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Gastrointestinal symptoms in autistic children during Covid-19 lockdown: A qualitative study of family experience

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ABSTRACT

Background: Autistic individuals face barriers to healthcare access and premature mortality. There is an increased prevalence of gastrointestinal (GI) disorders in autistic children compared to non-autistic children. There is a complex interplay between these GI symptoms and various aspects of behaviour, sleep, and mental health in autistic children. Lockdowns during the Covid-19 pandemic changed the delivery of healthcare for all patient groups, and it is particularly important to understand the effects of this on vulnerable groups. In this qualitative study we document the family experiences associated with managing persistent GI symptoms in autistic children and access to related healthcare for these children during Covid-19 lockdowns and restrictions.

Method: We conducted semi-structured interviews with 12 parents of autistic children and subjected data from these interviews to qualitative analysis.

Results: Two themes emerged (i) Covid-19 lockdowns and restrictions changed the children's reported GI symptoms in a non-uniform manner; and (ii) parents were divided on the appropriateness of telemedicine services for their child. Some parents reported an increase in their child's anxiety level that was linked to worsening of GI symptoms. Those parents who reported a reduction in their child's social anxiety during lockdown related this to improved GI symptoms. Parents reported advantages and disadvantages of both in-person and telemedicine consultations, and they were split on their preferences for these appointment types.

Conclusions: Telemedicine is preferred by some but not all families of autistic children. Clinicians should consider the interplay between anxiety and GI symptoms in autistic children when assessing and treating GI symptoms.

1. Introduction

Autism Spectrum Disorder (ASD) is a medical diagnosis that is based on observation and medical history taking. Some people with a

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diagnosis of ASD see it as a natural form of neurodiversity that should be accommodated with acceptance and reasonable societal adjustments. A recent systematic review calculated the median global prevalence of ASD to be 65 per 10,000 with an increasing prevalence over time (Zeidan et al., 2022). In the United Kingdom, the prevalence estimate is one in 57 or about 1.76% of children (Roman-Urrestarazu et al., 2021). ASD is characterised by difficulties in social communication and understanding, and a rigidity of interests with repetitive behaviour patterns, as specified in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013). There is wide variability in the day-to-day impact and manifestations of core characteristics of ASD among people with this diagnosis, some of which is situation dependent (Haydon et al., 2021), potentially confusing the optimal assessment procedures. Sensory responses that differ from not-autistic people frequently present in autistic individuals (Ben-Sasson et al., 2009) and they are now considered part of the diagnostic criteria and core autism characteristics (Case-Smith et al., 2015). Social situations can be very challenging for autistic individuals and their sensory perception of environments can differ from that of not-autistic individuals, such that autism is commonly associated with sensory overload.

In a large Swedish cohort study with matched controls (Hirvikoski et al., 2016) autism was associated with significant premature mortality due to a multitude of medical conditions. Associated health conditions are common and varied in autistic children (Wills and Evans, 2016) and amongst them GI symptoms often co-occur with other conditions of increased prevalence, including epilepsy, anxiety, intellectual disability and sleep disorders. Symptoms of co-occurring disorders and prescribed medication side effects can become interwoven into a complex medical picture. Added to this, there is evidence that autistic individuals face barriers in accessing healthcare on several fronts (e.g., challenges that stem from autistic characteristics, challenges at the point of clinical care, and other access barriers) (Walsh et al., 2020). The National Health Service (NHS) in England has recognised autism and learning disabilities as a priority in their Long-Term Plan and the needed actions they identified include increasing an understanding of the needs of autistic people amongst all NHS staff and reducing health inequalities for this group.

There is a higher prevalence of GI symptoms in autistic children compared with not-autistic children (McElhanon et al., 2014) and this appears to be consistent across ethnicities (X.-L. Yang et al., 2018). A review of studies reporting on GI symptoms in autistic children, found the median prevalence rate to be 46.8%, range 4 – 97% (Holingue et al., 2017). In their systematic review of GI symptoms in autistic individuals, Leader et al. (2022) confirmed a high incidence rate of GI symptoms and found some evidence of a causal effect for autism from a gut-immune-brain pathway (Leader et al., 2022). There is evidence that GI symptoms may present differently in autistic children than in other children. Parents of autistic children report that their children have difficulty verbally expressing their experience of GI discomfort; consequently parents rely on stool appearances and behaviour changes, such as increased irritability, to signal GI distress (Holingue et al., 2021). In a consensus report, Buie et al. (2010) presented a list of behaviours that may indicate abdominal pain in autistic individuals (Buie et al., 2010). Correlations have been reported between the severity or presence of GI symptoms in autistic children and the presence or severity of certain behaviours, core autistic characteristics, sleep disturbance, anxiety, sensory over-responsivity, unusual eating habits and motor skills (Adams et al., 2011b; Maenner et al., 2012a; Mazurek et al., 2013; X.-L. Yang et al., 2018). However, there are currently no controlled longitudinal studies clarifying the direction of influence between GI symptoms in autistic children and other associated symptoms. Overall, the evidence suggests a complex multifaceted relationship between GI symptoms and behavior in autistic children. This impression allies with research in children without autism for behaviour related to GI disorders in which reported functional constipation and related behaviours shared a complex, multifactorial pathophysiology (dos Santos et al., 2021).

Many studies have reported the effects of Covid-19 lockdowns on autistic children of varying ages, in a variety of countries. Some reported mostly negative effects (Franz & Kelly, 2021; Nonweiler et al., 2020), while others have reported mostly positive effects (Guidotti et al., 2020; Meral, 2022; Siracusano et al., 2021) and finally a number have reported mixed effects (Amorim et al., 2022; Di Renzo et al., 2020; Polónyiová et al., 2022; Tokatly Latzer et al., 2021). Few investigators reported on any aspect of self-care or dietary habits that may be relevant to the management of GI symptoms. Di Renzo et al. (2020) reported no change in self-care abilities (which included toileting) and no change in taste or smell sensitivity. Latzer et al. (2021) reported a mixed picture regarding dietary habits, with some parents reporting a worsened food-related behaviours (including food selectivity) while others reported greater flexibility in their child's dietary habits during lockdown. Meral (2022) found that parents reported an improvement in their child's ability to meet their own self-care needs, including performing a greater variety of self-care skills (toileting skills are specifically mentioned). Guidotti et al. (2020) reported that there was no change in children's appetite during lockdown. None of the studies have specifically focused on the management of GI symptoms in autistic children and access to related healthcare during the Covid-19 lockdowns and its restrictions. Even for children without the additional challenges of autism, managing GI symptoms can be difficult due to the complex interplay between GI symptoms, psychological symptoms, environmental/social factors, and a dearth of research evidence to guide clinical practice (Athanasakos et al., 2020). The Covid-19 pandemic changed the delivery of healthcare for all patient groups, with increased use of telemedicine commonplace. It is important to understand how this new model of healthcare affected those groups who were already facing barriers to healthcare access. One way to study this issue is to use population-based research that includes qualitative interviews with service users that might document and provide detail to better understand their experience. We used this approach in our research to document and understand how the Covid-19 lockdowns and restrictions affected persistent GI symptoms in autistic children and to better describe the family experience in managing their healthcare within telemedicine.

2. Methods

We sought to answer the question, "What are the lived experiences of families managing persistent GI symptoms in their autistic child during Covid-19 lockdown and restrictions?"

2.1. Participants

We conducted interviews with parents of 12 autistic children with persistent GI symptoms. All participants in this study were parents of children who had previously participated in a clinical trial of the Vivomixx probiotic (VIVO-ASD). This larger study was approved by the National Health Service Health Research Authority and the study protocol and results have already been reported (NCT03369431, 2017). Our participants were selected to achieve a range of experience from those participating in the VIVO-ASD study, such that we used the following criteria in making selection decisions for this qualitative study: two girls on the child dose; two boys on the child dose; two girls on the 11 + dose; two boys on the 11 + dose; two girls who withdrew before the end of the study; two boys who withdrew before the end of the study. Within these criteria, participants were invited to participate in reverse chronological order of completing the VIVO-ASD study as their experience was more recent. Where we were unable to fulfil one of the criteria, we invited participants in simple reverse chronological order of their completion date for the VIVO-ASD study. 12 out of 13 parents that responded to the invitation agreed to take part. The parent that declined to take part felt they did not have enough to say as their child withdrew from the VIVO-ASD study after 4 weeks. Interviews were organized at the convenience of the parents and as such two of the interviews were done with both parents, nine were done with the mother only and one with the father only.

At the time of the interviews, the children were aged between 5 and 15 years old. All the children had a diagnosis of autism, confirmed with a copy of the letter giving the child their autism diagnosis. We interviewed the parents of 3 girls on the child dose, 5 boys on the child dose, 1 girl on the 11 + dose, 2 boys on the 11 + dose and 1 boy that withdrew early from the VIVO-ASD study. The children had a variety of GI diagnoses (Table 1) and GI symptoms (Table 2). Their dietary habits were varied, and they were geographically spread out across England. The participants included children identified by their parents as Asian/Asian British, Mixed/Multiple ethnic and White. Specific data on socioeconomic status was not recorded in the study. No incentive was offered to participate.

2.2. Researcher characteristics

Both researchers are based at the GI physiology department in University College Hospital London, one as a specialist bowel nurse and the other as a graduate researcher studying dietary approaches to managing GI symptoms in autistic children. One researcher met with all the participants as part of the VIVO-ASD study, and the other researcher had no contact with participants. One researcher has personal family experience of autism.

2.3. Semi-structured interviews

A topic guide was developed and used as a basis for the interviews. Invitations to participate and information on the topics that would be discussed were sent by email. We obtained informed consent from parents by email, and this was confirmed at the beginning of the videocall interview. The interviews took place between 25th August 2020 and 18th January 2021 and were all conducted by videocall by SS. All parents were reporting on Lockdown 1 in England (starting March 2020), restrictions at schools that occurred in summer and autumn of 2020, and, in later interviews on Lockdown 2 in England during the winter of 2020–2021. Situational notes and reflections about the interview were made by SS at the time of the interview and were considered in the analysis. The interviews averaged about 60 min in length (range: 41 – 90 min) and were audio-recorded and transcribed verbatim except for anonymising any of the parent's personal details. The transcript was shared with the interviewee for their confirmation that it was a true reflection of the conversation.

2.4. Data analysis

We used Framework analysis of these data which is suited to experiential data, can be shaped by the data, and automatically builds an audit trail (Goldsmith, 2021). SS and CB familiarised themselves with the data by reading all the transcripts and discussing them

Table 1
GI diagnoses current or previous.

Gastrointestinal diagnosis (current or previous)	Number of participants
Functional constipation	2
Reflux	3
Coeliac disease	1
Impacted bowel	1
Immature bowel	1
Rumination syndrome	1
Helicobacter pylori infection	1
Duodenal ulcer	1
Mega bowel	1
Irritable bladder	1
Enuresis	1
No gastrointestinal diagnosis	6

Table 2

Current GI symptoms.

Current gastrointestinal symptoms	Interviewee
Constipation managed with 3 sachets of Movicol daily but with regular soiling of underwear.	1
Odorous flatulence with slightly loose, sticky stools	2
Impacted, immature bowel, celiac, food allergies, swinging between severe constipation and diarrhoea, with some faecal incontinence at night	3
Vomiting after meals, and not yet toilet trained	4
Occasional stomach-ache, not affecting appetite, otherwise no symptoms	5
Constipation managed with ½ sachet of Movicol and several lifestyle measures, but needs very careful attention by parents	6
Bloating and odorous flatulence	7
Occasional undigested food in stools, otherwise no symptoms	8
Constipation, irritable bladder, nocturnal enuresis, urgency for bowel movements, occasional daytime soiling.	9
No current symptoms	10
Constipation with irregular bowel movements, not toilet trained for stools	11
Occasional very large stools, otherwise no symptoms	12

together. Following this, we developed a list of Framework categories that were primarily based on the subjects in the topic guide. This initial Framework was piloted on five transcripts by SS and CB independently to check whether it was a good fit for the data. Once the Framework was agreed, SS and CB indexed all the transcripts independently and held regular meetings to discuss the emerging themes and the fit of the Framework. The indexed data were summarised and charted independently by SS and CB into an Excel spreadsheet, along with selected quotes from interviewees that illustrated topical themes. Each category for each participant was analysed to identify recurring themes and inter-relationships and to identify a structure from the coded interview content, referring to the interview transcripts where necessary. The result was written as a narrative that was discussed by the research team and then presented to the GI physiology team at University College Hospital London. Discussing the results with the clinical team helped to sense-check the findings and further shape data mapping and interpretation.

2.5. Community involvement

The topic guide for the interviews was actively reviewed by an experienced public health researcher who also has family experience of an autistic child with GI symptoms. Following this, a revised topic guide was reviewed by three parents with their autistic child for comments on its relevance, appropriate wording, and any needed additions.

3. Results

The overarching theme from this study's results was that Covid-19 lockdowns and restrictions led to non-uniform changes in the GI symptoms of autistic children. A second theme was that parents were divided on the appropriateness of telemedicine or video medicine for their autistic child.

3.1. Theme 1: Covid-19 lockdown and restrictions resulted in changes to autistic children's GI symptoms in a non-uniform manner

There appears to be several interacting factors contributing to a change in GI symptoms in the autistic children during Covid-19 lockdown. Home is a 'comfort zone' for most children and from the interviews, this also applied to the autistic children in this study. All the children were not able use a toilet outside of the home for bowel movements and many would withhold bowel movements while at school with subsequent discomfort. In contrast, during Covid-19 lockdown they were able to use the toilet whenever they needed. Consequently, some parents reported that their child's constipation improved during lockdown. For the children that were anxious in social situations, parents reported that their child was calmer, less anxious and happier during lockdown as there was no socialising.

"He's really happy at the moment because he hasn't been to school for six months. So he has been very different"

Parents identified anxiety as a trigger for the onset of diarrhea in their child and for the worsening of constipation.

"Because he was a lot calmer during (covid) lockdown, you know a lot of his anxieties went because he was in the house and managing it all a bit better. So, knowing he was going back to school, that, obviously he's a bit more constipated at the minute."

All the parents reported that managing their child's GI symptoms was easier at home, and some parents reported being more relaxed about their child's GI symptoms during lockdown.

(after lockdown) *"his friends were coming round to see him so, you know, he suddenly felt that pressure again. I'd forgotten that we haven't had that pressure for a while"*

Covid-19 lockdown meant a change in the children's usual routines and there were restrictions on time spent outdoors and where you could go to exercise. Some parents reported that this had a detrimental effect on their child's GI symptoms and mood;

“when things change, or routine’s different, then we get a lot more of that (soiling of underwear). And at the moment, because things, we’ve had so much changes (Covid restrictions and lockdown)... After the last couple of weeks he’s got the most alarming reflux.”

Prior to schools shutting for lockdown and when they re-opened after lockdown, the children had to get used to new Covid-safe procedures. Not only was this a change to the usual school routine, but the new procedures also introduced extra challenges in the management of autistic children’s GI symptoms. One child who was routinely vomiting after every meal was sent home whenever this happened as the school staff couldn’t take the risk of cleaning up the vomit. Unfortunately, this meant a lot of missed lessons and impacted the child’s learning. Other parents reported that the water fountains were switched off and children were unable to refill their water bottles, making it difficult to stay adequately hydrated. Several parents reported that it was more difficult for their child to access the toilet when they needed to, as children were allocated to a specific toilet that could be a long way from their classroom, or that the children were only allowed to use the toilet at a set time during the day, which didn’t necessarily fit with their child’s needs.

“with the Covid thing she’s got to go miles to HER toilet (at school) because they’re not allowed to use each toilet – they have their own toilet now. So at the moment it’s even worse really”

For two children, the lockdown and subsequent return to school routine had affected their regular bowel habits. One child who was withholding when at school, was opening their bowels multiple times a day without any regular routine while at home during lockdown and had found it hard to establish a regular routine after lockdown finished.

“it’s not settled again, when he goes to the toilet. We had to get him going in the morning(because of going back to school). It did change to the afternoon, it seems to have gone back to the morning again now. I think he likes to go before he goes to school, and if he doesn’t then he’s holding it until he gets home. And during lockdown he could go whenever you wanted so I think it got later in the day.”

3.2. Sub-theme: extra family time allowed a focus on self-care and life skills

The whole family being at home during Covid-19 lockdown and regular clubs and activities being closed, allowed some parents the time to encourage lifestyle changes that could help manage their child’s GI symptoms. One parent took the opportunity to toilet train their child. Several parents encouraged their child to expand the range of foods they could enjoy, or helped them establish a regular routine of exercise. One parent encouraged their child to become involved in cooking the family dinner with great success;

“So one of the things that we did through lockdown was that he had to cook a meal and cook a sweet treat once a week, so that he would have different meals that we knew he could cook, and trying to get him more interested in food, I think that definitely helped.” (talking about expanding variety in the diet)

3.3. Theme 2: parents were divided on the appropriateness of telemedicine or video medicine for their autistic child

As video and phone consultations have become part of standard medical care since the Covid-19 pandemic, we asked parents how they felt about these for their autistic child. The group of interviewees were split on whether this was helpful for their child or not and analysis did not uncover an obvious characteristic driving this preference. There were three minimally verbal children in the group and the parents of two of these preferred video or phone consultations and one did not. There were two autistic children with complex needs in this study and both families preferred video or phone appointments. There were four parents who reported that their child had suffered a very stressful experience at a previous medical appointment, and three of these preferred video or phone appointments and one did not.

Overall, half of the parents were not comfortable with video consultations for medical appointments as they were concerned that things could be missed, and they wanted the reassurance of a doctor seeing their child in person. Some also felt it would be difficult or impossible for their child to participate in a video or phone consultation. A few parents mentioned that they thought their child would not get as much out of a videocall and that the recommendations of the doctor would not be taken so seriously by their child;

“(my son) sitting with that consultant is part of what changed his experience. I think just hearing it from me or hearing it on Zoom wouldn’t have the same gravitas as it did”

In contrast, three parents were delighted with the advent of phone and video consultations as taking their child to the doctor’s surgery or hospital was fraught with difficulty and very stressful for the child and parent;

“..so now the system is you take a photo, you send it into the doctor, and you discuss it over the phone. Well, that’s brilliant because it does, it means that he doesn’t have the trauma of waiting and sitting in a doctor’s room, and I’m able to take lots of angles of it on my camera and send it through. So I don’t, I think in a way, this system is better, unless he needs a physical examination or unless they are specifically looking at his autism, for example, in a paediatric appointment. I don’t see the value of it at all, it’s just very traumatic.”

Points raised in favour of a video consultation was that it would be less intimidating for the child and it would be less stressful for the child to be in their safe space at home.

There was a feeling amongst some parents that video or phone consultations would be fine for some types of medical appointments, particularly where there was no need for the child to be examined by the doctor.

Given the wide heterogeneity within the autism diagnosis, it is perhaps not surprising that there is not a type of medical

consultation that suits all families. Overall, parents expressed a desire to have access to a choice of consultation types including in-person as well as remote. This could allow the parent and child to choose the most accessible and appropriate type of consultation for them. The nature of medicine dictates that sometimes a physical examination will be needed. Medical professionals should be aware of the stress in-person consultations may cause for the child and parent and enquire in advance about reasonable adjustments that may facilitate successful attendance.

4. Discussion

In this qualitative study we sought to understand the impact of Covid-19 lockdowns and restrictions on families managing persistent GI symptoms in their autistic child. Our two key findings are that Covid-19 lockdowns and restrictions did have an impact on their child's GI symptoms, but this was not in a uniform fashion across the study group (Theme 1); and that parents are divided on the appropriateness of telemedicine for their autistic child (Theme 2).

Our results regarding the change in nature and severity of GI symptoms in autistic children during home confinement due to Covid-19 lockdown, reflects previous research which has indicated a complex interplay between GI symptoms and various aspects of behaviour, sleep and mood (including anxiety) (Ferguson et al., 2019; Dovgan et al., 2022; J. Yang et al., 2020; Adams et al., 2011a; Maenner et al., 2012b; Mazurek et al., 2013). The parents in this study reported that an increase in anxiety was a trigger for the onset of diarrhea or for a worsening of constipation or reflux in their child. The prevalence of an anxiety disorder in autistic children has been estimated at 40% (Jenkinson et al., 2020) and a lifetime prevalence of anxiety disorders in autistic adults is estimated at 42% (Hollocks et al., 2019). The response rates to standard anxiety treatments like Cognitive Behaviour Therapy (CBT) are low in autistic adolescents (Wood et al., 2015). Dovgan et al. (2022) found a bi-directional relationship between internalising symptoms like anxiety and GI symptoms in autistic children (Dovgan et al., 2022). This indicates that anxiety can affect GI symptoms and vice versa in autistic children and resolution of either may require the treatment of both. In this study, parents generally reported a reduction in anxiety in their child due to the lack of social pressures while at home during Covid-19 lockdown. This may contribute to the reported improvement in GI symptoms in some participants. This appears to be in contrast to Amorim et al. (2022) where parent-reported levels of anxiety in autistic children were significantly higher than those in not-autistic children during Covid-19 lockdown in Portugal (Amorim et al., 2022). It should be noted that they used a non-standard measure of anxiety. Polonyiova et al. (2022) used a standard measure for internalising behaviour which included anxiety in a combined score with fear, sadness, apathy and social withdrawal (Polonyiová et al., 2022). They found significantly higher levels of parent-reported maladaptive internalising behaviour in autistic children compared to not-autistic children in Slovakia at all three timepoints studied (before lockdown, Wave 1 lockdown and Wave 2 lockdown). Comparing the mean scores for parent-assessed maladaptive internalising behaviour in autistic children from before lockdown to during Wave 2, there was a significant increase in the level for autistic children. We did not measure anxiety levels in our participants as this was a qualitative study, but some parents reported an increase in anxiety in their child as a result of changes in their usual routine and this was accompanied by a worsening of their GI symptoms.

Our findings regarding the appropriateness of telehealth for families of autistic children generally reflect the findings of Franz & Kelly (Franz & Kelly, 2021). The parents in our study were happier to take part in a telemedicine consultation when they felt there was not a need for a physical examination. Franz and Kelly (2021) asked parents about their willingness to participate in behavioural telehealth appointments for their child and the mean willingness score was 6.89 on a scale of 0–10 (higher score representing more willingness to participate). Parents expressed advantages and disadvantages to both telemedicine consultations and in-person consultations for their child. Telemedicine obviously removes the difficulties of travelling with their child and some parents reported that their child found public transport or long car journeys challenging. However, where the child can communicate with the doctor independently, parents felt that attending an in-person consultation could aid the child's understanding and commitment to the treatment. Parents also expressed concerns about telemedicine consultations where their child was non-verbal or unable to accurately report pain: They felt that a physical examination was essential in some instances and, given the communication difficulties and sensory processing issues commonly found in this patient group, there may be a lower threshold for this need. Further research is needed on the identification and expression of pain by autistic children with GI symptoms.

The limitations of our study are that all participants are a subset of those who participated in the VIVO-ASD probiotic clinical trial. The retention rate in the VIVO-ASD study was high with only 9 participants not completing the study (compared to 60 who completed) and consequently we were unable to fulfill some of our original selection criteria for the participants of this study. In hindsight, it was perhaps unrealistic to expect to interview 4 participants that withdrew early from the study. The interview questions were drawn from our experience with families during the VIVO-ASD study taking a pragmatic, real-life approach. As with other studies done during Covid-19 lockdown, parents' thoughts and feelings may have been affected by stressful events at that time. Strengths of the study are the fact that the interviews were done while parents were experiencing Covid-19 lockdown or restrictions including the closure of schools. The participants included a mix of girls and boys and a range of ages, with a geographical spread across England, and a variety of GI symptoms. All the transcripts were indexed, summarised and charted independently by two researchers from different professional backgrounds. Using the Framework analysis technique means that there is an audit trail of the data analysis.

In conclusion, we found that persistent GI symptoms in autistic children changed during the home confinement of Covid-19 lockdown but not in a consistent manner across the group. The absence of socialising outside the home reduced anxiety to many of the children and had a positive effect on their GI symptoms. All children in the study would only use the toilet at home for bowel movements so having access to this all day may also have improved GI symptoms. Restrictions on outdoor exercise and the cancellation of all sports clubs had a negative effect on the GI symptoms of some children. Changes in the child's usual routine caused by Covid-19 lockdowns and restrictions unsettled some children and a consequent worsening of GI symptoms was observed by some parents. Covid-

safe measures in schools had a uniformly negative effect on the child's GI symptoms due to restricted access to toilets and the closure of water fountains in schools. Regarding telemedicine consultations, parents had very mixed views with advantages and disadvantages stated for both telemedicine and in-person consultations without any clear identifying characteristic emerging for the different views.

5. Implications

Telemedicine was the preferred type of consultation for some families of autistic children but not for all. Medical professionals should be aware of the stress in-person consultations may cause for the child and parent and enquire in advance about reasonable adjustments that may facilitate successful attendance. The view of parents was that both modes of consultation should continue to be readily available to patients. This qualitative research reports parent observations of an interplay between anxiety and GI symptoms in autistic children and this interplay has previously been reported (Dovgan et al., 2022). Clinicians should consider this relationship when assessing and treating GI symptoms in autistic children. As qualitative research, this study focuses on the experience of a relatively small number of families. To get a more complete understanding of the topic, further research is needed on how the management of persistent GI symptoms in autistic children impacts on the child themselves and their family, and how this relates to their healthcare experiences.

CRedit authorship contribution statement

Susan D. Simmons, Anton V. Emmanuel: Conceptualization. **Susan D. Simmons:** Data curation, Investigation, Methodology, Writing – original draft. **Susan D. Simmons, Concetta Brugaletta:** Formal analysis. **Anton V. Emmanuel:** Supervision. **Anton V. Emmanuel, Concetta Brugaletta:** Writing – review & editing.

Declaration of Competing Interest

None of the authors have any actual or potential conflict of interest that could inappropriately influence this work.

Data availability

Dataset contains data relating to 2 other papers so will be shared once all are published.

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