons, 2016, Saudi Arabia and UK	Investigating the Use of SM Technologies by Adults with Autism Spectrum Disorder in Saudi Arabia	The aim of this research is to understand the role that technology plays in the lives of adults with ASD in Saudi Arabia, to make recommendations for research and practice.	13 participants were interviewed, 5 had limited verbal skills and caregivers were interviewed. 6 used SM.	- There was a large variability in how and why SM was used. - However most used it for some form of engagement with other people via chatting, texting, or sharing photos. - it enabled them to engage with a community.

9	Abel, Machin and Brownlow, 2019, Australia	Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups	They aimed to characterise the purpose of Facebook groups related to autism and see their membership.	Content analysis of 500 autism/ autism related groups found on Facebook.	- Purposes of groups - for support (60.4%), social companionship (16.4%), advocacy (15.8%), treatments (5.6%), sales (1.0%) and fundraising (0.8%). - Group membership- parents and families (57.4%), autistic people (23.4%), and women (10.4%). Many groups specified group etiquette (36.4%), or the geographic location members (42.8%).
10	Large and Serrano, 2018, USA	What Does it Mean to be Autistic? Examining How Identity Threats and Coping Strategies Influence the ASD Identity through Analysis of Identity Talk in Online Communities.	They aimed to explore how autistic individuals made sense of their identity through online communities.	Grounded theory analysis of posts by autistic people on two groups AspiesCentral and AsperClick.	- through their analysis they found that there are two main threats to the autistic identity- stereotypes about autism and prescribed identity- being told who they are based on attributes. - these threats threaten a person's self-esteem, their sense of belongingness, difference and control. - Autistic individuals adopt certain strategies that help them cope like acceptance of diagnosis, social support, positive differentiation, concealment, and fantasy.
11	Ahmed et al. 2019, USA	A Tale of the Social side of ASD	They aimed to understand interaction patterns, expectations and user experience people on autism and asperges subreddits.	Content analysis of Asperger's and autism subreddits on reddit.	- sub reddits can help by the formation of communities to support autistic people, their families and carers. - communities can also serve as a knowledgebase providing information about new research, diagnosis and coping strategies.

3.4 Video games and socialising

Four studies fit this group, of these, one was qualitative and three were quantitative (See Table 1.4). One study explored the relationship between online gaming, friendships and loneliness (Sundberg, 2018)**;** two studies reported that video games facilitated social communication or acted as a social outlet for autistic people **(**Finke et al., 2018; Mazurek et al., 2015)**;** the fourth study looked at the differences in screen-based media use among autistic children and their typically developing (TD) siblings **(**Mazurek & Wenstrup, 2013). The ages of the participants in the three studies ranged from 10-60 years of age. While the quantitative studies had both autistic and non-autistic participants, the qualitative study had only autistic participants.

Based on this literature, I tentatively argue that, with increased access to internet, it is easier for people to play online games. Compared to offline games, the online video games can be played as multiplayer games and tend to stimulate player involvement and communication (Ducheneaut & Moore, 2004). However, along with the social benefits that accompany the ease of access, there are some negative consequences, like problematic video gaming (addiction), difficulty to stop playing or disengaging and spending too much time playing games **(**Mazurek & Engelhardt, 2013; Mazurek et al., 2015**)**. Nevertheless, as will be described below, further research is needed to understand the ways in which autistic people use social gaming, its impact and how this compares to their neurotypical peers.

3.4.1 Friendship

Though there were differences in methodologies, three of the four studies reported that playing video games enabled participants to make and retain friends (Finke et al., 2018; Mazurek et al., 2015; Sundberg, 2018). It seems like video gaming acted as a 'social bridge' enabling the individuals playing them to connect with others **(**Durkin, 2010). Sundberg (2018) through the analysis of 3 self-report measures found that autistic people who played video games had more friends than those who did not and 40.5% of the autistic sample indicated that they had met a close friend online. The two qualitative studies exploring the motivations of autistic individuals for playing video games found that friendships and socialising were associated with playing video games (10/10 participants (Finke et al., 2018); 12/58 participants (Mazurek et al., 2015). Video games facilitated friendships by reducing stress (Mazurek et al., 2015; Mazurek & Wenstrup, 2013), providing a community, enabling meeting others with similar interests (Finke et al., 2018) and providing topics to discuss (Mazurek et al., 2015).

Though video gaming facilitated social communication, Sundberg (2018) found that autistic people still reported higher perceived loneliness, as compared to the non-autistic sample. Mazurek et al. (2015) found that, despite the perceived social benefits of online video gaming, there were also negative social interactions, including insults and arguing. The frequency of such interactions was not indicated.

Table 1.4- Summary of articles relating to Video games and socialising

Sno.	Author, Year, Country	Title	Aim	Methodology and sample	Results
1	Sundberg; 2017, Hungary	Online gaming, loneliness and friendships among adolescents and adults with ASD	To explore the possible links between online gaming, loneliness and friendships	85 autistic participants (14-60yrs) and 66 non autistic participants (15-48yrs). Quantitative analysis of the responses to 3 questionnaires.	- Autistic people spent more time playing online games as compared to the non-autistic sample - Autistic people who play online games have more friends than those who do not. - Autistic participants who spend a moderate amount of time playing video games have reduced perceived loneliness.
2	Finke, Hickerson, KremKow, 2018, USA	"To be quite honest, if it wasn't for video games I wouldn't have a social life at all": Motivations of young adults with autism spectrum disorder for playing video games as leisure	To understand the experience of autistic people who play video games.	10 participants 10-24, 9 male, 1 female. Purposive sampling. grounded theory used to analyse Qualitative interviews	- Playing video games enabled the participants for make and retain friends by becoming a part of the video gaming community. - It positively impacted their cognitive skills and helped some make career choices. - It also helped them feel calm and happy but at time frustrated when they didn't do well. - It helped them have new experiences and escape the real world if required. - videogames provided a social outlet.
3	Mazurek, Engelhardt, Clark, 2015, USA	Video games from the perspective of adults with autism spectrum disorder	To examine the preferences and motivations for video game play among adults with ASD	Qualitative analysis of 58 interviews with autistic adults aged 18-25 years.	- Video game play helped in relieving the stress of day to day life, by enabling the participants to escape reality. - Video games helped pass time or procrastinate. - 12 participants reported that gaming helped them socialise and interact with others. - videogames helped them get a feeling to achievement and autonomy through different story lines. - Video games can be addictive for the same reasons that they are fun and helpful.

4	Mazurek and Wenstrup, 2013, USA	Television, Video Game and Social Media Use Among Children with ASD and Typically Developing Siblings	To examine the way television, video games and social media were used by autistic children compared to their TD siblings	Quantitative analysis of data collected from 202 autistic children and 179 TD siblings.	- Children with ASD spent an avg. of 4.5 hours a day playing video games or in front of a screen as compared to2.5hours on non-screen activities. - Children with ASD prefer video games. - Children with ASD had more parent reported problematic videogame use. - Commonly reported problems included, more time playing video games, problems disengaging from games, getting angry when interrupted, problem stopping self from playing.

4. Discussion

This scoping review aimed to summarise existing research on SM use by autistic people and identify gaps in the literature. Though only 27 studies matched the inclusion criteria, the literature suggests that a majority of autistic participants used screen-based media to socialise with others, through blogs, microblogs, SM websites and video games. Previous research found that, compared to typically developing children and youth, autistic children and young people spend more time on screen-based media, especially computers and playing video games (Engelhardt & Mazurek, 2013; Mazurek et al., 2012; Mazurek & Wenstrup, 2013).

Although SM use by autistic people is understudied, existing literature suggests there seems to be both risks and benefits of SM use. The benefits include ease of access, control over one's own environment, ability to interact with people, meeting new people, less pressure in social communication, increased happiness, more secure friendships and development of coping strategies. The potential risks of SM use include problematic use of computers/video gaming, threats to mental health (self-esteem, threats to identity) and not knowing the norms of online interaction, e.g. how much to disclose online.

Despite the limited nature of the current literature, preliminary themes have emerged from the reviewed papers. First, based on studies with autistic children and young people, it is possible that some autistic people use computers more than their typically developing peers (Mazurek et al., 2012; Mazurek & Wenstrup, 2013). As some computer use may be linked to problematic behaviours (Mazurek & Engelhardt, 2013), such as addiction, compulsion, inability to disengage, and preoccupation, it may be important for future research to explicitly explore these aspects and compare them between different groups.

Second, based on the reviewed literature, autistic adult participants reported greater satisfaction and happiness, however, it is possible that people who were happier and more satisfied tended to respond to and take part in research on SM. This could be because of the potential relevance of certain features of SM for autistic adults, such as ease of access, control over their environment, ability to meet people with similar interests and less social pressure (Benford, 2008; Benford & Standen, 2009; Burke et al., 2010; Kuo et al., 2014; Massier, 2017; Mazurek, 2013; Sallafranque-St-Louis & Normand, 2017; van der Aa et al., 2016; van Schalkwyk et al., 2017; D. M. Ward et al., 2018). However, there is little research exploring SM's influence on autistic people's friendship quality and overall social communication. Almost no research has been conducted on how SM affects social communication and functioning, online or offline, nor on its effects on romantic relationships and mental health. This could partly be due to the lack of theoretical frameworks about how SM may impact autistic people. The presence of theoretical frameworks may aid in the generation of hypothesises regarding the impact of SM.

Third, SM helps connect people that may not have otherwise met or become part of a community and it may help strengthen bonds and communities that already exist outside of SM (Ahmed et al., 2019; Hong et al., 2013; Mashat et al., 2016; Stendal & Balandin, 2015; Zhao et al., 2019). These online communities may provide social support for autistic people and their families and friends, as well as spaces for advocacy, venting, meeting others with similar interests and learning more about autism (Abel et al., 2019; Ahmed et al., 2019; Saha & Agarwal, 2015a).

Fourth, the sharing of stories, articles and being a part of groups may allow some autistic people to connect with, give voice to and affirm their autistic identity (Bordignon et al., 2015; De Sausmarez, 2018; Large & Serrano, 2018; Stendal & Balandin, 2015). Though SM may also pose threats to the formation of identity (Large & Serrano, 2018), these may be resolved by the development of coping strategies through the support of the community, facilitating the tolerance of threats (e.g. not letting all the negativity on SM affect them, setting boundaries) and self-acceptance (Large & Serrano, 2018).

Fifth, with increased access to the internet, people are playing video games online, facilitating interlayer communication and enabling autistic people to make and retain friends by becoming a bridge for social communication (Finke et al., 2018; Mazurek et al., 2015; Sundberg, 2018). Though there are many perceived benefits of online video gaming, the four studies also found that despite the perceived social benefits there are also negative impacts (no change in feelings of perceived loneliness, problematic use of video games and negative social interactions like arguments and insults), however, the frequency these is unknown and not further researched within the adult population (Engelhardt & Mazurek, 2013; Finke et al., 2018; Mazurek et al., 2015; Mazurek & Wenstrup, 2013; Sundberg, 2018).

Finally, in terms of age and gender-based trends, one study found that autistic females may use SM more than autistic men (Benford, 2008). However, no other gender differences were observed based on the studies in this review. Research in this field is this in its infancy and has its limitations, such as a majority of the included studies might be relying on samples of convenience, rather than aiming for a broader range of diversity and narrower age range. Since the samples tend be convenience based, they do not consider the experience of the participants (participants ranging from 16-64) or their ease of access of technology. Other important factors such as the SM use based on narrower age gaps, gender, severity of ASC symptoms have not really been investigated; though these may have an impact on variables such what SM is used for, social communication and impact on mental health and wellbeing.

The following section highlights two characteristics of SM that may be helpful to study benefits and risks in associated with the use of SM by autistic populations: 1) engaging with a larger audience and social community; and 2) ease of use for social communication.

4.1 Engaging with a larger audience and social community

SM allows users to engage with others on both a one-to-one and one-to-many level, though autistic people tend to use the chat functions on many sites. Twitter, Facebook groups, Blogs, Circles, and Instagram increasingly allow users to communicate with an unquantifiable audience. In reviewing the literature, both risks and benefits of SM use were identified. The nature of such communication may increase the risks involved with using SM as it may make it easier to initiate cyberbullying and threaten one's autistic identity (Burke et al., 2010; Large & Serrano, 2018; Schroeder et al., 2014). Due to the one-to-many mode of communication, the potential that a large number of people might witness communication may have both a negative (self-esteem, loss of control, low mood) and a positive impact (more social support, advocacy and coping skills) (Burke et al., 2010; De Sausmarez, 2018; Engelhardt & Mazurek, 2013; Large & Serrano, 2018; Mazurek & Engelhardt, 2013; Sallafranque-St-Louis & Normand, 2017).

This mode of communication may also help some autistic people feel like a part of a larger community. Research findings so far report that autistic people use SM to connect with other people with similar interests, to increase their friendship circle, connect with offline friends and learn more about themselves and others (Benford, 2008; Benford & Standen, 2009; Burke et al., 2010; De Sausmarez, 2018; Gillespie-Lynch et al., 2014; Mashat et al., 2016). Engaging with a larger number of people in a meaningful way may support self-reliance and self-esteem in autistic people and the use of certain SM sites also reduced the reliance on immediate family (Hong et al., 2013; D. M. Ward et al., 2018).

Yet connecting with new people online comes with risks, such as threats to an individual's privacy or a difficulty knowing who to trust/how much information to share with new online friends (Burke et al., 2010; Massier, 2017). This could mean that autistic people at times find it difficult to maintain online relationships offline (Benford & Standen, 2009). Thus, SM use for social purposes may not necessarily lead to a net increase in the emotional and social wellbeing in the day-to day life of some autistic people (van der Aa et al., 2016). However, there is a paucity of studies that explore the impact of online social connections on the offline life of an autistic person, in terms of friendships, wellbeing, and social skills. There is also no research on the impact that these online social connections have on an individual's offline life, in terms of quality of offline relationships and time needed to build these e.g., does more time spent online mean that there is lesser time available to spend offline (Engelhardt & Mazurek, 2013; Mazurek et al., 2012; Mazurek & Wenstrup, 2013)?

In conclusion, research findings highlight both the risks and benefits of SM use. Yet there is a lack of specific studies exploring the impact of one-to-many communication on diverse autistic people in terms of mental health, wellbeing, and social communication.

SM allows users to engage with others on both a one-to-one and one-to-many mode, though autistic people do tend to use the chat functions on many sites; Twitter, Facebook groups, Blogs, Circles, Instagram increasingly allow users to communicate with an unquantifiable audience. In summarising the literature, I tentatively argue that this comes with both risks and benefits for autistic people. The nature of such boundaryless communication may increase the risks involved with using SM as it may make it easier to initiate cyberbullying and threaten one's autistic identity (Burke et al., 2010; Large & Serrano, 2018; Schroeder et al., 2014). Due to the one-to-many mode of communication, the potential that a large number of people might witness this may have both a negative (self-esteem, loss of control, low mood) or positive impact (more social support, advocates and coping skills) on the individual (Burke et al., 2010; De Sausmarez, 2018; Engelhardt & Mazurek, 2013; Large & Serrano, 2018; Mazurek & Engelhardt, 2013; Sallafranque-St-Louis & Normand, 2017).

4.2 Ease of use for social communication

There are certain features of SM that make it an easier tool for communication, such as its asynchronous nature, and its permanence. The norms of online social communication include delays and lags, i.e. there is no expectation for it to be uninterrupted or have a continuous back and forth flow; time delays and responses are more flexible and based on an individual's convenience. Some autistic people may prefer this online communication norm, as it eases the pressure of real-time reciprocal communication and provides time to think of responses (Benford, 2008; Burke et al., 2010). Communication online allows the users to respond in a more comfortable and deliberate manner, allowing more control than a time-bound response of face-to-face communication (Benford & Standen, 2009; van der Aa et al., 2016). This also takes away other pressures of face-to-face communication, including reading non-verbal cues, processing information quickly, turn-taking, taking time off when needed and allows autistic people to practice social communication (van der Aa et al., 2016). However, it is important for future research to explore these potential advantages in greater depth, with diverse samples and use comparison groups with same-aged peers.

SM also makes most communication permanent, and, therefore, some autistic people may be able to use these records to communicate and socialise at their own pace. The permanence could mean that it is available to re-read, examine, and digest later. This may allow for application of problem-solving methods, understanding of abstract forms of communication and clear up any misunderstandings. These opportunities may not be as available in other forms of communication (Benford, 2008; Sallafranque-St-Louis & Normand, 2017; van der Aa et al., 2016). However, the same social norms that allow for better communication can also be confusing, since there are major differences to face-to-face communication with its own set of short forms, norms for entering and exiting conversations and emoticons (Burke et al., 2010; Massier, 2017).

4.3 Limitations

The review used a vast number of search terms and did not limit the dates, allowing for the discovery of as many relevant papers as possible. However, with SM being such a vast term, with hard to define boundaries, the inclusion of a different definition of SM may have also yielded more or different research papers.

Though it was out of the scope of the current review, research that relates to SM use by neurotypical children/youth/adults with autistic traits and the broad autism phenotype, could also be explored in future reviews. These papers may help fill some gaps that are highlighted in the present literature or provide future directions for research with autistic people. The present review did also not include any papers published after November 2020; a future review including new papers and a broader scope may help provide a better picture of the current state of research on SM use by autistic people.

5. Conclusion

The current review found that autistic people regularly use SM and play online computer games. Though there is research that points towards the risks and benefits of this, there is limited information on the full impact this has on the lives of autistic people. There is a need for a theoretical or conceptual framework to investigate how the features of SM are relevant for autistic people to access their true risk and benefit. Future research should investigate the life satisfaction and both the quality and quantity of social connections online and offline to see how they map on to each other and might be mediated using SM. Future research should also look at how variables like age and gender impact the use of SM. There is also need for future research to involve autistic people, families, and wider networks to co-produce research for it to answer question they would like answered.

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Part 2: Empirical Paper

How do Autistic Young People use Social Media: A Qualitative Study of the Experience of Online Social Networking Site Usage.

Abstract

Introduction: Emerging Adulthood/Young People is used to describe the period of development between adolescence and adulthood (Arnett, 2004). As is the case with neurotypical populations, it is important for autistic young people to navigate this stage of life. Research has found that mental health concerns for autistic people often manifest during emerging adulthood (18-25 years) when social interactions are key to a healthy development of the self. Researchers have found that though face to face interactions may pose difficulties for some autistic people, they may show strengths in screen-based technologies, which facilitate connections and identity development in a safe space. Based on the current literature and gaps the present study aims to explore the social media (SM) in the context of autistic young people.

Method: Twelve autistic young people using SM were interviewed about their experience of SM using semi-structured interviews. The collected data was analysed using constructivist Grounded Theory (Charmaz, 2006).

Results: Based on the findings a theoretical framework has emerged from the data. The five main themes reflected by the participants were: social connectedness, flow of information, the context, disempowering SM, and boundaries.

Conclusion: In convergence with previous literature the study found that there are risks and benefits associated with the use of SM by autistic young people. However, the study also provided some new insights into the development and adaptation of coping strategies as a response to the risks associated with SM use. The study also provides insides into the transitional nature of online learning to offline environments. These findings can be used by schools, professionals, and organisations to support autistic young people learn skills and access SM in a safe way.

1. Introduction

SM may be defined as an application or a website that enables its users to participate in sharing or creating content (Oxford dictionary, 2018). SM also refers to any website that allows for social interaction, such as "Facebook, Myspace, and Twitter; game sites and virtual worlds like Club Penguin, Second Life, and the Sims; video sites like YouTube; and blogs." (O'Keeffe & Clarke-Pearson, 2011, p. p.118). As described in chapter 1, at its core, SM has two key components: 1) connection with other people and 2) creation and sharing of content (Kaplan & Haenlein, 2010; Press, 2018).

Over the last 15 years, the use of SM has grown and expanded rapidly, with a 60% increase in its users in USA in 2015 as compared to 2005 (Perrin, 2015). As the number of people using SM increases so does the interest in its impact on people’s lives. Seeing this growth and expansion of SM, one can posit that SM and its usage is a rapidly evolving phenomenon; the technological characteristics and habits of its users, as well as the number of users, are likely to evolve and change over time. This makes it important to continuously update the literature.

1.1 Social Media use by Autistic people

Autism spectrum disorder (ASD) is currently conceptualised by social communication differences and restricted and repetitive behaviour & interests (APA, 2013). Though older conceptualisations of autism described a lack of interest in social interactions (APA, 2013), autistic people’s accounts and recent research have indicated that there is a strong desire for social connections, friendships and other relationships (Bauminger & Kasari, 2000; Carrington et al., 2003; Parlangeli et al., 2021; White et al., 2007). Having meaningful social connections may have long-lasting positive impacts on autistic people, such as facilitating the development of social skills and social identity, that act as protective factors in difficult situations, and may increase confidence in one’s abilities (Benford, 2008; Mazurek & Kanne, 2010; Renty &

Roeyers, 2006). A lack of meaningful relationships, on the other hand, may have a negative impact on autistic people, from school performance to marginalization, leading to poor mental health outcomes (Bellini et al., 2007; Kasari et al., 2011; Rotheram-Fuller et al., 2010). As highlighted in chapter 1, though autistic people may experience difficulties in largely neurotypical contexts, they may show strengths in screen-based media (D. M. Ward et al., 2018) as it enables autistic people to make connections without the complexities of face-to face communications (Ahmed et al., 2019; Hong, 2014) and there are indications that autistic people may spend more time on their computer and SM as compared to their neurotypical peers (Engelhardt & Mazurek, 2013; Mazurek & Engelhardt, 2013; Mazurek et al., 2012; Mazurek & Wenstrup, 2013).

Though there is a paucity of research in the field, studies so far suggest that SM provides a communication platform with beneficial features relevant for some autistic people. These features include the pacing of online conversations, non-verbal elements, such as gifs and emojis, and control over the interaction and connection with people that they would otherwise not be able to meet (Abel et al., 2019; Benford, 2008; Benford & Standen, 2009; De Sausmarez, 2018; Kuo et al., 2014; van der Aa et al., 2016; Wang et al., 2020; D. M. Ward et al., 2018; Zhao et al., 2019). Thus, SM may alleviate some of the stresses of face-to-face communication, for some potentially leading to decreased anxiety, better quality of friendships (van Schalkwyk et al., 2017), increased confidence in their abilities to express themselves (Benford, 2008; De Sausmarez, 2018) and a safe space to develop their identity (Bordignon et al., 2015; Gillespie-Lynch et al., 2014; Stendal & Balandin, 2015). However as mentioned in chapter 1, SM also has disadvantages and risks for autistic people. Potential risks of SM include problematic use of the internet e.g. addiction-like behaviour, not knowing how much to disclose online, the inability to maintain online relationships offline, cyberbullying, negative impact on mental health (threats to identity and self-esteem), and increased masking behaviours (Benford, 2008; Benford & Standen, 2009; Engelhardt & Mazurek, 2013; Engelhardt et al., 2017; Engelhardt et al., 2013; Large & Serrano, 2018; Mazurek, 2013; Murray et al., 2021; Sallafranque-St-Louis & Normand, 2017).

Summarising the literature so far, it can be concluded that there are both risks and benefits associated with SM use by autistic people. Though research in this field is young, based on the review in chapter 1, there are gaps in the literature that make it difficult to draw conclusions based on age, gender, the translation of skills from the virtual to the outside world, ease of access of technology or the impact of physical and mental differences. It is important to address these issues in future research as they may have an impact of how and what SM is used for as well as the impact it has on the participants.

1.2 Emerging Adulthood/ Young People and Autism

In the current cultural environment, where marriage and parenthood occur later than in previous generations, Arnett (2004) coined the term 'emerging adulthood'[2] to characterise the transitional phase between late adolescence and early adulthood (Arnett, 2019). He described this period as one of self-discovery and instability, associated with a plethora of shifts and possibilities. There are a few key elements connected with this stage of development: identity formation, increased autonomy in decision-making, planning and future-oriented thinking, the creation of close connections and the formation of a peer group/community (Erikson, 1994; Kroger, 2005). Friends and peer groups are important during this stage of development, as they facilitate identity development and act as a buffer for the stress associated with the mastering

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[2] In the present study the term young people will be used interchangeably with emerging adults.

of these tasks or during the failures to do so (Cohen & Hoberman, 1983; Radmacher & Azmitia, 2006).

As for typically developing young people, navigating this stage of life is important for autistic young adults as well. There is little research on how neurodivergence impacts these stages of development, as well as what role the stigma associated with autism, mental health and 'difference' plays on these transitions. Research shows that emerging adults on the spectrum show poor outcomes in terms of increasing mental health problems, poor quality of life, lack of independence and social isolation (Billstedt et al., 2005; Engström et al., 2003; Howlin et al., 2004).

However, as autistic people may show strengths in screen-based media and research suggests that connecting with others in a safe and reduced-stress online environment provides autistic people with a sense of empowerment and support to facilitate social connections and engage with, develop and explore their identity (Bordignon et al., 2015; De Sausmarez, 2018; Gillespie-Lynch et al., 2014; Stendal & Balandin, 2015; Zhao et al., 2019). SM might offer a medium for autistic young people to master some of the tasks set out by this stage of development, namely identity and social connectedness. However, due to the paucity of research looking at particular age groups within the adult population, there are no studies so far that address the risks and benefits of SM use for autistic young people.

1.3 Aims and Rationale

Given these open questions and gaps in the literature, as well as research suggesting that autistic people may show strengths in screen-based communication technology (Mazurek, 2013; Ward, Dill-Shackleford, & Mazurek, 2018), and the risks identified, this study aims to explore SM in the context of autistic young people. Further objectives are to understand whether there are any potential autism-specific factors discussed or highlighted by the participants. The method selected as most appropriate for analysis was the grounded theory approach, based on the work of Charmaz (Charmaz, 2006).

2. Researcher Position

I am an Indian middle-class female, who moved to England in 2014 to pursue higher education. I grew up in a country where an important aspect of training to be a psychologist is dealing with the stigma related to mental health. I had participated in various outreach activities, such as led marches, spoke to government officials, and the wider communities to shed light on the importance of providing holistic mental health care (‘no health without mental health’). Stigma meant that children who had developmental disorders were hidden, ostracised from society seldom sent to school and rarely seen experiencing life. Though I do not have children, I do hope to become a mother in the future. My prior experiences of working with autistic children, adults and young people were based on my work in a ground-breaking NGO in India, started by someone who wanted her child to be included in life, and my research experience in the UK and USA.

Due to the lack of information and stigma attached to the field of developmental disorders and my curiosity to learn more about autism drew me to the field of autism research. As a young person staying away from friends and family, I have first-hand experience of the important role SM plays in my life, enabling me to keep in touch with family and friends. As a trainee clinical psychologist, I have also supported individuals who have experienced the negative impact SM can have on their body image and mental health.

Both during and prior to training I have had the opportunity to work with families that have autistic children and have previously trained as an ABA therapist. However, during my years in the United Kingdom (UK) and the United States of America (USA), interacting with autistic children and learning more about neurodiversity, reading resources on “Autistic

Twitter" made me want to hear more about the experiences of autistic people from autistic people themselves.

I attempt to explore and bracket my prior experiences and understand how they affect the way I think about what people share with me and what I read, to be aware of my biases and thus minimise them throughout the research process. However, there will of course be an influence of my past and current experiences, perceptions, and internal schemas affecting the study. Doing bracketing interviews, reflective logs and discussions with my autistic co-researcher and supervisor have brought to consciousness the impact these factors may have on my approach to the process, becoming more aware of my subjective impact on the data.

3. Methods

3.1 Grounded Theory

Grounded Theory (GT) is a qualitative method that focuses on the construction of a theory based on the relationships between identified themes that are grounded in the data. GT not only focuses on the described experience but also offers an abstract understanding of the phenomenon. This goes beyond other approaches, such as Interpretative Phenomenological Analysis and Thematic Analysis. The final theories that are generated are based on inductive coding and data categorisation, which is influenced by pre-existing constructs and theories.

For the present study, a constructivist (Charmaz, 2006) approach of GT developed by Glaser and Strauss (1967) was used. This approach follows the same principles of data collection and analysis as described by Glaser and Strauss (1967) but allows for more flexibility and accounts for the researcher's role in the process. Charmaz's (2006) GT approach is embedded in constructivism and, therefore, recognises the subjective nature of research and how the entire process, from data collection to theory generation, is shaped by the subjective experience of the researcher. The present researcher aligned with the position that research provides an idea of the world but not the absolute truth, facilitating the choice of GT.

A qualitative research method was important for the current project, given the limited literature and knowledge about the benefits and drawbacks of SM for young autistic people. Furthermore, though existing literature consists of qualitative research, the majority of studies had wide age ranges, focussed on specific aspects of internet use or on the analysis of its content. Therefore, the most critical requirement of the present study was to capture the experiences of the participants' own perceptions of SM's role in their life, with respect to their developmental stage. This research method will lead to the generation of a model outlining the use and experience of SM by autistic young people. It is anticipated that using GT can provide a framework that can help inform services, clinical psychologists, and other professionals about the role of SM for autistic young people. This may help them use SM as a tool to work with autistic young people or aid with their therapeutic understanding of some experiences. This is particularly pertinent given the salience of SM in the current world, more so during Covid-19.

3.2 Participants

3.2.1 Inclusion Criteria

Young people between the ages of 18-25 and with an ASD diagnosis were eligible for the study. All participants needed to use SM on a regular basis (5 to 7 days a week- as a general operationalization of the term regular). Since data was collected in an interview format, only participants who were independently able to respond to questions, whether written or spoken (via chat, voice call or video call on Microsoft Teams) could take part.

3.2.2 Recruitment

Participants were recruited through advertisements (Appendix 1) on SM sites (Twitter, Instagram, and Facebook), especially in groups for autistic people (Neurodivergent UK, Autistic Questions with Lia, Autistic UK and National Autistic Society). Specific hashtags; #AskingAutistics, #CallingAutistics, #AutismResearch, #ResearchAutism and #uclautismresearch; were used to make sure the posts reached the desired audience. Though all participants were recruited on SM, all subsequent research work was carried out via a UCL email address. Those who expressed interest in the study were sent an introductory email with an information sheet (Appendix 2). All participants were then sent a consent form (Appendix 3) and given a chance to ask any questions prior to giving consent to the research. The researcher arranged a time and communication mode for the interview.

3.2.2 Sampling

Purposive sampling was used. Since the present study aimed to capture important aspects of SM use by autistic young people, this method was thought to be the most appropriate (Charmaz, 2006).

3.2.3 Participant Characteristics

GT asserts that data collection should stop when categories reach saturation, such that no new codes emerge (Glaser & Strauss, 1967). Though the exact number of interviews required to attain saturation is difficult to estimate, research shows that saturation can be reached in as little as 12 interviews, and meta-themes can arise in as little as 6 interviews (Guest et al., 2006). Working within the constraints of the doctorate program, the number of needed participants was roughly estimated to be between 12-15. 12 autistic young people participated in the study (24 people showed interest but, due to participant personal reasons, only 12 were interviewed). See Table 2.1 for the demographics of the participants.

Table 2.1 Participant Demographics

Participant	**Age (Years)**	**Age of Diagnosis (Years)**	**Interview Format**	**Gender Identity, Pronouns**	**Ethnicity**	**Co-Occurring behavioural, physical, or mental health difficulties**
P1	19	11	Video Call	Male, He/Him	White British	-none-
P3	20	18	Video Call	Female, She/Her	White British	Depression, Eating Disorder
P4	18	15	Chat	Female, She/Her	White British	Anxiety, Depression, Eating Disorder
P5	22	8	Video Call	Non-Binary, They/Them	Asian British	Eating Disorder, Social Anxiety, Eating Disorder
P7	21	17	Video Call	Non-Binary, They/Them	White British	Depression, Eating Disorder

P8	18	17	Video Call	Female, She/her	White British	Anxiety, EUPD (prior to Autism)
P12	21	7	Voice Call	Female, She/her	White British	ADHD
P13	25	6	Video Call	Male, He/Him	White British	None
P16	23	21	Video Call	Female, She/Her	White British	Tourette’s
P18	18	18	Video Call	Female, She/Her	White British	Eating Disorder
P20	19	17	Chat	Female, She/her	White British	None
P21	23	14	Voice Call	Female, She/her	White British	Dyslexia and Dysgraphia

3.3 Ethical Approval

Ethical approval was granted by the University College London (UCL) Research and Ethics committee in May 2020 (Appendix 4). The information sheet highlighted- voluntary participation, right to withdraw, confidentiality and complaint procedures (further explains in the procedure below).

The study focused on recruiting participants who responded to the advertisements online, and therefore it was assumed that they had the capacity to consent. Time to debrief was offered to all participants after their interviews. None of the participants displayed any concerning risk, distress or requested to withdraw. All participants reported that they enjoyed the interview process and it helped them think about their SM use, something many had not considered before.

3.4 Procedure

After consenting, each participant was interviewed individually. To ensure the validity of the data, efforts were made to accommodate individual needs. Multiple modes of communication (chat, voice call and video call on Microsoft Teams) were offered to reach more participants. The interviews were carried out by the primary researcher. Each interview began with a discussion on confidentiality, the right to withdraw, and data protection. The limits of confidentiality were also explained. Participants were informed that their GP would be contacted if they disclosed any information that made the interviewer concerned about their safety, although they were assured these steps would be discussed and explained to them beforehand. They were also asked to be mindful of disclosing the names of people and locations.

3.4.1 Interviews

All interviews were conducted by the primary researcher on Microsoft teams. Data was collected via semi-structured in-depth interviews, allowing the researcher and the participant to be flexible and explore topics that may arise spontaneously in interview (Charmaz, 2006).

The interview schedule (Appendix 5) was developed by the research team and was reviewed by an autistic co-researcher. Within GT, the creation of the interview schedule is viewed as an iterative process; however, no substantial amendments were made to the interview schedule.

3.4.2 Analysis

The interviews were transcribed using a software called Trint and checked by the primary researcher for correction and accuracy. All transcripts were then anonymised and analysed using an analytic software called N-Vivo. This allowed for the codes and categories to be tracked, sorted, re-coded and for memos to be written. Coding was carried out using the process outlined by Charmaz (2006) and was supported by memo writing.

The coding process-

- The initial line by line coding was done which provided the basis for more in-depth analysis and further data collection (Appendix 6).
- the second stage of coding focused codes, brought the initial codes together and helped build more conceptual ideas (Appendix 7).
- The Theoretical coding brought the focused codes together to help form the relationships between the codes and create categories and build an analytical story/framework.

During the process, N-Vivo was used to identify the frequency of initial codes and cross-examine them across multiple levels. Coding focused on incidents that demonstrated the role of SM in accomplishing tasks set out by the stage of development.

In keeping with GT all themes and codes that arose from the data have been included in the model. However, illustrative terms were used to demonstrate how salient a theme was- All (represents all 12 participants), Majority of the participants (more than 70% but not all), Most (50-70%) and Some (Less than 50%).

Illustrative Quotes

Representational quotes that were vivid in conveying the meaning of each code were chosen from quotes that represented the codes in N-VIVO. The researcher tried to ensure that the quotes were chosen from across the whole sample rather than just a subset of participants.

3.4.3 Memo Writing

The researcher utilised memo writing throughout the process to investigate new theoretical concepts, explore alternative interpretations, and find substitute data collection pathways as needed. The analysis was then subjected to secondary analysis, whereby the emerging themes were shown to the autistic co-researcher and the research team. Over several weeks, the team worked collaboratively to refine the model, ensuring the results were accessible (Appendix 8).

3.5 Bracketing

Table 2.2- Sample Logs from the researcher's reflective journal

Date and Context	Excerpt
May 2020, Post Ethical Approval	'*Ethical approval required two sets of amendments as Covid hit after my amendments were submitted. It seemed like a never-ending process, but the comments from the committee helped me rethink some aspects of the research and have left me feeling very excited and more confident with the research. I am looking forward to recruitment and analysis.'*
September 2020, post the first three interviews	*'Listening back to the interviews and reading the transcripts, I noticed that I struggled to position myself between a researcher and a psychologist. I often found*

	myself being closer to a psychologist. Though it seemed like participants found my summarising helpful, I wonder if I am losing out on data. I reflected on this during a tutor meeting and wondered how different openness and curiosity of a psychologist might be from that of a researcher. *I hope to move forward with the interviews with this new understanding of the midway position between both and allowing myself to be both curious and open while also keeping my research hat on.'*
November 2020, Recruitment Plateau	*'Recruitment seems to have halted. Several participants have spoken about 'trust' or 'mistrust' for unknown people online and I wonder if that is a factor.* *Two participants also commented that they found my poster too crowded- my co researcher D.A. has volunteered to redesign the poster, I am hoping that this might help re-start recruitment.'*

3.6 Reliability

GT is inherently subjective as a qualitative research approach since no two analysts working with the same dataset will duplicate the other's analysis. Although proponents acknowledge this fact, it may create concerns about its reliability.

To overcome this, all participants were given access to the results to do credibility checks, ensuring that the results captured their experiences (Charmaz, 2006). In keeping with Covid-19 regulations, an email was sent, and all participants were given the option to respond.

Four of the 12 participants responded to the results and reported that the model resonated with their experience of SM (Appendix 10). The coding was also discussed with the co-researcher and the research team. The team worked together (discussions, reviewing, refining, and questioning connections) to refine the model.

This study further ensured rigour of the method through applying the guidelines set out by Yardley (2000). She proposed that the quality of a qualitative study can be assessed through attention to, sensitivity to context, commitment and rigour, transparency and coherence, impact and importance, and researcher reflexivity (Yardley, 2000).

4. Results

4.1 Overview

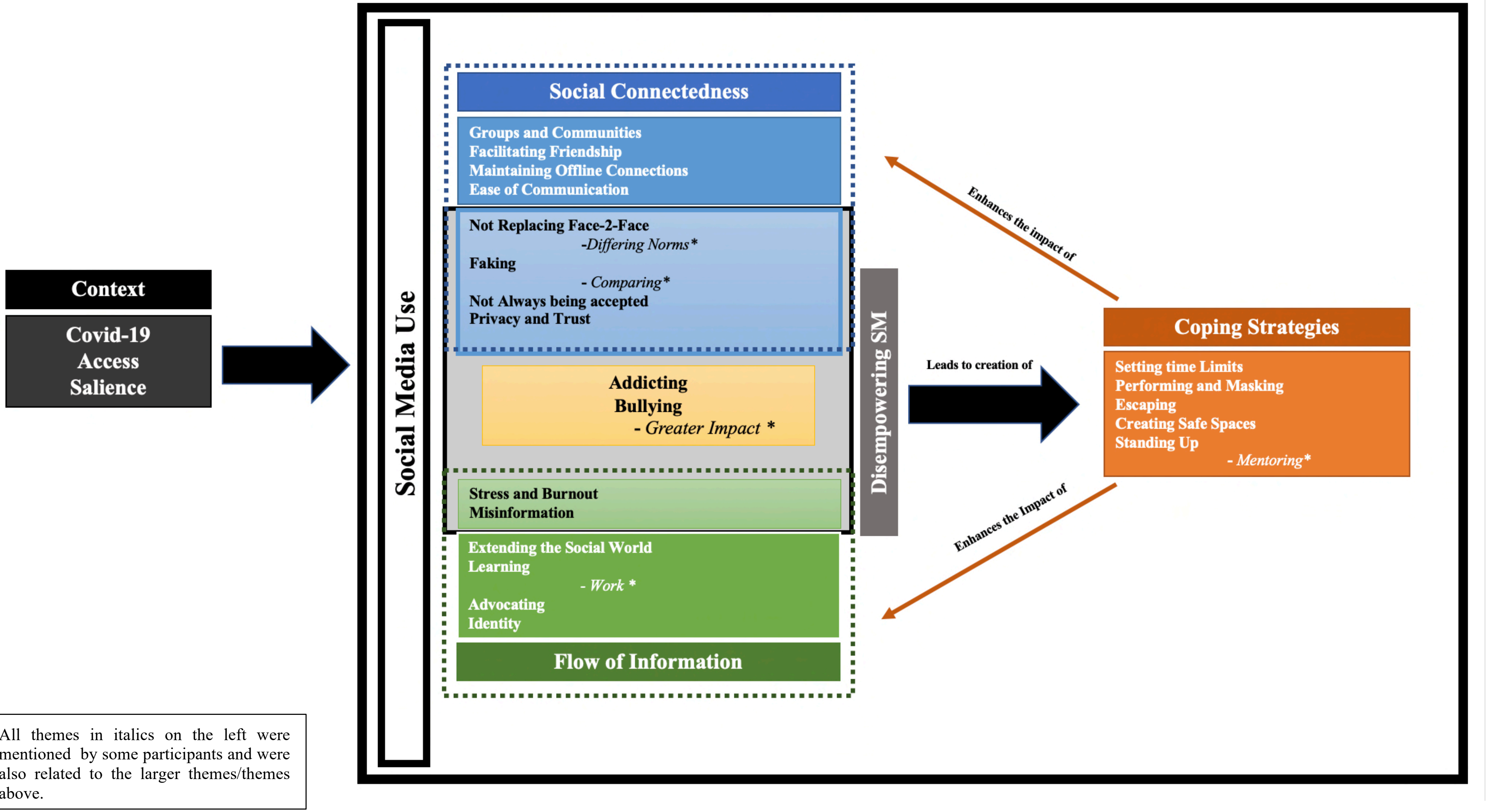
The grounded theory analysis is described in the sections below. The theoretical model constructed from the analysis represents how autistic participants negotiate the world of SM and how this, in turn, was related to their experience of SM.

4.2 A constructed theoretical model: Social Media Use by Autistic Young People

The “Boundaries Enhancing Empowerment” model of SM use by autistic participants in Figure 2.1 was constructed through the grounded theory approach, using the process of ongoing comparisons of the codes and category formation.

The model highlights the empowering and disempowering aspects of SM. At its core, autistic participants used SM for ‘Social Connectedness’ and ‘Flow of Information’. Within these two core categories, both empowering and disempowering factors were identified. Three key disempowering factors that influenced both the core components were ‘Bullying’ and ‘Addicting’ and ‘Greater Impact’. Within this model, autistic participants found ways to negotiate the disempowering aspects of SM, including the development of ‘Coping Strategies’ and, in turn, enhance the empowering aspects of SM within this model. SM use was impacted by ‘Covid-19’, (which led to increased use of SM over the past year) ‘Access’ and ‘Salience’, The value of being connected and transparent was high, which potentially led to SM having a less negative impact, specifically as there was high motivation to develop coping skills.

The whole model will be outlined followed by an analysis of the core components of this model in more detail in the following sections.



- All themes in italics on the left were mentioned by some participants and were also related to the larger themes/themes above.

Figure 2.1. ‘Boundaries Enhancing Empowerment’ Model of Social Media Use by Autistic Young People

4.2.1 Social Connectedness

SM was used by the autistic participants for connecting with others, in a one-to-one, one-to-many or group context.

4.2.1.1 Groups and Communities

SM allowed participants to connect with groups within local communities, special interest groups, work advice, and other autistic people. The majority of the participants in this study used SM for this purpose. Connecting with online groups and communities brought a sense of belonging and feeling supported in interactions, while the explicit norms of online groups and communities allowed for the adjustment of interaction patterns, with increased flexibility to moderate levels of engagement.

Participant	Quote
P12	'*Yeah, to some extent I'm in quite a few different groups on Facebook and stuff like that. It's easy online, they all have their rules on top and mostly people follow them [...] so I don't have to think about it [the norms of communication].'*
P16	*'I guess Twitter, [...] I don't like a lot of things about Twitter and am scared of it, but I like the fact that there are a lot of [...] like-minded people who are there and I can connect with them [through searches and hashtags]. It's also good, because when people go wrong, like lots of people call them out and support you. This cannot happen outside (SM)'*
P18	*'[...] one of the things that I like about social media that is kind of relevant to this is that there's a very large like autistic community and a lot of social medias. You know, if it wasn't [...] for those communities, [...] I might have not known that I was autistic.'*

P21	*'I would say I'm really part of a community and it's more like if someone else also likes gaming, then I just have something to talk about with them, so that you could say that about any interests shared [...] with another person.'*

Though groups and communities helped facilitate a feeling of belonging, some participants also reported feeling like they were ***'Not always being Accepted'***.

P12 '*Even the Facebook groups that are made for young autistic women, there's still a lot of negativity and [...] a lot of judgment. And it's like there's always room to be judged. There's never somewhere where you can just 'be' [yourself].'*

P20 *'I'm very blunt in comparison. I feel like sometimes [...] I would expect in our group, the way that I communicate, is accepted. But [...] there's been one issue where someone just like, took it the wrong way, even though it kind of misses the point of being in an autistic space.'*

4.2.1.2 Facilitating Friendship

Most participants reported that SM has been helpful in decreasing loneliness, facilitating new friendships, and expanding their existing social networks in the context of one-to one or group interactions.

Participant	**Quote**
P1	*'Well, it [SM] got me closer to a lot more autistic people. So, I didn't use to talk to very many and now I talk to about 200 young people with autism. They are my friends.'*

P13	*'I like how it allows you to reach out to people all around. I mean, I've spoken to people from all around the world? And I think I'm just talking to somebody from Togba. '*
P16	*'I think that social media has highlighted to me that I don't need to see that many people because, actually, if I feel lonely, then social media can help me with that. I do feel like mostly I have spoken to someone everyday [during lockdown].'*
P18	*'It is because a lot of the social media that I use [...] it's not so much interacting with people that I know, [...] but interacting with people that I don't know. [...] It's interacting with people because we have similar interests.'*
P20	*'It's had a huge impact. I wouldn't have many friends without it [SM] because of my social difficulties.'*

While SM helped participants meet new people, some of them were concerned about ***'Privacy and Trust'***. Participants worried about not being able to control how much other people know about them online, bringing a sense of vulnerability. Furthermore, risks such as hacking, 'doxing[3]' and catfishing[4] were mentioned.

P1 '*There is risk on social media. [...] You can get hacked if you don't have privacy settings on right. What do I do to stay safe? [...] I keep my accounts in the privacy settings*.'

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[3] It is the act of searching for and often publishing someone's private information online with the intent to harm the individual. Press, O. x. U. (2018). *Oxford Dictionaries*. https://en.oxforddictionaries.com/

[4] It is the act of pretending to be someone else online, using fake pictures, information, and persona to find friends or start relationships.

P16 *‘That can be a risk to anyone who doesn't want to be found by anybody or anyone who's been subjected to violence or someone who maybe works in a job where someone might be more inclined […]to you know […] where they live. […] keeping in mind, […] just like being aware that what you're posting… and that people might be to get more information from that than what you initially intended.’*

P18 *‘You have to be very careful about what information you disclose because, you know, you don't know who's on the other side and you don't know […] what they would do with your personal information if they have it and if they even have[…] very basic information about you, then it can be easy for them to find other things as well. So you have to be very careful about what you share.’*

P20 *‘You can get Doxed, which means someone shares your private information. [It] can lead to like, depending on […] what they share […] it's like if someone stated a political opinion, then they [other people] would go and they would hack it and get your personal information and then like call your workplace and be like, did you know that they voted for this party or that they said this on social media? […] there's like kind of hacking involved in it, yes. Sometimes there isn't.’*

4.2.1.3 Maintaining Offline Connections

All participants spoke about how SM helped them keep in touch with and maintain offline friendships and relationships with family members.

Participant	**Quote**
P1	*‘I use social media to keep in contact with my family.’*
P4	*‘I would use Instagram more to just share things with my friends. I use Snapchat if I want to share things just to one person or a smaller group. I use Facebook to keep up to date with family.’*

P7	*'I have a stronger connection with people I talked to, like both ways, like people I met offline I talk to a lot through social media.'*
P12	*'Most of the people I talk to through social media or interact with, are people I know in real life. Without it [SM] I think I wouldn't be in contact with my friends and family half as much.'*
P20	*'Keeping up with my offline friends.'*

4.2.1.3 Ease of Communication

Majority of the participants reported aspects of online communication that led to a perception online communication came with greater ease. The most prominent was the pacing of online communication. The slower pace gave participants time to reflect on and adapt their communication, making it less stressful and increasing sense of control. Certain aspects of SM, such as emojis, short forms and lack of non-verbal elements, helped facilitate communication for some.

Participant	**Quote**
P1	*'When you actually meet someone face-to-face, it can be quite nerve-racking and [...] a scary experience. Like when you're meeting someone that you've not met before and things like that. And that's very traumatic for autistic people. [...] So, you practice it online, where it is easier.'*
P4	*'I think that interacting with someone online is in some ways easier because there is less body language to navigate, and it can be clearer. I think that sometimes people are more able to express their views online, which can be a good or a bad thing.'*
P7	*'I guess the main thing that makes interaction easier- I tend to use a lot of emojis when I am typing to make sure I get my message across*

	properly. I am quite tired […]. I don't know if this applies to everyone, but I feel like I find it a lot easier to talk to people […] online rather than in person.'
P18	*'You have more time to think about your answers because, in real life, you can't necessarily, like, take a break for a minute to think about what you want to say, because then, you know, the other person will be like, what's going on. You haven't spoken for like a minute. And so, there's that aspect. And, you don't have to worry about presenting yourself physically. You don't have to worry about looking them in the eye or reacting appropriately with your facial expressions because they can't see any of that when you're talking to someone online.'*

4.2.1.5 Not a replacement for face-to-face

Though several aspects made online communication easier, most of the participants reported that there were limitations to relationships and communications online.

Participant	**Quote**
P3	*'Sarcasm on a text message is even harder. […] you can't read someone properly.'*
P12	*'You definitely miss out on a lot when you do things like online […] because you can't have the social interaction […with] body language and things like that. You can't tell what's happening when you're behind a screen.'*

P13	*'You can learn a lot about somebody online, but nowhere near as much as you can when you're with them.'*
P21	*'There's a lot missing in online conversation, versus when you meet face-to-face. I can never really tell how someone feels about something online.'*

This perception was further heightened by the ***'Differing Norms'*** of online communication; a sense that online communication is both somehow clearer and less clear due to the missing elements of non-verbal communication.

P8 '*This probably just me who thinks this, but when you have normal social rules and interactions, you have a certain set of rules... But then on social media it's different and you kind of have to adjust to that.'*

P12 '*It's like there's almost a different set of etiquette rules for each social media. So it could be hard to keep up with what you have to be like on Facebook compared to what you have to be like with Instagram.'*

4.2.1.4 Faking

'Faking' is the creation of a perception or a character or version of themselves that they want to portray to others, this was also supported by the behaviours of these users online. This is a was used to describe the behaviour by other users that the participants encounters on SM. Some participants reported feeling some people did not bring their authentic selves to SM.

Participant	**Quote**
P3	*'I hate that people [...] are so perfect. [...] it's so annoying because we all know it is not true. It just winds me up.'*

P8	*'I think [...] it's not representative of people at all. There are people that might like you see on social media, and they might ask to follow you. And then you look through their profile and then you create this picture of what they might be like. And then you meet them in real life, and they are nothing like it.'*
P16	*'It's a fake supportive place where people are just kind of trying to undermine each other. People would be asking for genuine advice [...] and then it just gets really backhanded. And I feel like whilst it sounds superficially supportive, [...] it just makes my hair stand on end. It feels like people are just trying to top each other down a little bit.'*
P21	*'People aren't really saying what they really feel online.'*

Some of the participant articulated how 'Faking' online meant they ended up ***'Comparing'*** themselves to others, leading to feelings of jealousy and inadequacy.

P5 '*I guess when people post about how productive during lockdown [they were], how much fun they're having, it can make you feel bad if, like, you're not doing it.'*

P8 'I think, in terms of mental health things, they can be toxic, some things aren't very helpful. But I think with like dieting and things like that. I guess especially Instagram - so obsessed with beauty and stuff like that.'

P21 *'Instagram. I don't know. Sometimes, like it looks like [...] there is only good stuff. So, it looks like they've got really nice lives going on. So sometimes it makes me a bit jealous.'*

4.2.2 Flow of Information

SM was used to share information, learn, and advocate. This category was further divided into three empowering aspects and disempowering aspects.

4.2.2.1 Extending the Social World

Getting information online helped extend the social world, either by providing multiple viewpoints on different issues, reading the news, or getting to know what is happening in the world. Most participants used SM to get news at 'high speeds'[5] and learn how the news impacted and affected the people around them.

Participant	Quote
P4	*'I like Twitter because I like to hear other people's viewpoints and know what is going on generally in the world. I think it has had a positive impact on my day-to-day life as it gives me something productive to fill my time with and I like to stay up to date with things.'*
P13	*'As a matter of fact [...] I learn news through Facebook. [...] So, I must go through my Facebook.'*
P21	*'[I use] Twitter once today for [...] general news. '*

Although SM extends the external world, providing ease of access to high amount of information, few participants spoke about how there is also a lot of ***'Misinformation'***.

P7 *'It's also been quite easy to share mis-information. [...] that's how it was distorted. I think I tend to trust, like implicitly trust, things I see online even when I shouldn't. So that [...] could be a problem.'*

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[5] The ability to get information online before it has been published in the news, via other people's personal accounts, warning on social media sites or 'mark yourself safe' on Facebook app,

P20 'I think there is a huge problem at the minute with non-autistic people talking for autistics online. Especially with companies such as 'Autism Speaks', misleading information can be hard to hear if you're autistic.'

4.2.2.2 Learning

SM was used to learn about hobbies, social justice issues, academic interests, and new skills. Most of the participants reported using SM as a tool that empowered them to learn with ease.

Participant	**Quote**
P3	*'I look at sh*t like cooking videos. I really like cooking and learning languages. So, I do a lot of looking at language memes and vocabulary....'*
P8	*'Sometimes it's quite useful. When you want to educate yourself about something [...]so I want to study medicine and there's quite like a lot of [...] accounts that gives you like advice and information about what to read and study.'*
P16	'*I quite like [...] the way hashtags work. I feel like I learn a lot as well. I feel like a lot of social media has social justice issues that weren't as much on my radar as they should have been if I was not looking for that kind of activity. And now on they are on my timeline because I follow people who care about justice issues. [...] So, I feel like I'm learning a great deal and I feel like I see things on Twitter and go to research further.'*

Few participants used SM to either find or promote their ***'Work'*** or get career advice.

P1 '*That's also one of the ways? we reach out to companies and help them employ and support like autistic people at work…'*

P16 *'I have been using groups and stuff recently on Facebook, but mainly career advice type things.'*

P18 *'I also have Instagram and Twitter and Facebook, but I tend to use those more for promoting my art.'*

4.2.2.2 Advocating

Most of the participants used their 'Autistic Voice' (own lived experience) to help both autistic and neurotypical people learn and understand autism better. SM gave access to a platform where multiple people can be reached out to.

Participant	**Quote**
P1	*'I actually talk about my diagnosis all the time. […] Some people […] try and put that [other's advice and experiences] into their lives. And it's interesting to see people using other people's techniques.'*
P4	*'I use Twitter for advocacy quite a lot and I follow Twitter hashtags to hear from other autistic people. […] I do advocacy with different organisations in real life as well - I am a youth consultant for xxxxxxxx, for example. [Online] I retweet a lot of things about being autistic and the autistic experience. '*
P20	*'I created an account to share experience with ADHD and Tourette's and mental health in general. I still use this account to document my experiences and meet people with similar ones. It's helpful because I can find people who relate to me, especially with autism. […] it helps us learn.'*

P 21	*‘I feel like because of social media, autistic people have been able to find a voice [...] it was really difficult to articulate before. Which is why there's so much backlash from like Autism moms and organisations like Autism Speaks and stuff, because before they were the ones that held the talking space. And now [...] all disabled people have more accessible means to talk about themselves instead of being spoken for.’*

4.2.2.3 Identity

SM helped some participants in accepting themselves through interacting with similar people, understanding different aspects of their identity, and their own and others’ limits. For most, SM provided a helpful perspective for developing one’s identity and integrating one’s experience in a safe positive space.

Participant	**Quote**
P4	*‘I think I have learnt about the way people react and respond to each other through social media and I find it interesting to watch sometimes. I have learnt that everyone has different opinions and that is good. Because then I can also be different.’*
P7	*‘I guess the main thing is being exposed to information about the LGBTQ+ community. I think social media and the internet helped me figure out my identities.’*
P16	*‘I feel like what I've learned [...] it has helped me to be better on the Internet, helped me to be a better friend in terms of what I can talk about.’*
P18	*‘I know a lot more about the way that I work. [...] There's not so many resources in real life. Being able to talk and listen to other autistic people*

	online was helpful in finding myself and understanding more the way that I worked.'
P20	*'It has made me feel slightly more comfortable with the label (Autistic/Autism), as, before, I wouldn't tell anyone except my SEN (Special education needs) teacher about it. But social media helped me to understand the positives, and that it isn't something to be ashamed of. I'm still struggling with this, but it has helped me to start shifting my perspective.'*

4.2.2.5 Stress and Burnout

Having access to large amounts of information and being able to witness everything that is happening around the world (positive and negative) triggered feelings of stress, overwhelm and burnout.

Participant	**Quote**
P4	*'I can sometimes find them quite overwhelming, especially Twitter. […] if something big is happening, like during the election, and everyone has strong opinions. '*
P13	*'[…] after some time, it got too much […there was] like a general lack of interest in helping people […] because it's too much…'*
P16	*'I think I felt a bit stressed towards the beginning of it [Covid-19] with social media and the news because I felt like I should be checking up on literally everyone who I know.'*
P21	*'There's a term I came across, someone just made up, but they called it "empathy burnout". You see so much bad news from all over the world*

	[...] you can't have empathy for all of it. So, you end up feeling tired of it.'

4.2.3 Disempowering SM

'Disempowering SM' elicited feelings of helplessness, loss of control, fear and anxiety.

4.2.3.1 Addicting

Some participants described or implied that their use of SM could be compared to an addiction. For some, there was a sense of feeling out of control: SM use could take over if it was not managed.

Participant	**Quote**
P3	*'I hate social media in general, I suppose [because] you can just spend hours on it without even thinking about it.'*
P5	*'So, I did use Tiktok a lot actually. At one point I was so obsessed with it [...] that I wasn't sleeping [...] I would keep going through it for hours and send it to my friends who also had insomnia and stuff.'*
P18	*'I would say I probably use it too much because it's quite easy to become addicted to it and just [...] keep scrolling all the time, you know, just like scrolling through like Instagram feeds and all that because it refreshes. [..] it is rare that you wouldn't have anything new to look at. So, it can be really easy for that to preoccupy your day.'*

4.2.3.2 Bullying

SM use involved unexpected encounters perceived as stigmatising, excluding, and shaming. Most participants reported 'hiding behind the screen[6]' and 'online anonymity[7]' had made it easier for people to engage in acts that were intentionally meant to cause harm or harassment.

Participant	**Quote**
P1	*'I've noticed recently that there's been a lot more people saying nasty comments to each other and there's a lot of threatening behaviour going on. It is difficult to understand especially from ones that [...] you've never met and you don't know why they're being the way they're being....'*
P12	'*I think people nowadays have learned a lot quicker from social media that nobody's quite that nice and people can be nasty. And I think that's been learned quite quickly than in past [...]'*
P20	*'I dislike the use of anonymous messages to bully people. It's very common and I see it every day. I also hate how people use social media to spread hate.'*

Few felt that some of the disempowering aspects had a ***'Greater Impact'*** on autistic people.

P1 *'We trust people [...]. It's not good...'*

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[6] not being face-to-face

[7] The ability to be anonymous or anyone online

P8 'I don't know. I definitely think there should be more awareness of how it could [...] affect autistic people because there's never any kind of [...] acknowledgement of how it can be greater or different.'

P12 *'There is quite a lot of negative small communities on the different platforms, like I said, about eating disorders and stuff like that. I think they can be quite harmful, especially to people who are vulnerable.'*

4.2.4 Boundaries

Some autistic participants developed strategies (including Boundaries) to cope with the disempowering aspects of SM and enhance the empowering aspects.

Participant	**Quote**
P4	*'I would say that social media has an overall positive effect on feeling isolated.'*
P7	'*I guess in general, when I'm at home from university without social media, I would be feeling quite isolated'*
P12	'*I really can't imagine not like using social media. I guess it's good.*'
P18	'*I would miss out on a lot if I wasn't on social media and I would miss out on a lot of events as well, because I rely on the Internet to find out about things that are going on, because often, if there's an event, it will be posted on a Facebook group.'*

4.2.4.1 Setting Time Limits

Some participants set boundaries by limiting the amount of time they spent on SM. This also helped them engage with other activities and take time to 'cool off' or de-stress.

The setting of this boundary was a dynamic ever-evolving process that depended on the individuals need at every moment.

Participant	Quote
P1	*'I switch my phone completely off [when I work] and I just ignore it [SM].'*
P3	*'I've got my app limit set, so I don't spend a lot of time on it [SM apps].'*
P4	*'I usually try and reply to messages in the evening so that they are done and out the way. I save that slot for doing this if I don't want to feel like I can keep having to respond during the day.'*
P 13	*'It [the news] was stressing me. What I do now is I just [...] stop after 10 o'clock [...] So now I read a book or something like that before I sleep.'*

4.2.4.2 Performing and Masking

Some participants described a process of selectively sharing aspects of their identity, such as by using anonymity and creating distance from certain aspects of themselves. This allowed some participants to cope in certain situations, develop other aspects of their identity, or help them feel more accepted on SM in general. ***'Selective Autism Disclosure'*** was one of the ways of performing or masking online.

Participant	Quote
P5	*'I have multiple accounts on Twitter. [...] I like compartmentalising things. I have got like an account for LGBTQ+, ADHD, Eating Disorder, Autism. They have different posts and followers [...] it's different parts of me...'*

P8	*'Because I was quite unwell […] I've never […] posted about it. […] If you look through my Instagram […] you wouldn't think I have autism or mental health problems. So, I think in that sense, I have learnt more about […] how much I don't want things like that out there.'*
P21	*'I wanted people who had known me to kind of understand me more [by sharing the autism diagnosis]. But, to be honest, most people don't understand autism at all. So, they were just alienated.'*

4.2.4.3 Escaping

Several participants used SM as an escape from what is happening in the immediate environment. For example, some used it to passively look at things when bored, as part of procrastination. Others created a 'fantasy' of a problem-free and perfect life, using their SM persona.

Participant	**Quote**
P3	*'When I'm on social media it's because it's downtime.'*
P8	*'Instagram's more […] just when I'm bored; when I just don't know what else to do.'*
P12	*'Sounds a bit sad, but [it's] like a place to escape to. I can go to my phone and post my Instagram and pretend that my life is all perfect and happy to everyone else […] And I think I've definitely used it a lot like that, when I have poor mental health……Yeah, I definitely used my social media to sort of like help me get away from everything that was happening.'*

4.2.4.4 Creating Safe Spaces

Some participants developed boundaries by blocking people, connecting only with known people, letting others support them, giving out limited information online, and following more positive accounts, to create safe and helpful spaces for themselves.

Participant	**Quote**
P1	'*That's why I say to a lot of young people: keep your privacy settings on as high as you can and block and report people who bully you.'*
P3	*'I keep myself to myself. I don't put details on there that I don't want people to know. I don't post images that I don't want people to see. Anything you put on social media, anything you put online is there, online. Being careful, that's what I do.'*
P5	*'Over time I started following more like positive, more diverse accounts [...]. So, you can't get quite that affected.'*
P7	*'Typically, I just stick to the feeds of the people I'm following or the people I'm friends with…'*
P18	*'I would never disclose my information to people who I didn't know. Um. And I'm always very careful about what I post.'*

4.2.4.5 Standing Up

Many participants received support from or gave support to others in difficult situations. Participants reported developing resilience and confidence using SM that enabled them to support others.

Participant	**Quote**

P13	*'One thing I should say is I have a low tolerance for intolerance. And I can find it most when I see somebody with disabilities being shamed on social media. I do come into it guns blazing, you know. We have to support them.'*
P16	*'I don't think cancel culture is necessarily a bad thing, and I think we really fear it, but I think it shouldn't be played in that way because it is just feedback, ultimately. I think I think that's generally a good thing.'*

A few participants also spoke about using social media for ***'Mentoring'*** other autistic people and teaching them how to respond to bullies and harsh comments online.

P1 'You get one-to-one mentoring with support staff online, which is good. You learn how to [cope] appropriately, not just fly off the handle because that's what they expect of you. They expect that you will just fly off the handle, whereas if you remain calm and professional like I am, then you know everything will be good.'

4.2.5 The Context

"*In order to analyse social processes, one must take into account the context of the situation*" - (Charmaz, 2006, p. 131)

4.2.5.1 Covid 19

The interviews took place a few months into the global pandemic which had an impact on the use of SM . Due to Covid-19 restrictions and lockdown (e.g., limited contact with friends) most participants reported an increase in SM usage for the purposes of connecting and getting/sharing information.

P7 *'I think [Covid 19] is the main reason why I've spent more time online, using my phone, my laptop. So, I don't spend quite as much time as I would like doing a lot of other things.'*

P12 *'I think with coronavirus [...] it's quite a good tool [...] because I know a lot of people aren't happy with meeting up with random people in-person to do schoolwork and stuff like that.'*

Some participants, on the other hand, reported that Covid-19 did not have an impact on the amount of time they spent on SM.

P21 '*I don't know if I really use my phone more than I used to. Even before covid I spent most of my time indoors anyway.'*

4.2.5.2 Access

It is defined by having easy access to technology that enabled the participants to use SM. All participants reported primarily using their smartphones for accessing SM.

P3 *'If I weren't on social media, I don't think I'd need my phone.'*

P5 '*[I use SM] usually on my phone and then sometimes my laptop. When I'm doing things online, I have Facebook and Twitter tabs open.'*

P18 'Mostly, I would say I use my phone because obviously I can take that with me on the go, but then I do use my computer as well.'

4.2.5.3 Salience

All participants reported that SM was a part of their lives. Though some reported periods during which they didn't use SM, it was still a part of their life that they could not completely cut out Especially, within the context of Covid-19, the choice of not using SM seemed to reduce.

P3 '*So I downloaded Snapchat when I was 13or 14. I think that was my first social media. I used it to chat with friends.'*

P4 'I do think that it would be much more difficult on a day-to-day basis without social media as it is hard to reach as many different people.'

5. Summary of Findings

Using GT and semi-structured interviews the current study explored the role SM plays in the lives of autistic young people. While several previous studies have focused on SM use by autistic people, this study was unique in its focus on emerging adults/young people (18-25 years).

Consistent with previous research with autistic populations, there were both benefits and risks associated with SM use. The key benefits articulated by participants included connecting with others e.g. communities, friends, and families, facilitating friendship, advocacy, identity formation and ease of communication (e.g. (Abel et al., 2019; Benford, 2008; Benford & Standen, 2009; De Sausmarez, 2018; Large & Serrano, 2018; Mashat et al., 2016; van der Aa et al., 2016; van Schalkwyk et al., 2017)). The key drawbacks and risks discussed by participants also aligned with previous findings, and included privacy and trust concerns, cyberbullying, addiction, SM not being a replacement for face-to-face communication, and differing (often confusing) social norms (e.g. (Engelhardt & Mazurek, 2013; Kuo et al., 2014; Massier, 2017; Mazurek et al., 2015; Sallafranque-St-Louis & Normand, 2017; Slobodin et al., 2019; Sundberg, 2018; van der Aa et al., 2016).

Participants from the current study also responded to these risks ('Disempowering SM') by developing strategies aimed at minimising them. These coping strategies involved ‘setting time limits’, ‘creating safe spaces’, ‘escaping’[8], ‘performing & masking’ and ‘standing up’ to behaviour that was seen as inappropriate. These findings were in convergence with a paper on identity and SM where via grounded theory analysis of online content, the researchers found that autistic people developed/utilised coping strategies as a response to perceived threats to identity (Large & Serrano, 2018).

Another key contribution of this study is the participants’ description of SM use for ‘extending the social world’, by accessing news; ‘learning’ new skills; and promoting and finding ‘work’. Some SM downsides not previously highlighted within the autistic populations included prevalence of ‘misinformation’, ‘comparing’ and the disempowering aspects of SM having a ‘greater impact’ for autistic people as compared to the neurotypical population.

In the following sections, the core components of the developed model (Figure 2.1) are discussed, with focus on novel findings and their impact on autistic young people. This will be followed by a section on clinical implications, and implications for communities and organisations.

6. Discussion

6.1 The Context

Before discussing the findings of the current study, it is important to keep in mind the context within which it took place. The three factors that influenced the results as articulated by the participants were – ‘salience’, ‘access’ and ‘Covid-19’.

Since its emergence in the 20th century, SM and the internet have played a role in the lives of most individuals (access differs within and between countries, based socio-

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[8] It is not a coping strategy in the traditional sense, but is it defined as a coping strategy as it uses some disempowering aspects of SM to escape real life.

economic-status and internet access). There has been a 60% increase in SM users from 2005 to 2015 in USA (Meng et al., 2017; Perrin, 2015). In the last decade the SM seems to have a had an important role in the lives of most people. It plays a fundamental role in the modern world, allowing people to communicate, develop and maintain careers, gather information, and entertain (Anderson et al., 2017; Murray et al., 2021). With the large shift and advent of technology, the internet and SM have become a part of normal lives. In line with previous research participants in the current study also discussed the 'salience' of SM in their life. Most of the participants started using SM in their early teens (12-13 years), to learn, unwind, communicate, and connect with both new people, existing friends and family.

Participants also discussed their concerns around losing friends, connections, and access to information if they stopped using SM and found it difficult to imagine life without it.

Participants highlighted that the salience of SM in their day to day lives was facilitated by the 'easy access' to technology. Access is defined as the act of using and owning devices that enable access to SM (Brault, 2012; Khanlou et al., 2021; Warschauer & Matuchniak, 2010). All participants reported their smartphones as the most frequently used device to access SM. Using smartphones gave them easy access to SM irrespective of where they were. Access to technology is important to enable individuals to participate in and engage with SM (Khanlou et al., 2021).

These contextual factors were further exacerbated by Covid-19 (a global pandemic) that redefined how people lived. Lockdowns across the UK led to the curtailment of movement, physical activity, and face-to-face social interactions, enabling people to rediscover SM. SM does and still plays an important role to facilitate social connections, disseminate information, support education and enable people to sustain offline relationships (Chan et al., 2020; Goel & Gupta, 2020). Participants reported that lockdowns and Covid-19 meant that SM was the only way to connect with and access their friends, keep in touch with university education and access news. Some participants also mentioned that being isolated at home meant that they ended up spending more time on SM as compared to before the pandemic, while others reported no such impact, as their lifestyle did not change with the lockdown.

6.2 Social connectedness

Participants in this study found that SM enabled them to socially connect with ‘Groups and communities’, 'Facilitating friendships’ and ‘Maintaining offline connections’. For some, this was enabled by ‘Ease of communication’, such as the pacing of conversations, lack of non-verbal cues, predefined rules and norms, and online communication tools e.g. emojis, and gifs. However, SM usage could also be accompanied by disempowering factors (risks): ‘Privacy and trust’ concerns; ‘Not always being accepted’; ‘Faking’, lacking valuable elements of face-to-face communication (‘Not replacing face-to-face communication’).

These findings align with previous literature showing that the rise of screen-based media use (Baker et al., 2013; Cleary et al., 2020) has created new communities ; allowed for the meeting of new people (Ahmed et al., 2019; Benford, 2008; Benford & Standen, 2009); and eased keeping in touch with family and friends (Hong et al., 2013; Massier, 2017; Saha & Agarwal, 2015a). However, with this ease arose new difficulties, such as the differing social norms online, not knowing who to trust, and concerns about privacy and faking.

Burke et al. (2010) described privacy and trust as ‘knowing how much to disclose and knowing whom to trust’. In their qualitative study, autistic participants reported concerns about not knowing whom to trust and how much information to share with others they met online, a phenomenon reported by participants in the present study as well (‘Privacy and trust’). Other participants reported histories of being taken advantage of or bullied, which some ascribed to difficulties with spotting deception (Van Tiel et al., 2021; Yang et al., 2017) which could also be contributing factors.

Another disempowering aspect of SM was ‘not being accepted’ which was defined as intolerance and judgement, even in spaces that participants felt were meant to be accepting. Participants specifically described situations in groups meant for autistic people where they felt like they were not accepted for being themselves. Burke et al. (2010) similarly reported that, due to the large diversity of autistic people, some participants reported ‘cliquish’ and ‘not accepting’ behaviours in online communities, leading to members feeling alienated. It can be hypothesised that with the salience of SM in the day to day lives of people processes similar to those that might happen in the social world are being played out in the online world as well.

‘Faking’, here defined as others’ use of false personas online to portray a certain image of oneself, further contributed to issues about ‘trust and privacy’. Fire et al. (2014) reported that 83 million accounts on Facebook were fake, while Jedrzejewska and Dewey (2021) reported that both autistic and neurotypical people showed masking behaviours online, though neurotypical people tended to mask more. Some participants reported feelings of jealously, envy and frustration when they compared themselves to what seemed like others’ ‘perfect lives’ (fake personas). Which had a negative impact on their mental health and self-esteem. These findings are like those in neurotypical populations where the use of SM has been linked to higher levels of envy, anxiety, depression, narcissism, and upward social comparisons (Bauminger & Kasari, 2000; Forest & Wood, 2012; Jan et al., 2017).

Due to reported difficulties with non-verbal communication and facial expressions in real world interactions, many participants thought SM was ‘not a replacement for face-to-face communication’ as it lacked vital non-verbal cues, shared experiences, and emotions that enabled building stronger connections. This is similar to previous findings (e.g. (Benford, 2008; Benford & Standen, 2009; Burke et al., 2010; Mazurek, 2013). This feeling was further heightened by the need to master and learn the norms of online communication, which tended to change with different SM platforms.

6.3 Flow of information

SM’s connectedness aspect also facilitates the ‘flow of information’, by allowing participants to access news, and learn from and advocate to wider audience. The fact SM is easy to access, and it allows users to rapidly learn about and from others’ views and receive support, made SM an important tool for the participants.

Benkler (2006) and Chadwick et al. (2015) found that the ease of access to the internet led to more diverse news and an increased engagement online. Some researchers have found that the exposure to news online leads to an increase in political and civic participation (Gil de Zúñiga et al., 2012) by allowing users to be exposed to news from heterogenous sources (Flaxman et al., 2016; Messing & Westwood, 2014). Participants from the present study also noted that using SM allowed them to learn about different social justice issues and participate in promoting them or reading about them more. This in turn increased their knowledge and enabled them to follow up with issues that they resonated with. However, some participants also reported that the ease of sharing meant, at times, they tended to read and believe misinformation or ‘fake news’[9]. Del Vicario et al. (2016) suggested that a possible reason behind the sharing of misinformation could be that SM

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[9] News of low quality that may contain intentionally fake information.

provides a platform that takes control of news-sharing away from journalists and gives it to everyone. Some have also argued that it could be due to 'echo chambers'[10] amplifying a single narrative (Messing & Westwood, 2014; Quattrociocchi et al., 2016). Participants in this study reported that to keep safe online, they often tended to follow people they knew, those who had similar views and made them feel positive. It can be hypothesised that this in turn could lead them to the formation of bubbles or echo chambers and prevent them from experiencing diverse opinions and enhance a single narrative.

Participants also noted that access to information and news on SM often led to an overload of negative information, which, in turn, led to feelings of ‘Stress and burnout’. Studies on SM with neurotypical populations have reported that burnout and fatigue due to information overload (Sharma et al., 2020; Whelan et al., 2020). These authors posited that there is a need for more cognitive and mental resources to process information which leads to more unpleasant feelings of stress (Cao & Sun, 2018). It is yet unclear how and if feelings of stress and burnout differ between autistic and neurotypical populations. However, since stress may lead to anxiety and autistic people report higher rates of anxiety, the link between stress, anxiety, burnout, and SM should be a priority for future studies (Kent & Simonoff, 2017; van Schalkwyk et al., 2017).

Being able to access information online also enabled participants to learn new skills, and hobbies, such as cooking and languages. This included learning new skills, and hobbies, such as cooking and languages. This was facilitated by an engaging and fun mode of learning on SM e.g., memes and entertaining videos. Participants also reported using

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[10] It is the process by which individuals surround themselves with people, beliefs or opinions that are like theirs or coincide with their own. This recreates an environment where their own views might be reinforces and alternate ideas are not considered. Press, O. x. U. (2018). *Oxford Dictionaries*. https://en.oxforddictionaries.com/

SM to get advice on and to read information related to work. Though these aspects of SM have not been studied with autistic people, a number of studies with neurotypical populations have reported that online learning led to increased confidence in own studying skills; allowed easy access to information; and facilitated generalization of skills outside SM (Akgunduz & Akinoglu, 2016; McCorkle & Payan, 2017).

Easy access also enabled users to create and share content and information with others. Similar to the participants in this study, existing research has reported SM offers a comfortable platform to share information about oneself, and engage in advocacy for autism-specific and other valued causes (Abel et al., 2019; Ahmed et al., 2019; De Sausmarez, 2018; Saha & Agarwal, 2015a, 2016). This was particularly because participants felt they could reach a wider audience (Benford & Standen, 2009; Saha & Agarwal, 2015a), and enhanced feelings of confidence and expression of authenticity on SM supported by the ease of communicating online (Jedrzejewska & Dewey, 2021; Stendal & Balandin, 2015; van der Aa et al., 2016). Participants also reported that advocacy allowed them to connect with similar others that in turn helped with creating a community for themselves.

Due to the presence of a large online autistic communities, whose users openly advocate and share their experiences of being autistic, participants also reported learning about autism and becoming more confident with their autistic identity (Davidson, 2008; De Sausmarez, 2018; Large & Serrano, 2018). Most participants, particularly those identifying as female, reported that, in the absence of easy access to autism information for autistic young people, SM was their prime source of learning about autism. It not only enabled them to learn about their diagnosis but also facilitated the learning of coping strategies and increasing self-understanding of different aspects of themselves.

Though identity formation is a complex process, it is aided by communication with others, which enables people to learn more about themselves (LaRose et al., 2001; Radmacher & Azmitia, 2006). Previous studies found that being part of online communities and interacting with others enabled autistic people to express themselves and develop and explore their identity (Barkley et al., 2006; Davidson, 2008; Gillespie-Lynch et al., 2014; Zhao et al., 2018). De Sausmarez (2018) through a mixed methods study reported that SM enabled autistic people to develop both their autistic and non-autistic identity. Participants from the present study also reported learning about both their autistic and non-autistic identities on SM as it provided them the platform to learn about and develop all aspects of themselves through social connection, advocacy, learning about diversity & autism and interacting with people with diverse views. This also in keeping the social identity theory that states that the individuals are not only defined by their own characteristics but also by those of the groups to which they belong (Tajfel et al., 1979).

6.4 Disempowering SM

The same aspects of SM that promoted ‘Social connectedness’ and ‘Flow of information’ also supported the disempowering aspects of SM: ‘Addiction’ and ‘Cyberbullying’.

On one hand, SM has made it easier for some people to meet others and become part of a community (Ahmed et al., 2019; Benford, 2008; De Sausmarez, 2018). On the other hand, SM has also made it easier for some people to harm others, through harassment, stalking and bullying. Some participants in this study reported experiencing ‘unkind’, ‘nasty’ and threatening behaviour, akin to cyberbullying. Cyberbullying is not a phenomenon that is exclusive to autistic people. Studies show 30-70% of young people have experienced cyberbullying (Microsoft, 2012). However, the research so far suggests that marginalised groups, such as autistic people might be at greater risk for (cyber)bullying

(Campbell et al., 2012; Schroeder et al., 2014). Reasons for this may include differences in communication and hence more frequent misunderstandings, linked to the frequency and at times fast pace of online communication (Campbell et al., 2012; Estell et al., 2009; Schroeder et al., 2014; Sticca et al., 2013). Due to communication differences, autistic people may also be more likely to perceive non-bullying situations as bullying and vice-versa (Estell et al., 2009) although more research is required to substantiate this. Additionally, autistic people experience stigma (Large & Serrano, 2018) and bullying due to their identity (De Sausmarez, 2018; Schroeder et al., 2014), which may be more easily experienced online for the discussed reasons. Experiences of cyberbullying have been linked to depression, anxiety, and higher rates of suicidality in the autistic people and those with ADHD (Wright & Wachs, 2019; Yen et al., 2014) and may therefore need to be addressed and also need further research. However, Cooper et. Al (2017) through a quantitative study found that the development of the autistic identity online led to increased self-esteem and was negatively associated with anxiety and depression. This is similar to the findings of the present study where being a part of communities not only helped the surrent participants with the development of their autistic identity but also enabled them to stand up to bullies and mentor other autistic people to do the same.

Participants in this study reported that they often found SM 'Addicting'. It was easy to spend time on it, due to easy access and the constant stream of novel content. This is similar to previous findings from both qualitative and quantitative research (Benford & Standen, 2009; Engelhardt & Mazurek, 2013; Engelhardt et al., 2017; Murray et al., 2021). Addiction to SM has been associated with depression, ADHD, and anxiety (Akin & Iskender, 2011; Wang et al., 2017; Yen et al., 2017). Since 50% of autistic people report mental health conditions, such as depression and anxiety (Kent & Simonoff, 2017; Lugo-Marín et al., 2019; Taylor et al., 2014), it is possible this could mean higher vulnerability to the addictive aspects of SM on the flip side it is also possible that autistic people who experience depression and anxiety are more likely to use SM. . Mazurek et al. (2013) also suggested that autistic people may be more likely to develop addiction to video games, as 'repetitive and restrictive behaviours', and poor response inhibition are difficulties some autistic people may experience. It may be hypothesised that the same underlying reason applies to increased vulnerability to SM addiction as well, however, further research should explore addictive online behaviours in diverse populations of autistic people.

Some participants reported that these disempowering aspects of SM may have a 'Greater impact' on autistic people due to the higher rate of mental health conditions, and potential more time spent on SM (if it is the main source of community).

6.5 Coping Strategies

Consistent with a qualitative study on the development of autistic identity by Large and Serrano (2018), experiencing the various disempowering aspects of SM led to the development of coping strategies. These were skills used to compensate for the potential negative impacts of SM.

6.5.1 Setting Time Limits

This coping mechanism was mentioned by most of the participants and included setting time limits for specific SM apps and leaving SM for periods of time to manage well-being. This was a dynamic process that depended on how a particular person felt at a specific time point. This boundary was specially used by the participants to counteract the 'Addicting' nature of SM and 'Stress and burnout'. Participants reported that the 'time limit'[11] setting on smart phones and creating a stringent routine to switch off from SM facilitated the setting up of this boundary (for example- not using the phone during working hours or switching it off at 10pm).

6.5.2 Performing and Masking

'Performing and masking' involved selectively disclosing certain aspects of one's identity (masking the others) while masking others or creating an ideal identity online to showcase to others (performing). Within this study it is differentiated from 'Faking', performing and masking is normally done to either develop aspects of non-autistic identity or to protect from 'Cyberbullying' and alienation. This coping strategy allowed participants to control what aspects of themselves they shared with other users (Burke et al., 2010). Performing and masking (including 'camouflaging') are usually seen as inherently negative, with adverse consequences for wellbeing (Cook et al., 2018). However, Some studies, have also found some positive impacts on the autistic people, allowing them to feel more accepted (Cook et al., 2018), enabling coping (Bradley et al., 2021), allowing control over the disclosure of autism (De Sausmarez, 2018), bringing distance from the social stigma of the autism label (Benford, 2008) and freeing the person to explore different aspects of their identity (Cooper et al., 2017). In convergence with these findings most participants articulated the positive impact of performing and masking.

Though, some participants acknowledged that portraying a 'perfect' image of themselves online might negatively impact others, none of the participants commented on the impact on continued performing and masking; might have on their own wellbeing. This could involve the emotional impacts of keeping up the pretence, as well as the emotions

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[11] It is setting on both android phones and iPhones that allow the users to specify how much time they would like to spend on a particular app. after they have reached this allowed time limit the app locks and users have to go through an additional step of unlocking the app to use is again.

of guilt related to being dishonest with others (Bradley et al., 2021; Jedrzejewska & Dewey, 2021). Perhaps since masking and performing a persona online is arguably one defining feature of SM (Jedrzejewska & Dewey, 2021), it may be felt as an acceptable norm.

6.5.3 Escaping

Escaping was arguably a form of fantasy (Cooper et al., 2017), where participants reported using 'performing and masking', 'faking', 'funny content' and 'selective autism disclosure' to make themselves feel better about their lives. Pretending that the difficulties and negative experiences within one's lives do not exist was one arguable feature of this fantasy. These findings are similar to some studies with neurotypical populations (Cooper et al., 2017), where people who wanted to escape their current contexts tended to use SM more (Kraut, Kiesler, Boneva, Cummings, & La, 2002; Kraut et al., 1998; Kwon et al., 2013; Papacharissi et al., 2011; Park et al., 2009). This coping skill may also act as a motivator to use SM more frequently when issues arise in daily life, which could, in turn, for some, lead to addiction-like experiences.

6.5.4 Creating Safe Spaces

Just as in previous studies, participants reported tackling issues of 'Comparing' and 'Privacy and trust' by connecting with known familiar people (Benford & Standen, 2009; Burke et al., 2010); and following trusted people or positive accounts (Massier, 2017). Participants also reported that one of the ways they dealt with bullies was by making sure they blocked[12] individuals who made them feel uncomfortable or harassed them. Another commonly used strategy to create a safe space was adjusting privacy settings to limit the types of content shared online. Some participants also made SM a safe space by allowing others to support them in difficult situations where they were getting harassed or

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[12] It does not allow the 'blocked' person to communicate with/contact you or see anything you post online.

bullied or ‘told off’ for saying the wrong thing. However, as mentioned above this may lead to the formation of echo chambers and bubbles that in turn lead to a distorted view of SM and general reality (Del Vicario et al., 2016; Flaxman et al., 2016) or decrease in tolerance for other viewpoints: which participants mentioned is one of positive aspects of SM.

6.5.5 Standing Up

Some participants reported creating a safe space for others, by supporting other autistic or disabled people when they were being bullied or harassed. This helped people feel that SM was a safe and supportive place, where they could explore different aspects of themselves and socialise. These findings are in line with previous studies related to social support and online communities (Saha & Agarwal, 2016; Zhao et al., 2019). ‘Standing up’ was further supported by the presence of advocates (Abel et al., 2019) and features of SM, such as ‘ease of communication’ that enabled participants to be free and show their true selves online (Gillespie-Lynch et al., 2014). However, losing a filter could enable people to be nastier or meaner online than they would face-to-face.

Some participants reported that the support online led to an increase in self-confidence that enabled the participants to support others or behave in a way that may not be in line with their offline selves. Few participants also reported that the communication and coping skills they learned online translated into their offline lives and increased their confidence in their own abilities.

6.6 Implications

With the advent of SM and its salience in the current world, it is impossible to avoid its use in daily life. However, the current study revealed that there are both benefits and risks associated with SM use by autistic young people as articulated by the participants, though they it can be tentatively concluded that SM may have net positive impacts for the participants in the study. The following section will first explore some practical implications of the current findings followed by implications for future research.

6.6.1 Practical Implications

The present study provides a GT model of SM use by autistic young people, which can facilitate a better understanding and help clinical psychologists, families and organisations understand the benefits and risks of SM use. This can help them better support autistic people, reduce the risks or facilitate the of use coping strategies:

- The role of ***SM for provision of therapy and support*** should be explored. This may be especially helpful with the current advent of the of online therapy during Covid-19. SM might act as a supportive tool for 'Cognitive Behaviour Therapy' (CBT) which has a wide evidence base for online delivery and effectiveness and is suitable for autistic people. One example could be the use of online forums and groups for experiments for social anxiety or the use of SM to establish initial contact with clients. It can also be used to build rapport with clients of all ages by using different aspects of SM as ice breakers (video games, current conversation threads on SM among other things). It may provide a comfortable, safe and structured environment to learn skills that can then be transferred into the offline world. Participants in the present study spoke about learning about hobbies online as well as how social interactions online increase their confidence in their own abilities, this information can be used to inform learning in CBT as well. The therapist can then help the client generalise the learning to offline settings.
- There are risks involved with using SM like bullying, addiction, masking, issues with trust and privacy, stress and burnout. Professionals in the field of psychology, schools and families may need to consider the impact these risks have on the

wellbeing of autistic people. It may be important to enquire about the ***role of SM in how the individual is feeling*** and addressing its impact on them within different settings. Participants spoke about the ***development of coping strategies*** to deal with the negative impacts of SM, this can help provide ideas for how other autistic people may be able to develop coping strategies in the offline world as well. However, as discussed in section 6, some strategies (performing and masking, escaping, creating safe spaces) may have short term benefits but long-term negative consequences, there may hence be a need to help people moderate the use of these coping strategies both on SM as well as in the offline setting.

- Participants in the current study and in previous studies have mentioned ***the positive impact that groups and communities as well as connecting with similar others has on them***. SM provides a platform that makes connecting with others easy and it may therefore be used as a resource to help autistic people connect with and follow #ActuallyAutistic influencers and supportive groups, This, in turn, may help facilitate a sense of belonging and self-acceptance. It also aids in understanding and learning about autism and autistic identity; which can be described as a type of social identity (Cooper et al., 2017). Organisations, families and friends can help connect autistic people with advocates and groups online or use these resources to enhance their own learning and understanding. Both trainee and qualified clinical psychologists can also use SM as a resource to learn more about autism, autistic identity and issues via the autistic voices online.
- All participants in the current study, who identified as female, spoke about ***the lack of resources for autistic females offline***. Organisations and clinical psychologists along with autistic people can co-produce resources to support them on topics that they feel would be the most beneficial.

- Making research accessible: a majority of the participants spoke about using SM to read about recent research and topics as it helped provide different perspectives and easy to understand summaries of findings, which wasn't the case with regular research. Therefore, trainees should be taught about and allowed to make their research papers accessible to the non-academic and neurodiverse population, this could be in the form of lay summaries, easier to understand language throughout the papers, images, posters, or articles. Again, co-production with autistic people would be an important part of making research easier to access.

6.6.2 Implications for Future Research

Qualitative research methods like GT are meant to study a particular issue or phenomenon in those who take part in the study, with generalisability not being an aim of GT (Leung, 2015). The developed model can be used as a framework to guide future research with a larger sample, which can help with the generalisation of the results better.

Since the findings of the present study are preliminary, future research should focus on the generalization and validation of the findings. This could take the form of a qualitative piece of work with a larger sample size or a quantitative piece of work like a survey, focussing on different aspects of the model (Social Connectedness, Flow of information, Disempowering SM or Coping strategies). It may also be useful to analyse the associations between the different ways in which SM is used and its impact on wellbeing, social involvement, and development. Longitudinal research may also help understand causal relationships and the long-term impact of SM use. However, it may be difficult to find a control group that has no contact with SM to be able to accurately draw conclusions about its impact. Although the current research has highlighted the potential risks and benefits of SM use for autistic young people, using multiple methods of communication (chat, video and voice call) during data collection, it has not addressed the implications of SM use for people who may be less able than the participants of the present study (mental and physical difficulties). Future studies also need to investigate ways to include participants with mental, physical, and communicative difficulties to be able to correctly assess the impact of SM. Future studies should question how the impact of SM differs between neurotypical and neurodiverse people, including the role and impact of cyberbullying.

However, the most important implication for future research is co-production of both research topics and research with autistic people, so that it cannot just fill gaps in literature but also be useful for the intended population.

6.7 Limitations

However, before wider applicability of the developed model, it is important to be aware of the sample characteristics and methodological limitations of the present study. The sample predominantly consisted of White-British autistic cis-gender females (8 of 12). This is not representative of the autistic population with a sex ratio of 4.2 males for every female diagnosed with autism (Loomes et al., 2017), and there is a higher gender dysphoria as compared to the neurotypical population (George & Stokes, 2018). However, an over-representation of participants who identify as female could be because research suggests that autistic women may use SM more (Benford, 2008).

Recruiting self-selected participants via SM may have led to a selection bias in the sample. It is possible that those who were drawn to participate in the research were those who were more vocal and comfortable connecting with unknown people on SM. They may have been more likely to have coping strategies in place to deal with the negative aspects of SM as compared to those who did not respond. The research was only advertised on Twitter, Facebook and Instagram and autistic people who did not use these websites were therefore excluded. To overcome these sample drawbacks, it may be helpful for future studies to recruit in services aimed for autistic young people and a wider range of SM sites and websites, this may enable them to reach a greater participant pool.

It is also important to note that the current study did not have a comparison group of autistic young people who do not use SM. Therefore, it is difficult to accurately know the impact of SM on their lives and how this could have been different had they not been using SM. The present study also only included participants who used SM 5-7 days a week and therefore may have excluded participants who use SM less often but are as engaged. This factor may have also limited the participants to those who may use SM more often as they have more pleasant experiences online or have developed coping strategies to help them cope with their negative experiences of SM. It is important to keep this limitation in mind when using the theoretical framework developed for further research.

Other factors not included in this study, such as prior experiences outside of SM (e.g., bullying and other experiences of social connectedness), may have had an impact on participants' online experiences and their use of SM. Though the researcher collected information on mental health difficulties, the participants were not explicitly asked about the impact of these on SM use and vice versa. The current research did also not consider the socio-economic-status and access to internet; with SM playing an important role in the lives of people, it may be important to study the impact access may have on individuals.

These limitations should be kept in mind before utilising the model as a framework to guide future research.

6.8 Conclusion

The current study provides a mixed picture of the impact of SM on autistic young people aged 18-25 years. The findings based on the participants of the present study tentatively suggest that SM may have a net positive impact on their lives, as it leads to the development and adaptation of coping skills which enhance the empowering (benefits) aspects of SM. These skills are developed or adapted to decrease the impact of the disempowering (risks) aspects of SM. Majority of the participants described the how SM facilitated social connection and identity development by allowing them access to people, communities and information.

Within the ever-changing landscape of SM, understanding the way autistic young people use it based on their own experience is vital to shape policy and organisational changes. It can improve our understanding about how to incorporate SM in a more positive way to facilitate its empowering aspects. However, the current findings should be viewed in relation to the existing literature to provide a better picture of how to support the use of SM by autistic young people.

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Part 3: Critical Review

This critical appraisal is an exploration of some issues that preoccupied me throughout the process of the research. It will focus on my assumptions and their impact on the research process, as well as the impact of the research process on my assumptions. It will end with a reflection on the results and the importance of co-production in the field of psychology.

1. Personal Assumptions and Qualitative Research

As mentioned in chapter 2 (section 2), my life experiences and assumptions may have influenced the analysis and results of the present study on multiple levels, starting with the choice of research topic, the chosen method for analysis, as well as the way the interviews were conducted and the generation of themes. Within the field of qualitative research, the role of researcher assumptions based on their beliefs and values and their influence on the research is well documented (Dowling, 2006; Palaganas et al., 2017; Willig, 2013). Since it is difficult to eliminate them, the value of the research may be increased by acknowledging one's underlying beliefs explicitly. The process of 'reflexivity' (presentation and consideration of researchers influence on the research) (Dowling, 2006; Palaganas et al., 2017; Willig, 2013), in my opinion helps generate findings that readers may find easier to access and understand in relation to their beliefs and assumptions.

As researchers become more aware of their own perspectives, they also become more open and receptive to different perspectives. Self-reflexivity enabled me to be less bound by my previous assumptions and approach the data with a more social constructionist view, which is at the core of constructivist grounded theory (GT) (Charmaz, 2006).

Chapter 2 (Section 2) is an account of my personal position and an attempt to be transparent as a researcher. Through the process of transparency, reflexivity, and openness, I hope to have produced an account of social media (SM) use by autistic young people that is contextualised and can therefore help inform future research in the field and enable the development of clinical practices. With the present study being a qualitative one, I am aware that another researcher analysing the same dataset with their own set of assumptions would have produced a different set of findings. Therefore, in the following sections I will reflect on and consider the influence of my personal assumptions, how my assumptions were challenged and consider how the results may have been different if the data was analysed by someone else.

1.1 Influence of Personal Assumptions and Changes to them

The first and most prominent assumptions I brought to this study was my view of autism. I subscribed to a stigmatised view guided by DSM-V criteria (APA, 2013) and person-centred language (Person with autism). I think this view emerged from my education and experiences in India, where a medical model is used to describe any differences, though there is a shift in terms of using a more social model over the last 5 years. My person-centred language use and views comes from my education in the United States of America, where the focus was on the person and not the 'disorder'. However, during the study, interacting with my supervisor, my co-researcher, the participants and learning more about autism has led to a shift in my assumptions and thinking patterns.

One of the most powerful aspects of the present study was the conversations with the participants. The participants articulated their thoughts and experiences with eloquence and used empathy and humour to ensure that I felt comfortable during the process of the interview as well. Like experiences of previous researchers (Benford, 2008; De Sausmarez, 2018; Scott, 2004), participants of the current study spoke not just about their autistic identity (not about their identity as a person with autism) but also challenged stereotypes and stigmas.

Though Autism Spectrum Disorders are currently conceptualised by social communication difficulties and restricted and repetitive behaviours (APA, 2013), my experience of the data collection process was not dominated by a lack of interest in communication or difficulties with it. Irrespective of the mode of interview, building a rapport and continuing a conversation with the participants was engaging and enjoyable. What surprised me was that all the participants within the study showed an astute understanding of both autism and their own communication needs often comparing it with their neurotypical peers and breaking down concepts to explain them to me. Most participants were both analytical and pragmatic in their approach to the questions, which may be reflective of their superior systemising skills (Baron-Cohen, 2010; Grove et al., 2013) or their superior fluid intelligence (ability to approach a problem and reason independent from prior knowledge) (Hayashi et al., 2008).

These interactions made me reflect on and question my own assumptions about autism, autistic people, and neurodiversity. I now hold a view which is not bound by the restrictive tick box symptom cluster of DSM-V and use identity first or person first language, depending on the person's preference. Like Happe and Frith (2020), I have come to realise that there are many 'autisms' where people may not always show difficulties in all autistic traits (Happé & Ronald, 2008; Robinson et al., 2011). This change in perspective led me file for an amendment to my research ethics to change the language to identity first, to reflect both the voice of my participants and the shift in my underlying views. As can be seen form my language use in both chapter one and two, I have used identity first language thought-out my research to reflect the views of my participants and research that indicates that most autistic people prefer identity first language (Kenny et al., 2016; Robison, 2019).

My second striking assumption was my 'Neurotypical' view. It is not neurotypical in the truest of senses, but through the process of bracketing and reflecting I found that I tend to believe that; a) people should meet certain expectations based on their age and development; and b) people prefer not to stand out. I believe this view emerged the stigmatised view of difference in India (Chapter 2, section 2). Though I do have a personal ethical stance that favours both inclusion and diversity, I never reflected on the pervasive nature of my previous experiences. By witnessing the effect of trying to fit everyone into the 'same' box through my clinical work, reflective practices, and research in the field, I realised how it went against my stance for diversity. I was affected by the impact internalised neurotypical concepts had on neurodiverse people, who may at times develop a negative view of their difference, which can be limiting. With my view I was primed to see the negative aspects of difference and focus on the struggles of participants against stigma, systemic segregation and never recognised its positive impact on self-development, identity, and resilience.

The impact of my view can be seen of the topic for research- 'How do autistic young people use SM?', where I focused on prescribed age norms for young people (18-25) and expectations attainment of specific tasks – Social connectedness and Identity (Erikson, 1994; Kroger, 2005). During data collection participants continuously challenged my underlying assumptions by embracing difference and their own identity.

'Why do you have such a narrow age group, can't emerging adulthood last till 30?'

'If not autistic then who? it is a part of me and makes me who I am, I don't have to be like anyone else.'

Though I didn't change the age group of the study, it did make me reflect on my assumptions and had an impact on data analysis and the way the paper has been presented. It also made changed my perspective from a more neurotypical view to one of neurodiversity. This shift would not have been possible if qualitative research wasn't collaborative.

1.2 Impact of a Different Assumptions

In this section I aim to reflect on how the results of the present could have been different with a different researcher or different underlying assumptions. As mentioned in chapter 2, had I not had the interest in the field of autism, this study may not have been conducted or may have looked very different (methodology or participant age group). Just seeing the impact of my assumptions on the choice of topic and methodology itself, suggests that researchers may need to be aware of their own biases and beliefs before even choosing a topic for research.

Had I not had an underlying ‘neurotypical’ perspective I might have focused more on the impact of SM in general rather than trying to structure my questions around identity and social connectedness. I may have been more inclined to question them more around other aspects of SM or the positives of not needing to use SM, which would have led to different answers and very different data. However, had this been the focus of the study, I would have never ended up presenting the present results, which to add to the present literature.

However, while the influence of my subjective experience is an inherent part of the research, the current study does help with a creation of a new ‘Boundaries Enhancing Empowerment’ model, that has shed light on the resilience, self-reliance, and coping skills of the participants. I hope that by being transparent about my experience and influence I kept myself open to seeing different perspectives and possibilities in the research, enabling me to represent the views of all the participants. In my attempt to help readers also view different perspectives I hope that the present research will be read alongside other research papers that highlight different viewpoints.

2. Reflection on Results

The present study (Chapter 2) generated more new findings compared to previous studies, than I had expected. There was some convergence with previous literature in terms of the risks and benefits of SM use but there was also some divergence, this is expected based on the limited previous literature (Chapter 1). However, these results are based on participants from the UK and there are bound to be differences based on countries, access to the internet and other individual factors, which were not a specific focus in the present study. Had there been more time, personal experience and factors would have been included in the results. However, it is important for psychologists, supporting organizations and individuals to be aware of personal factors that may have an influence the use of SM and its impact on them. This might help them understand if an individual may be more vulnerable to the risks associated with SM, it may also help the individuals support their own wellbeing.

The most striking findings of the present study was the development and adaptation of coping strategies (Setting a time limit, Escaping, Performance and Masking, Creating safe spaces and Standing up) to deal with the risks associated with the use of SM. There was only one previous study that had mentioned the use of coping strategies by autistic people to deal with threats to autistic identity based on the analysis of online content (Large & Serrano, 2018). However, no studies so far have mentioned them in terms of SM use. The reason I found this finding to be important is because there have been a number of previous studies that have mentioned that SM or rather internet use has net positive benefits for autistic people and have hypothesised the reasons for this and alluded to the use of different strategies (Benford, 2008; Benford & Standen, 2009; De Sausmarez, 2018; van der Aa et al., 2016; van Schalkwyk et al., 2017). None of the studies have explicitly named or described the different strategies and techniques. However, it is important to keep in mind the fact that though all these strategies seem helpful on face value some of them may have short term benefits but longer-term costs (Performing and Masking, Creating safe spaces and Escapism). These longer-term costs may be in terms-

a) Mental health and wellbeing in terms of the emotional of constantly presenting a version of yourself or hiding an aspect of yourself while performing and masking (Bradley et al., 2021).
b) The creation of echo chambers or bubbles and lower tolerance to different perspectives that may arise due to the over of blocking and unfollowing on SM to create a safe space (Del Vicario et al., 2016).
c) Escaping ones current environment by using SM, may be negatively linked to forming social connections and connecting with others (Kwon et al., 2013).

Therefore, as mentioned in chapter 2 it may be important for families and psychologists to enquire about strategies used to keep safe on SM and weigh the pros and cons of these strategies. There may be a need for an understanding of the safe use of these strategies or the development of other strategies that may not have negative impacts on the individual.

The findings of the present study may also be extremely relevant in the current context of Covid-19, where lockdowns, restrictions and social distancing have become a norm over the last 18 months. Everyone globally has needed to use SM a lot more for work, university and to create and maintain connections (Parlangeli et al., 2021; Sharma et al., 2020).

3. Importance of Co-Production

One important conclusion I have drawn from the present study is the importance of including the autistic voice within autism research, not just as participants but also as researchers. Though there has been a lot of mention of co-production within the field of psychology, it is still unusual to see within the research community (Aabe et al., 2019).

Some researchers argue that this may be because the research community may privilege theoretical work over policy and practice-oriented research (Newman, 2012; Walker, 2010). However, others reported that co-production may be the answer to the 'relevance gap' between research and the population it is meant to impact (Durose et al., 2012). Gaventa (2005) argued that co-production of research and policy is the right of every individual and enables social justice.

Based on the shift in my assumptions and reading on co-production the present study aimed to get close to a co-produced piece of work, by recruiting an autistic co-researcher and involving participants in both the stage of data collection and analysis. The prescience of an autistic co-researcher in the form of the autism panel had the greatest impact on the research, right from reformulating the research question to refining the model. She helped make sure the study was relevant, used the correct language and that the results reflected the views of the participants. Majority of my insights about my underlying assumptions came about via conversations with her. I believe that the present study would not have been the same had it not included autistic people throughout the process of research.

4. Conclusion

The process of the current research has led to a shift in my perceptions about inclusion, neurodiversity, and difference. Though it was just a study looking at the impact of SM use by the autistic young people it had an overall impact on my underlying assumptions, led to a shift in my world view and has strengthened my passion for co-production not just for research but within the NHS as well. In addition to using my role within mental health services to ensure that co-production becomes a norm within the field. I am also working towards preparing a lay summary of the present research and findings to be able to disseminate the findings, in order to make the present research accessible. The whole process has been transformative, and I hope to carry these positive changes forward as I progress though my career.

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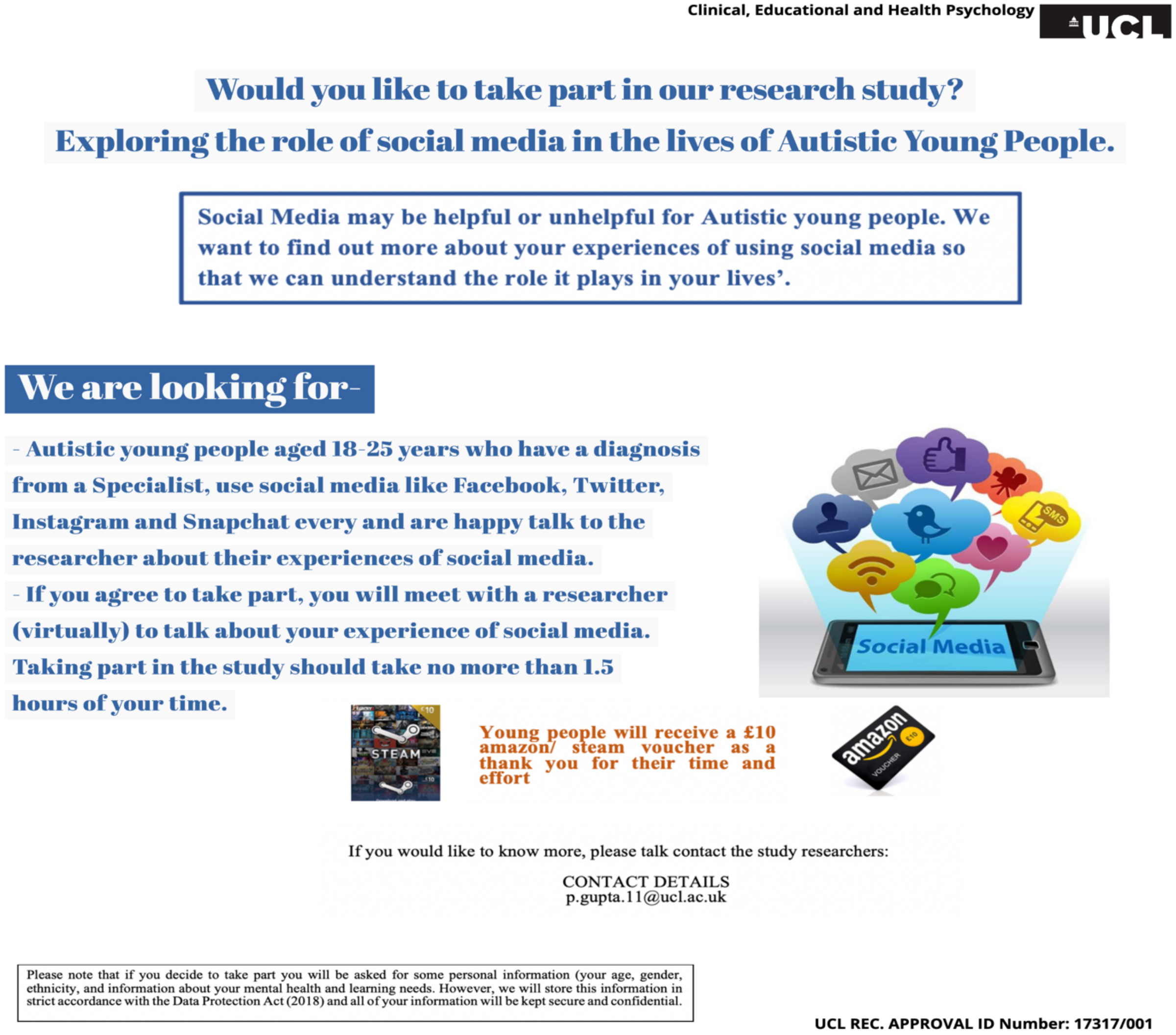
Appendices

Appendix One: Recruitment Flyer

1.1 Initial Recruitment Flyer



Clinical, Educational and Health Psychology

Would you like to take part in our research study?

Exploring the role of social media in the lives of Autistic Young People.

Social Media may be helpful or unhelpful for Autistic young people. We want to find out more about your experiences of using social media so that we can understand the role it plays in your lives'.

We are looking for-

- Autistic young people aged 18-25 years who have a diagnosis from a Specialist, use social media like Facebook, Twitter, Instagram and Snapchat every and are happy talk to the researcher about their experiences of social media.

- If you agree to take part, you will meet with a researcher (virtually) to talk about your experience of social media. Taking part in the study should take no more than 1.5 hours of your time.

Young people will receive a £10 amazon/ steam voucher as a thank you for their time and effort

If you would like to know more, please talk contact the study researchers:

CONTACT DETAILS
p.gupta.11@ucl.ac.uk

Please note that if you decide to take part you will be asked for some personal information (your age, gender, ethnicity, and information about your mental health and learning needs. However, we will store this information in strict accordance with the Data Protection Act (2018) and all of your information will be kept secure and confidential.

UCL REC. APPROVAL ID Number: 17317/001

1.2 Amended Recruitment Flyer

EXPLORING THE ROLE OF SOCIAL MEDIA IN THE LIVES OF AUTISTIC YOUNG PEOPLE

UCL

We are looking for autistic participants (aged 18-25),
to complete an interview about social media experiences.
Participants will recieve a £10 Amazon/Stream voucher for their time.
For more information, please contact p.gupta.11@ucl.ac.uk

Appendix Two: Information Sheet

Clinical, Educational and Health Psychology UCL

Young Person information Sheet for Participants

A study looking at the role social media for Autistic Young People

Would you help me with my research?

Hi! My name is Prakriti (Praku), I am a student at University College London studying for a Doctorate in Clinical Psychology and I would like you to take part in a research study about social media. Please read this information sheet and ask me any questions before you decide.

Why are we doing this study?

Social Media maybe helpful/unhelpful for autistic young people with things such as mental health, relationships, finding jobs and learning new things. I want to learn about how you use social media so that I can understand its role and impact in your life.

Who can take part in this study?

Young people aged 18-25 years who use social media like Facebook, Twitter, Instagram and Snapchat every day, have a diagnosis of Autism and who can answer questions about their experiences of Social Media.

This Photo by Unknown

What will happen if I take part?

1. After you give consent to take part, I will contact you and answer any questions you have.
2. If you are still interested, I will ask you to sign a consent form. I will give you copies of the signed consent form and this information sheet.
3. I will meet you online via video call, voice call or chat.
4. We will talk for 60-75 minutes. I will ask you about your social media usage and about how it fits with different areas of your life - like your family and friends, your mental health and learning about yourself. You don't have to talk about anything you don't want to talk about. I will record our conversation to make sure I don't miss anything important.
5. I will ask you to fill out a form about your age, gender and your Autism diagnosis and learning disabilities.
6. At the end of the meeting I will offer you a £10 Amazon/steam voucher to thank you for your time and effort.

Do I have to take part?

No! It is completely up to you. If you don't want to take part that is fine, and it is your decision which won't affect you in any way.

You can stop taking part at any time during the study, you don't have to say why – you can just say "I don't want to do it anymore" and nobody will mind at all.

Version IS.V1.3

UCL REC. APPROVAL ID Number: **17317/001**

Clinical, Educational and Health Psychology UCL

Young Person information Sheet for Participants

What happens to information you collect about me and what I say in the study?

- The information that we collect about you and what you say is confidential- that means that nobody except the researchers will have access to the information we collect about you and what you tell us.
- The only time we have a duty to tell other people is if we are worried about your safety or the safety of other people around you.
- After we collect all the interviews, we will write a report about the study and what all the young people who took part in the study have told us. We might use 1-5 quotes from what you say, but neither your name nor any personal details will not be used, so that nobody could know you took part in the study. We can send you a copy of this report if you would like.

Data Protection privacy notice

The controller for this project will be University College London (UCL). This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Your personal data (name, contact details, gender, ethnicity).

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Version IS.V1.3

UCL REC. APPROVAL ID Number: 17317/001

What will happen to the recording of what I say?

- We will write down the recorded conversation or use a software that securely writes down what you say (Transcribes).
- We will read the written conversations and delete any personal information from them so that nobody could know it was you except the researchers.
- When it is written down, we will delete the recording from the recording device.

Are there any risks in taking part in this study?

As described in this information sheet, we will only be talking about social media and how you use it. However, if you talk about any difficult experiences, this can be upsetting at times, if this happens you can let the researcher know and they can help you feel better or get you in touch with someone who can help you.

If I have any questions, who can I ask?

Ask the researcher: Prakriti Gupta-Stelk

CONTACT DETAILS

p.gupta.11@ucl.ac.uk

Appendix Three: Consent Form

Consent form for Young People with Autism in Research Studies

Exploring the role of social media in the lives of Autistic Young People

Division of Psychology and Language sciences

If I have any questions, who can I ask?

Ask the Researcher: **Prakriti Gupta-Stelk** CONTACT DETAILS- p.gupta.11@ucl.ac.uk
Ask the Principal Researcher: **Dr. William Mandy** CONTACT DETAILS- 020 7679 1675 (Ex: 45922)

If I have questions or concerns about data protection, who can I ask?

You can read about it on –: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice and get the details of your rights at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/
Ask the UCL Data Protection Officer: **Alex Potts** CONTACT DETAILS- a.potts@ucl.ac.uk

Please read the statements below and tick the box to confirm. If you have any further questions, please feel free to ask the researcher or get in touch with any of the people mentioned in the box above.

		Tick Box to Confirm
1.	I confirm that I have read and understood the Information Sheet for the above study.	
2.	I have had the opportunity to ask questions and understand what is expected of me and would like to take part in the Interview.	
3.	I consent to my interview being audio/video recorded and understand that the recordings will be stored pseudo- anonymously, using password-protected software and will be used for specific research purposes. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and 'research purposes' will be the lawful basis for processing special category data.	
4.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified (except as might be required by law).	
5.	I understand that I will be compensated for my participation with an amazon or steam voucher.	
6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	
6.	I understand the direct/indirect benefits of participating.	

7.	I am aware of who I should contact if I wish to lodge a complaint	

Use of information for future research-

Would you like your data to be retained anonymously (All identifying information will be removed) and for future research by UCL researchers?

	Yes, I would be happy for my interview to be stored	
	No, I would not like my interview to be stored	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

	Yes, I would be happy to be contacted in this way	
	No, I would not like to be contacted	

Name of participant Date Signature

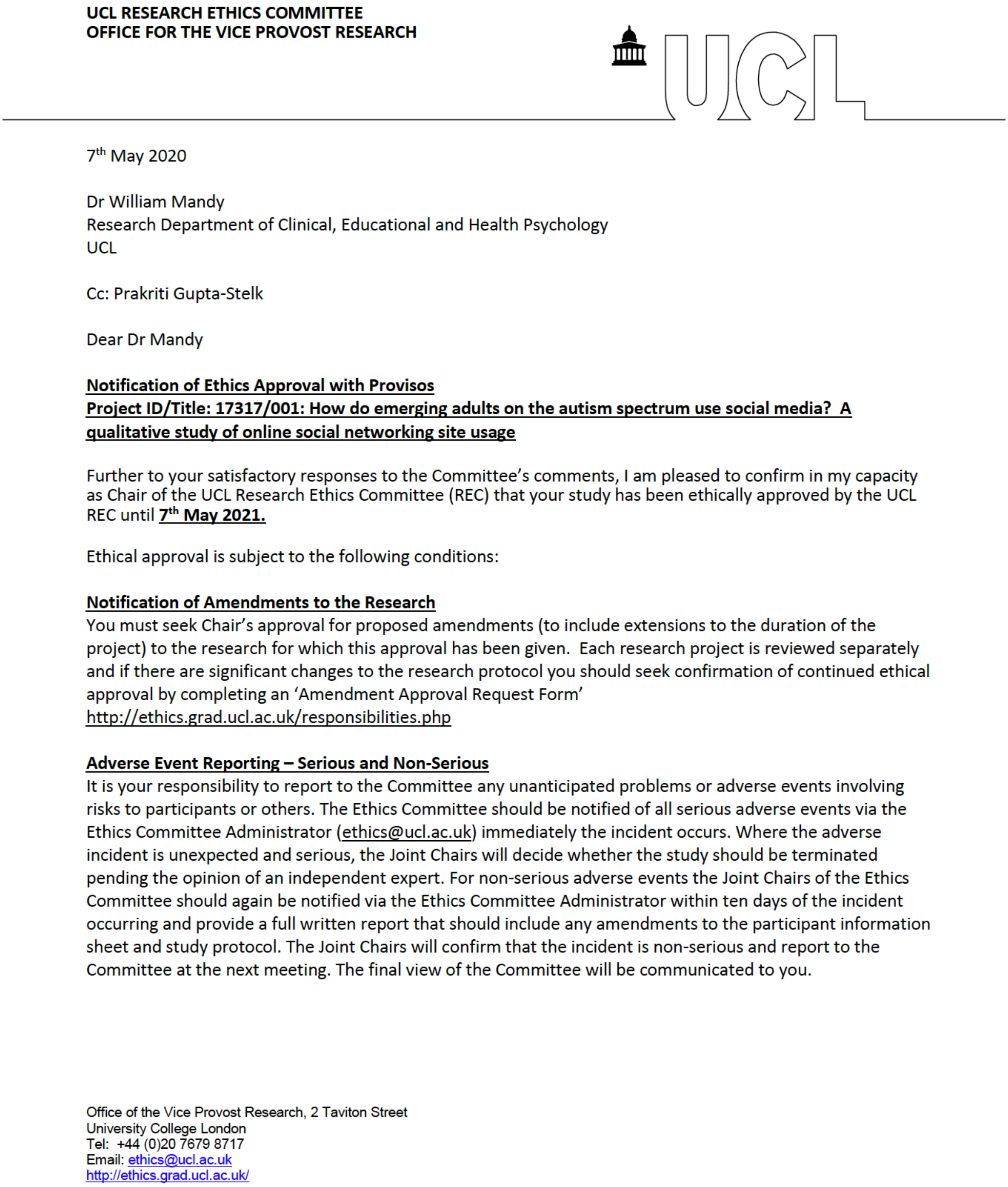
__________________ __________ ______________________

Name of Researcher Date Signature

__________________ __________ ______________________

Appendix Four: Ethical Approval

4.1 Initial Approval



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

7th May 2020

Dr William Mandy
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Prakriti Gupta-Stelk

Dear Dr Mandy

Notification of Ethics Approval with Provisos
Project ID/Title: 17317/001: How do emerging adults on the autism spectrum use social media? A qualitative study of online social networking site usage

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **7th May 2021.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: https://www.ucl.ac.uk/srs/file/579
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

4.2 Amendment Approval

Dear Prakriti

The REC has approved your attached amendment request. Please take this email as confirmation of that approval.

<u>IMPORTANT: For projects collecting personal data only</u>
You should inform the Data Protection Team – data-protection@ucl.ac.uk of your proposed amendments, including requests to extend ethics approval for an additional period.

Best wishes,
[redacted]

Appendix Five: Interview Schedule

Clinical, Educational and Health Psychology UCL

How do Autistic Young People use social media? A qualitative study of online social networking site usage.

YOUNG PERSON'S QUALITATIVE INTERVIEW TOPIC GUIDE

1. **What do you think 'social media' means? What are your most frequently used social media sites/aps?**

Prompt- Facebook, Instagram, snapchat? you can also check this on your phone, by seeing which apps are open or your screen time

2. **How often do you use each social media site? (you can look through your phone/computer/ tablet and let me know)**

Prompt- (i.e., several times per day, once per day, several times per week, once per week, 1-4 times per month, less than once a month). You can use the suggestions we've provided or describe this in your own way.

3. **What device do you use to access these sites?**

Prompt- (i.e., on a home computer, personal mobile phone/tablet/laptop, school computer or elsewhere?)- is it just on your phone

4. **What do you like about the social media sites that you use (replace social media with names of apps they have said)?**

Prompt- I can name the different sites you use, and you can tell me what you like about them if there is anything by saying – e.g. I like__________ or I like nothing.

5. **What do you dislike about the social media sites that you use?**

Prompt- I can name the different sites you use, and you can tell me what you dislike about them if there is anything by saying – e.g. I dislike/ do not like __________ or I like nothing.

6. **When did you start using social media sites?**

Prompt- You can tell me the year the you started using them, or how many years ago. Or how old you were.

7. **Can you tell me more about what you use social media for?**

   follow up questions-

   a. What do you like doing online?
   b. If you were not using social media how would you do this (replace this with what they use social media for eg. talking to people/ playing games etc.)?

Participant ID:

REC Ethics: 17317/001

Questionnaire v.1.1

   c. What else do you do online? (play, chat, join communities and groups, read the news etc.)

8. **Since you have started using social media, how has using these sites impacted on your day-to-day life?**
   Prompts-
   a. How is your relationship to people online similar to those offline?
   b. Where do you have more friends online or offline?

9. **Do you think interacting with someone on social media and interacting with someone face-to-face are different experiences? In what way do you think they are different? In what way do you think they are similar?**

Prompts-
   a. How are they similar?
   b. What makes them different?

10. **Have you learnt anything about yourself by using social media?**

Prompts- you can say I learned that _______________,
   a. If yes - Do you think this is something you could have learned offline?
   b. If yes – How has this learning made a difference to you?

11. **Have you learnt anything about people in general by using social media?**
   c. Do you think you would have been able to learn this information offline?
   d. What impact has this learning had on you?
12. **If you stopped using social media, what would change in your life?**
   a. What would be similar to now?
   b. What would be different?
   c. Would you be doing something else in that time?
   d. Would your (current?) relationships change? Would meeting new people change?
13. **Do you think there are any risks involved with using social media? What do you do to stay safe on social media?**
   Prompt- If you would like to talk about different social media sites, just say the name before you start.
14. **Do other people on social media know that you are autistic? If yes, how did they find out? if Not, is there a reason for this?**

Prompt- If you would like to talk about different social media sites, just say the name before you start.

15. **Do you connect with other autistic people on social media?**

Participant ID:

REC Ethics: 17317/001

Questionnaire v.1.1

Prompt-

- **a.** If yes – how is this different to interacting with non-autistic people?
- **b.** If yes – has talking to other autistic people been helpful/unhelpful? How?
- **c.** If no – are you happy to discuss/share why not?

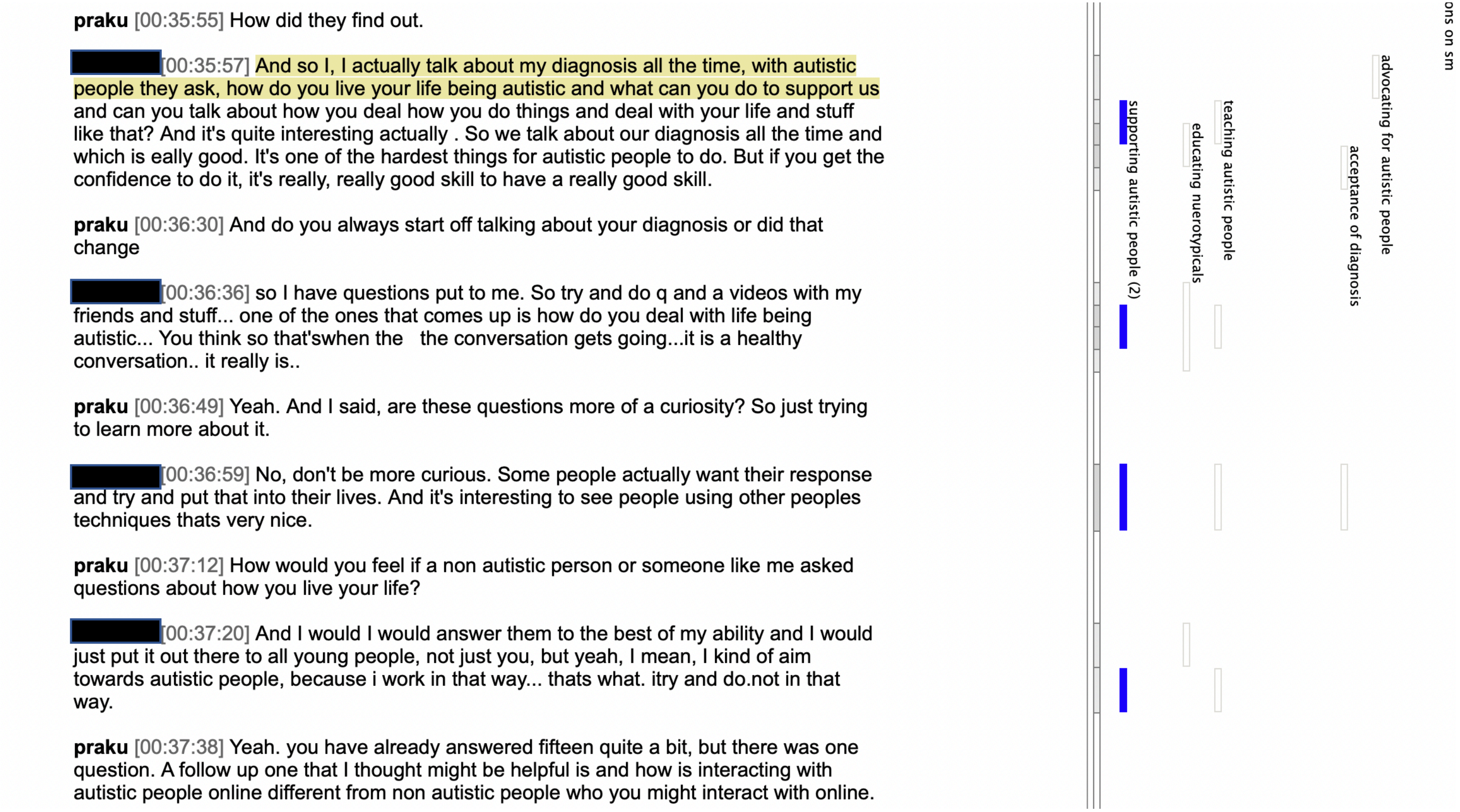
16. What impact has covid-19 had on your social media use?

Prompt- Some people say they might use it more or less than before.

17. Is there anything else about using social media, as an autistic person, that you think we should know?

Appendix Six: Line-by-Line Coding

6.1 Example of Line-by-Line Coding P1



praku [00:35:55] How did they find out.

[redacted] [00:35:57] And so I, I actually talk about my diagnosis all the time, with autistic people they ask, how do you live your life being autistic and what can you do to support us and can you talk about how you deal how you do things and deal with your life and stuff like that? And it's quite interesting actually . So we talk about our diagnosis all the time and which is eally good. It's one of the hardest things for autistic people to do. But if you get the confidence to do it, it's really, really good skill to have a really good skill.

praku [00:36:30] And do you always start off talking about your diagnosis or did that change

[redacted] [00:36:36] so I have questions put to me. So try and do q and a videos with my friends and stuff... one of the ones that comes up is how do you deal with life being autistic... You think so that'swhen the the conversation gets going...it is a healthy conversation.. it really is..

praku [00:36:49] Yeah. And I said, are these questions more of a curiosity? So just trying to learn more about it.

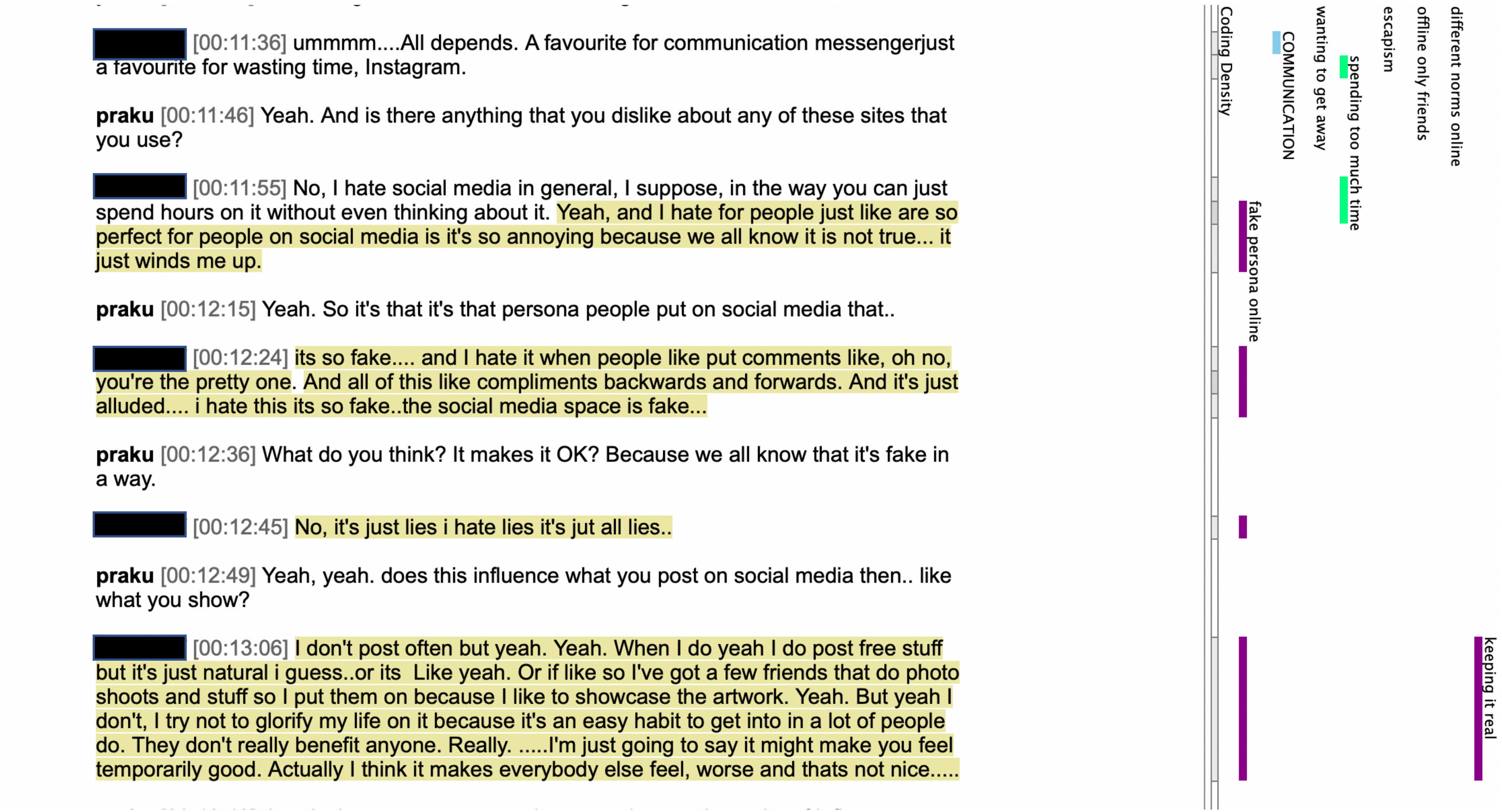
[redacted] [00:36:59] No, don't be more curious. Some people actually want their response and try and put that into their lives. And it's interesting to see people using other peoples techniques thats very nice.

praku [00:37:12] How would you feel if a non autistic person or someone like me asked questions about how you live your life?

[redacted] [00:37:20] And I would I would answer them to the best of my ability and I would just put it out there to all young people, not just you, but yeah, I mean, I kind of aim towards autistic people, because i work in that way... thats what. itry and do.not in that way.

praku [00:37:38] Yeah. you have already answered fifteen quite a bit, but there was one question. A follow up one that I thought might be helpful is and how is interacting with autistic people online different from non autistic people who you might interact with online.

6.2 Example of Line-By-Line Coding P3



[redacted] [00:11:36] ummmm....All depends. A favourite for communication messengerjust a favourite for wasting time, Instagram.

praku [00:11:46] Yeah. And is there anything that you dislike about any of these sites that you use?

[redacted] [00:11:55] No, I hate social media in general, I suppose, in the way you can just spend hours on it without even thinking about it. Yeah, and I hate for people just like are so perfect for people on social media is it's so annoying because we all know it is not true... it just winds me up.

praku [00:12:15] Yeah. So it's that it's that persona people put on social media that..

[redacted] [00:12:24] its so fake.... and I hate it when people like put comments like, oh no, you're the pretty one. And all of this like compliments backwards and forwards. And it's just alluded.... i hate this its so fake..the social media space is fake...

praku [00:12:36] What do you think? It makes it OK? Because we all know that it's fake in a way.

[redacted] [00:12:45] No, it's just lies i hate lies it's jut all lies..

praku [00:12:49] Yeah, yeah. does this influence what you post on social media then.. like what you show?

[redacted] [00:13:06] I don't post often but yeah. Yeah. When I do yeah I do post free stuff but it's just natural i guess..or its Like yeah. Or if like so I've got a few friends that do photo shoots and stuff so I put them on because I like to showcase the artwork. Yeah. But yeah I don't, I try not to glorify my life on it because it's an easy habit to get into in a lot of people do. They don't really benefit anyone. Really. .....I'm just going to say it might make you feel temporarily good. Actually I think it makes everybody else feel, worse and thats not nice.....

Appendix Seven: Focused Coding

7.1 Example Focus Codes - Fake Persona Online

Files\\chat interviews\\P21 - § 1 reference coded [0.13% Coverage]

Reference 1 - 0.13% Coverage

Instagram is like showing off. umm and then.

Files\\voice interviews\\P16 - § 1 references coded [0.66% Coverage]

Reference 1 - 0.49% Coverage

Like a fake supportive place where people are just kind of trying to undermine each other, like people would be asking for genuine advice and people ready to apply for this thing, and then I just get backhanded. Yeah. Replies and people who acting like they know exactly what they need to do with their life. And I feel like whilst it sounds superficially supportive, it just feels it just it just makes my hair stand on end, like it feels like people are just trying to top each other down a little bit. Yeah. And I really like her that way. Yeah. So I've kind of avoided that now.

Files\\voice interviews\\P3 - § 8 references coded [5.66% Coverage]

Reference 1 - 0.55% Coverage

Yeah, and I hate for people just like are so perfect for people on social media is it's so annoying because we all know it is not true... it just winds me up.

Reference 2 - 0.52% Coverage

And all of this like compliments backwards and forwards. And it's just alluded.... I hate this it's so fake. The social media space is fake...

Reference 3 - 0.18% Coverage

No, it's just lies I hate lies it's just all lies.

Reference 4 - 1.94% Coverage

I don't post often but yeah. Yeah. When I do yeah, I do post free stuff but it's just natural, I guess. Or it's Like yeah. Or if like so I've got a few friends that do photo shoots and stuff, so I put them on because I like to showcase the artwork. Yeah. But yeah, I don't, I try not to glorify my life on it because it's an easy habit to get into in a lot of people do. They don't really benefit anyone. Really. .... I'm just going to say it might make you feel temporarily good. I think it makes everybody else feel, worse and that's not nice....

Reference 5 - 0.50% Coverage

It's used is like. Platforms to promote stuff like black history month and not just like flicking for your post, nobody's doing anything.

Reference 6 - 0.50% Coverage

They think they're doing something because they're put in a post on this story like it's not doing anything like go out, make a difference.

Reference 7 - 1.03% Coverage

Another reason why I think it's fake. So, I don't do any of that anyway. it doesn't mean I don't support it I just think there are better ways to do it. And people just jump on the bandwagon and I'm like Yeah, I don't know. Yeah. Always. It always like if we're talking and communication. Yeah.

Reference 8 - 0.43% Coverage

Yeah. This fake life that they've got, the number of friends that they're with and the things that they do and deal with.

7.2 Example Focus Codes – Getting Information

Files\\chat interviews\\P21- § 1 reference coded [0.44% Coverage]

Reference 1 - 0.44% Coverage

Twitter is for. Politics. And there's a small section of Twitter that I don't know about, but it's like for academics and it's not got opinions on it...

Files\\chat interviews\\P3- § 4 references coded [2.56% Coverage]

Reference 1 - 0.80% Coverage

Yes, I hate reading books online. I love books like Holding them and reading them and that books like just as an example, I read the picture of Dorian Grey the other day because I found that for free online, just like as a PDF. I find it difficult but like in my own time and because it's free. I hate spending money. So I would rather have the book in person. But if it's free, I'm not going to

Reference 3 - 0.52% Coverage

I've never read like the newspaper or anything like that. There's not much different. But I read headlines, I don't read the actual articles.

Reference 4 - 0.63% Coverage

You do.. you Know everything and see everything. There's power. And that isn't this great power about knowing stuff about someone without actually having to talk to them.

Files\\chat interviews\\P5 - § 8 references coded [0.80% Coverage].

References 7-8 - 0.65% Coverage

I mean, yeah, Twitter is my main. the Feed, yeah. OK. It's so much like type of information, like such a high speed as well, because like I follow like hundreds of people who are just constantly tweeting

Files\\chat interviews\\P 7- § 1 reference coded [1.32% Coverage]

Reference 1 - 1.32% Coverage

ummmm i used to watch a lot of videos on YouTube? i don't know I have Been using it for finding information, like even doing things like finding e-books so I can read ahead before my course starts again.

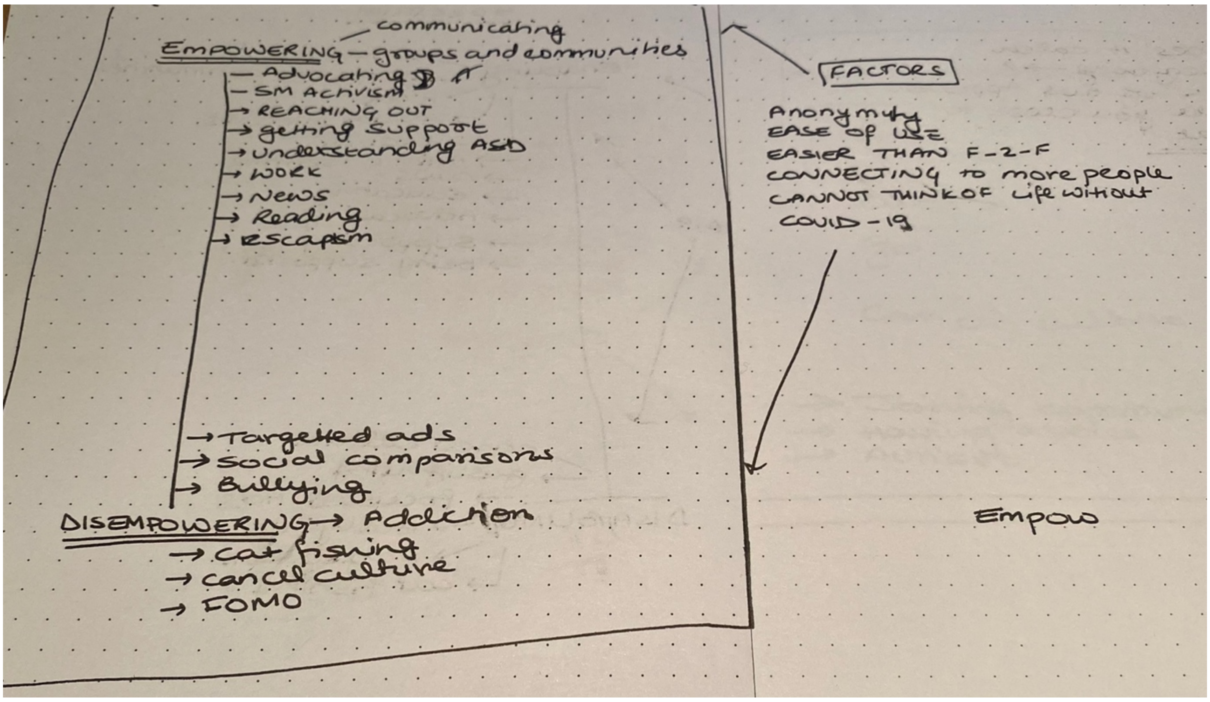
Files\\chat interviews\\Research_interview_18A1112V - § 1 reference coded [1.14% Coverage]

Reference 1 - 1.14% Coverage

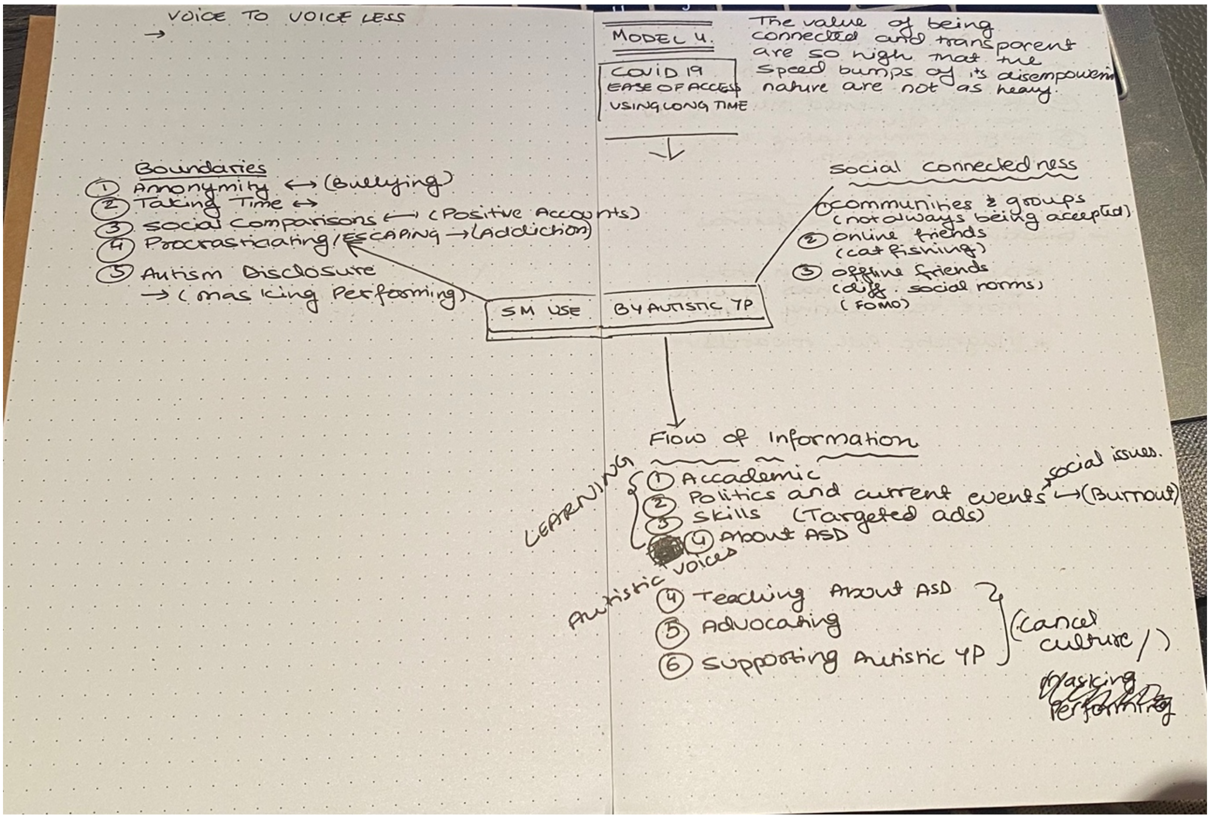
I like to look through Instagram to get inspiration for my own art and I'll look at other people's art to get inspiration, which can be good. Yeah, there's a lot that I like about social media and it's a good way to discover new things as well. Like there's things that I might not have like gotten into so much if it wasn't for social media.

Appendix Eight: Diagramming and the Model

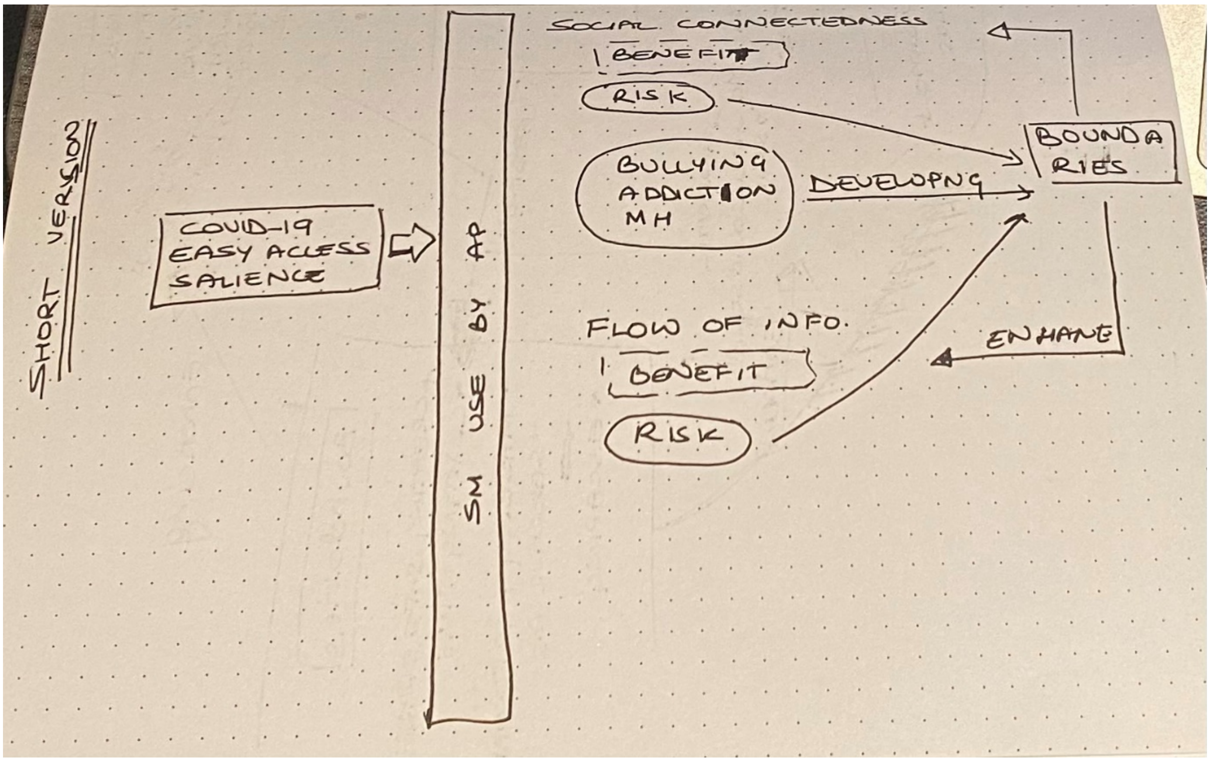
8.1 Initial Diagram



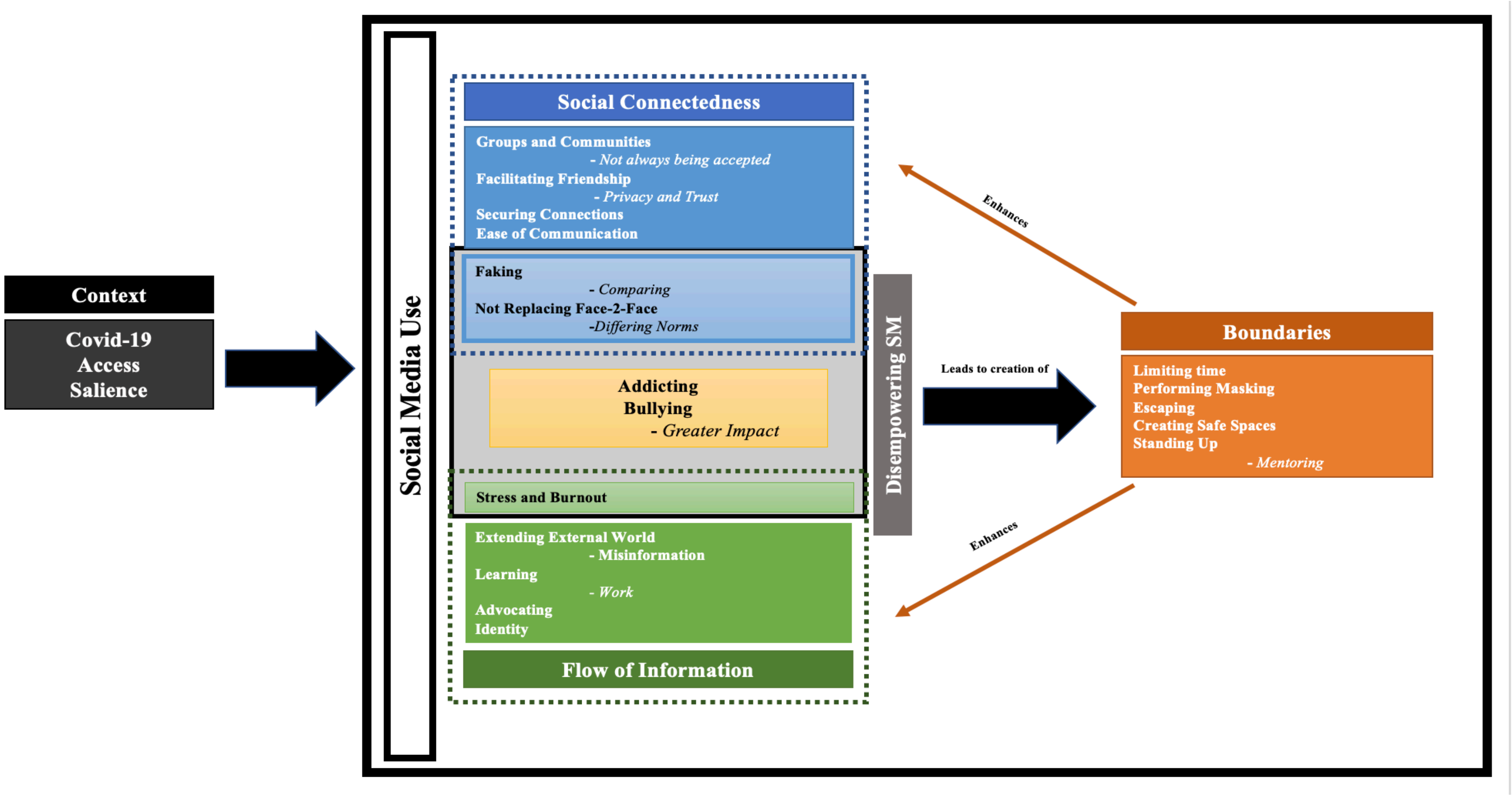
8.2 Diagram 4



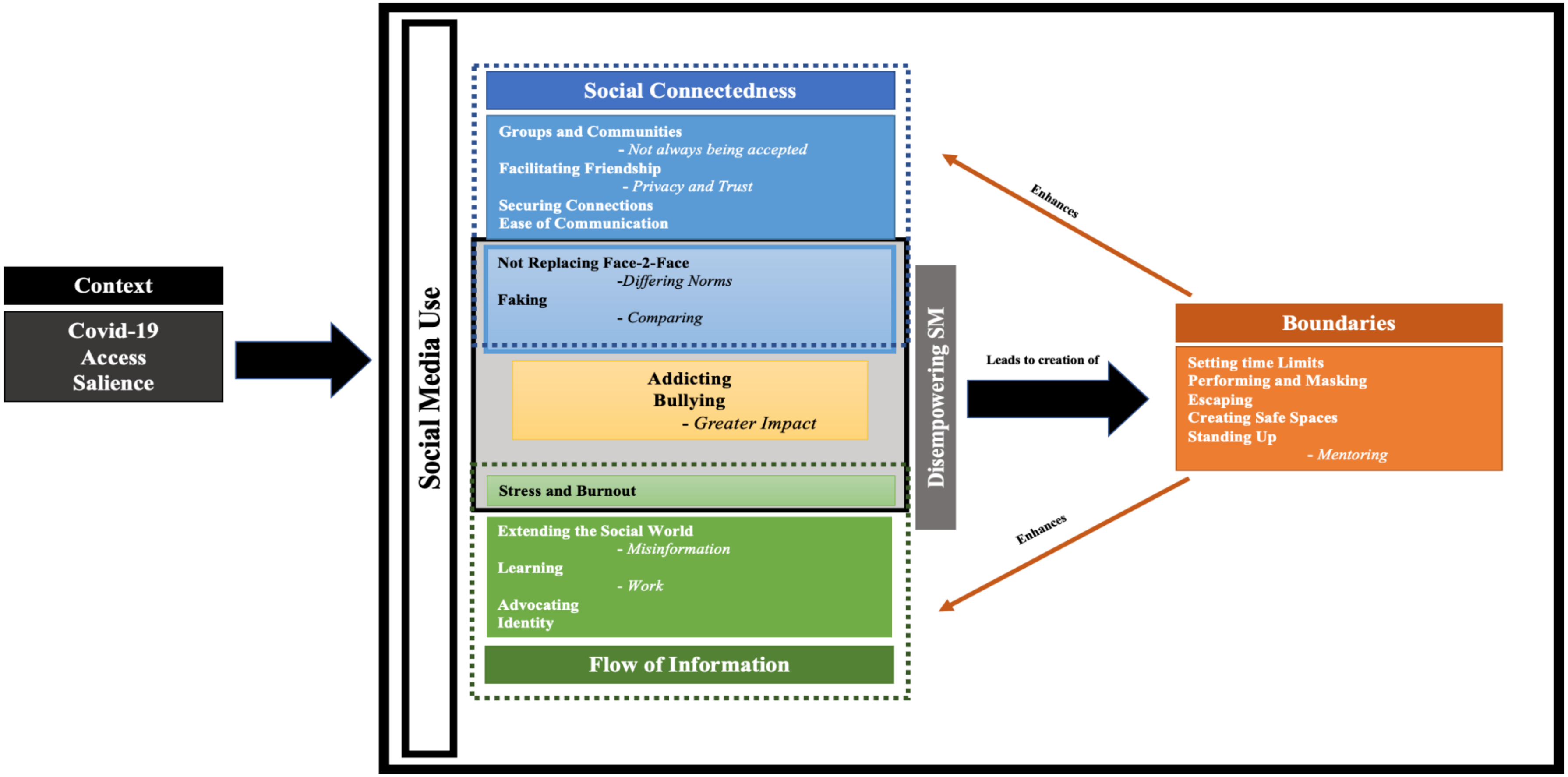
8.3 Short Version Model 5



8.4 Model 6


Context
Covid-19
Access
Salience
Social Media Use
Social Connectedness
Groups and Communities
- Not always being accepted
Facilitating Friendship
- Privacy and Trust
Securing Connections
Ease of Communication
Faking
- Comparing
Not Replacing Face-2-Face
-Differing Norms
Addicting
Bullying
- Greater Impact
Stress and Burnout
Extending External World
- Misinformation
Learning
- Work
Advocating
Identity
Flow of Information
Disempowering SM
Leads to creation of
Enhances
Enhances
Boundaries
Limiting time
Performing Masking
Escaping
Creating Safe Spaces
Standing Up
- Mentoring

8.5 Final Model after Participant Responses



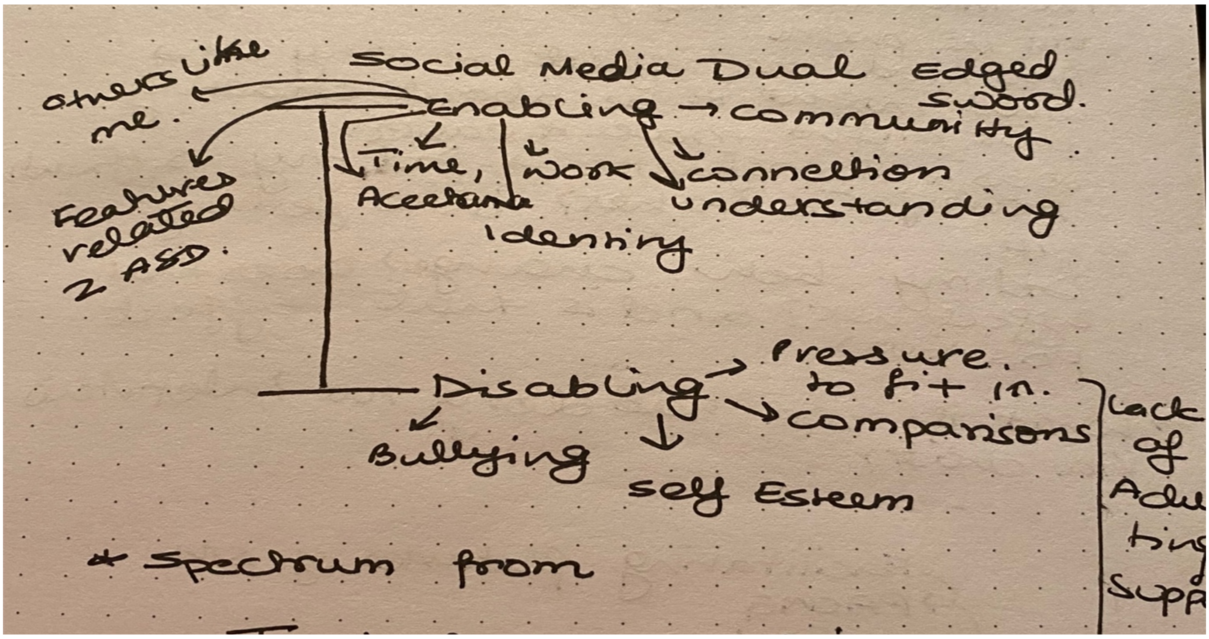
Appendix Nine: Examples of Memo’s

November 2020, Supporting

This code overlaps with 'telling off', observing other autistic or disabled or marginalised people is hard, especially when you cannot understand why someone is being mean. Stepping in and supporting them facilitates the feeling of community and being supported. However, does this help the person being bullied? is there another way of doing this?

December 2020, After coding 6 Interviews

After coding 8 interviews I wonder if the impact of social media also lies on a spectrum like autism or the spectrum from neurotypical to neurodiverse. Is social media a dual edged sword for autistic people? or this the same for everyo



January 2021, Learning

The node 'Academic' has been renamed to 'Learning' collapsing three codes together, as it seems like SM is used for learning a lot more that about academic work. 'Learning' is composed of- 'Academic', 'Hobbies and Skills' and 'Social Justice'.

Appendix Ten: Participant responses

P1

Dear Praku,

It is always nice doing something to increase awareness about autism. I like your study; hope you make it available soon.

Best of luck

P5

Dear Praku,

Thank you so much for sending this over, it looks good, I have added some comments in the document.

Best

P8

Dear Praku,

I liked taking part in the study, I have one comment- I find the code, limiting time difficult, is it possible to change the name to make it easier to understand.

Thanks, and good luck,

P20

Dear Praku,

I like the word boundaries, I enjoyed reading it and hope you do well.

Best

P.S. I now use SM a little less, I have been able to routine my time for the evening session after the interview.