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COVID-19, Autism, and Isolation: Good Practices for Continuity of Care During the Pandemic

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ABSTRACT

The COVID-19 pandemic, and particularly the associated conditions of isolation, has detrimental effects on the mental health of the population that are not yet fully understood. Variables such as individual stress, anxiety, and tolerance to uncertainty may play a role in the ability of individuals to adapt to the isolation situation. In this context, it is necessary to pay attention to population groups that present difficulties in adapting to this situation of uncertainty, such as people with autism. This narrative review of the evidence has as objectives to explore (1) the effect that the autism community has experienced as a result of the lockdown and isolation due to COVID-19; and (2) opportunities for health, educational, and social services providers to support people with autism and their families in isolation in an attempt to ensure that specialized interventions continue as much as possible. We map suggestions regarding information delivery, time management at home, recognition and emotional expression, and some suggestions to maintain support with service providers.

KEYWORDS

Autism spectrum disorders; COVID-19; isolation; mental health

Introduction

The COVID-19 pandemic has generated a sudden change in our lives that demanded substantial changes to individual and population behavior, as well as resource distribution and utilization (Rettie & Daniels, 2020). One of the common consequences of the pandemic has been the implementation of lockdowns or other isolation measures that have forced the population to be very flexible and creative in replacing habits (Bavel et al., 2020). However, adapting or establishing new habits can be difficult for some population groups, such as the autism community (Hassiotis et al., 2020).

Autism refers to a group of neurodevelopmental conditions characterized by heterogeneous deficits in social interaction and communication, and the presence of restricted and repetitive behavioral patterns (American Psychiatric Association, 2013; Chawarska et al., 2013; Ozonoff et al., 2014; Pandey et al., 2008). It is conceptualized by the Diagnostic and Statistical Manual of Mental Disorders (fifth edition; American Psychiatric Association, 2013) as a spectrum that can range from mild to severe manifestations without established subtypes and can present differently across individuals. Recent

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prevalence estimates of autism indicate a prevalence of just under 2%: a prevalence of 1.85% was reported according to data from the Center for Disease Prevention and Control (Maenner et al., 2020), while a prevalence of 1.76% was reported in a population study of school children in England (Roman-Urrestarazu et al., 2021). People with autism have experienced substantial changes in their lives and have faced significant challenges generated by the changes and in-securities brought about by the pandemic and the subsequent lockdowns (Vermeulen, 2020a). Some of the characteristic difficulties in autism, such as difficulties in anticipating and assimilating routine changes in daily life (Vivanti et al., 2019a), tolerating uncertainty (Boulter et al., 2014), deficits in emotional processing and expression (Lerner et al., 2013) or difficulties in achieving emotional regulation in situations of anxiety and stress (Mazefsky et al., 2013a) may make people with autism disproportionately more vulnerable to the effects of the pandemic, even more so without specific support (Courtenay & Perera, 2020; den Houting, 2020; Griffiths et al., 2019; Narzisi, 2020a; Pellicano & Stears, 2020).

Furthermore, the pandemic may have disproportionately negative effects on the mental health of the autism community (who already often cope with mental ill-health; see (Lai et al., 2014)) (Holmes et al., 2020). Recent reports on the impact of the COVID-19 pandemic on the mental health of the general population in China suggest that about 25% of the population experienced some degree of psychological distress during the first quarter of 2020—the peak of the first wave of COVID-19 in that region (Qiu et al., 2020), which gives an indication of the effect the pandemic and the responses to it have on the mental health of neurotypical people.

The pandemic inhibited the ability to properly and safely address the elevated levels of mental ill-health as a large part of society migrated to digital spheres to remain functional (Almeida et al., 2020). Since the beginning of the pandemic, research has predominantly focused on understanding the virus and developing healthcare responses. However, there has been evidence of a gap in social, educational, and healthcare that may have important implications for those who require it, especially from the field of educational inclusion (Colizzi et al., 2020a; Cortese et al., 2020; van Kessel, Walsh, et al., 2019). It is particularly important to pay attention to how the COVID-19 pandemic affects vulnerable population groups, such as people with Autism Spectrum Disorders (ASD, henceforth autism).

Institutions and professionals are challenged to minimize the negative effects that the COVID-19 pandemic may have on individuals with autism and their families (Eshraghi et al., 2020; Golberstein et al., 2019; Patel et al., 2020). Given the novelty of the situation, we employ a narrative literature review in order to map important themes and topics that should be investigated more carefully in a systematic manner. In particular, the research objective is to explore the effect that the autism community has experienced as a result of the lockdown and isolation due to COVID-19. We also explore opportunities for health, educational, and social services providers to support people with autism and their families in isolation in an attempt to ensure that specialized interventions are interrupted as little as possible.

Methods

Articles were extracted from PubMed and Google Scholar (first 200 hits [Haddaway et al., 2015]) using the search terms “Autism OR ASD OR ASC OR Autism Spectrum Disorder OR Autism Spectrum Condition,” “COVID-19 OR coronavirus,” and “Isolation OR lockdown” in titles, abstracts, and keywords. Articles between November 2019 and January 2021 discussing the impact of isolation on the field of autism as a result of COVID-19 and articles outlining good practices for supporting people with autism and their families in times of isolation were briefly reviewed afterward.

Results

The search strategy of this narrative literature review resulted in 282 hits (82 in PubMed, 200 in Google Scholar), of which 45 articles were ultimately included. A PRISMA flowchart depicting the article selection process is added in Figure 1.

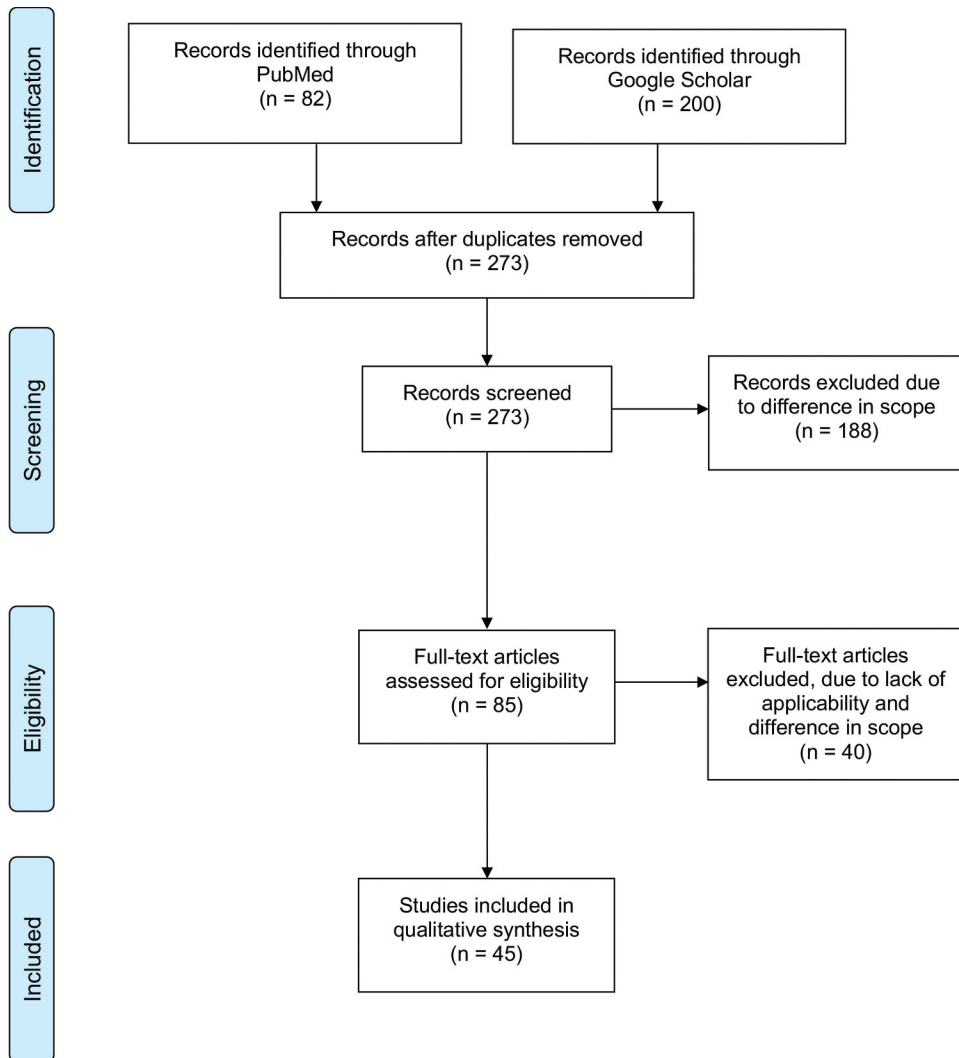


Figure 1. PRISMA flowchart showing the processes of Identification, Screening, Eligibility and Inclusion of narrative literature review articles.

Effects of the COVID-19 pandemic on people with ASD and their families

Since the early stages of the pandemic, several studies have highlighted the negative effects on people with autism in areas like physical health, emotional health, employment, family context, and the risk of skill loss and developmental regression (Amaral & de Vries, 2020; Ameis et al., 2020; Courtenay & Perera, 2020; Lai et al., 2020).

Impact of the pandemic on physical health

Preliminary studies in people with autism have not shown that the symptom profile of COVID-19 in people with the condition is very different from that observed in neurotypical people. A case series study conducted in a neurodevelopmental unit showed that 81.8% presented with high respiratory symptoms, 63.6% presented with gastrointestinal symptoms, 63.6% presented with fatigue, and 45.5% presented with low respiratory symptoms, while 18.75% of the cases of infection remained asymptomatic (Nollace et al., 2020).

In terms of the transmission of the virus, it has been suggested that there is a greater probability of infection among people with autism than the rest of the population (Landes et al., 2020; Turk et al., 2020), particularly due to difficulties in maintaining social distance, understanding the need to reinforce hygiene habits and guidelines, and in anticipating risk situations, among other factors. The risk is further increased in certain residential settings where bedrooms, bathrooms, and other spaces are shared with other residents (McMichael et al., 2020). Given this higher risk environment, the implementation of specific protocols for accessing medical care in health services is recommended (Nicholas et al., 2020). Moreover, children and youth with autism are more likely to attend emergency care, primary care, and mental health services than other population groups (Aishworiya & Kang, 2020; Laupacis, 2020; Liu et al., 2017; Weiss et al., 2018). Finally, people with autism often have co-occurring conditions that are also associated with an increased risk or higher severity of infection, such as intellectual disabilities, genetic disorders, heart conditions, metabolic disorders, or respiratory problems (Courtenay & Perera, 2020).

Impact of isolation on the provision of specialized services

Diagnosing autism is further complicated in times of isolation since direct contact with and interaction between the professional and the child are essential for detection (Dawson et al., 2012; Pickles et al., 2014; Vivanti et al., 2018). The inability to carry out evaluations during isolation has generated a delay in detection, diagnosis, and early intervention, all of which are factors that improve the prospects of children with autism and their families.

The use of video conferencing or other means to connect remotely is raised as a potential response to this new environment (Alfuraydan et al., 2020a), as it would allow professionals and teams to remotely interact with, consult, and evaluate the child. In addition, a Store-and-Forward method is suggested to upload behavioral videos to a web portal that allows professionals to perform an assessment remotely (for example, the Natural Observation Diagnostic Assessment system) (Alfuraydan et al., 2020a). Results of using these systems seem positive, with high levels of diagnostic agreement being reported between remote and on-site methods and high satisfaction among families and physicians. The findings also indicate the potential for telehealth methods to improve access to evaluation and diagnosis of autism used in conjunction with existing methods (Alfuraydan et al., 2020b).

Narzisi (2020b) proposes a telemedicine model for the diagnosis and early intervention of children with autism. The diagnostic stage is composed of two successive phases: pre-specialistic consultation (PSC) and specialistic assessment (SA). In the first PSC phase, self-report questionnaires are sent to parents. They are explained remotely how to make five short videos (15–20 minutes each). The aim of these videos is to analyze the child's behavior in everyday situations such as playing with parents, playing alone, playing with a sibling, mealtimes, or any behavior of concern to the parents. In the SA phase, an interdisciplinary team analyzes the videos and self-report questionnaires, interacts remotely with the child and his/her family, synthesizes the observations and finally, makes psychoeducational and diagnostic proposals to the family. Although this model does not yet have empirical data regarding its usefulness, it provides an interesting model of remote diagnosis of autism.

Several articles have reported positive outcomes in situations where functional and parent-mediated interventions were delivered by remote and telehealth routes in areas such as social communication and problem behaviors (Anderson et al., 2014; Lindgren et al., 2020a; Nevill et al., 2018a; Parsons et al., 2017a). In view of the possibility that the pandemic will persist for a prolonged period of time or that new stressful situations arise in the future, it is urgent to design new support options, which, in most cases, implies reinventing the provision of services to some degree to enable using virtual modalities (Smile, 2020a). So far, organizations and professionals have resorted to the possibilities offered by online care with the aim of mitigating the disproportionate negative effects experienced by people with autism that are associated with the interruption or decrease of direct specialized intervention and support, as well as the change of contexts and routines (Zaagsma, Volkers, Swart, et al., 2020). Online support could move and

adapt to fluctuating support needs more easily compared to regular on-site services. It is still too early to confirm the effect this form of support has specifically on people with autism. However, in those people with autism who possess the necessary communication skills, online support may be effective.

Impact of isolation on routines and individual/family stress level

Nonweiler et al. (2020) studied the effects of the COVID-19 pandemic children and adolescents in the UK. They compared scores on the Strengths and Difficulties Questionnaire (SDQ, see (Goodman et al., 2003)) in a group with neurodevelopmental conditions and a group of neurotypical controls, with previously published data from a cohort of English children and adolescents. Both groups had worsening emotional symptoms in the post-COVID-19 period, but the group with neurodevelopmental conditions had greater behavioral difficulties and fewer prosocial behaviors than the control group.

Overall, mothers of children with autism seem to have experienced higher levels of stress compared to mothers of typical children during the COVID-19 pandemic (Ersoy et al., 2020; Smile, 2020b). Chen et al. (2020) studied factors related to the mental health of parents of autistic children during the COVID-19 pandemic. Poorer mental health was directly correlated with behavioral problems in the child ($r = 0.22, p < .001$), dysfunctional parent-child interactions ($r = 0.36, p < .001$) and parental stress ($r = 0.38, p < .001$). Perceived family and peer support correlated with better mental health in parents. Possibly, the limited access to support resources and the interruption of specialized intervention have an impact on the daily routines of people with autism (Crowell et al., 2019; Dany & Rodríguez, 2020a), which is related to the appearance or increase in problematic behaviors and the levels of stress and uncertainty in the family environment (Palacio-Ortiz et al., 2020a).

A survey conducted in Italy in April 2020 showed an increase in difficulties in managing activities of daily living and in family stress levels related to an increase in problem behaviors (Colizzi et al., 2020b). In this study, older age was considered to be a protective factor with respect to the frequency and intensity of these types of behaviors, which is also observed in the study by Bal et al. (2019). Similarly, a survey among relatives of people with autism in Serbia observed the perception of lack of support and importance in the face of the difficulty of managing their children, noting that many of them were capable before the pandemic (Stankovic et al., 2020). In Argentina, 56% of those surveyed indicated a deterioration in their family member with autism, which was associated with the appearance of problem behaviors (Ruggieri, 2021). Furthermore, 34% of the family members reported experiencing high levels of anxiety related to uncertainty and difficulties in reconciling family and work life. A notable result of this study was the report of a greater isolation in children between 3 and 5 years old since it refers to the increase of a characteristic symptom of autism. The author stresses that it is essential to increase awareness about these characteristic symptoms since they can go unnoticed and contribute to negative health and social outcomes if parents are not sufficiently aware of them and how to address them (Valdez et al., 2021).

The disruption of daily routines during confinement has been linked to repercussions in other areas of mental health for people with autism (Lai et al., 2020). More specifically, the absence or reduction of routines associated with a structured intervention may have a negative impact on the physical health of persons with autism, manifesting itself through increased sedentarism, obesity, altered sleep patterns, and increased selective eating behaviors (Lai et al., 2020). Likewise, a situation of isolation can reinforce obsessive tendencies and restrictive interests focused on a repetitive and very limited repertoire of activity (Grove et al., 2018a). Using a qualitative approach O'Sullivan et al. (2021) investigated the experiences associated with isolation and lockdown of children and adolescents in Ireland. The most recurrent experiences were feelings of isolation, depression, anxiety, and increased maladaptive behaviors. Families of children with autism reported worsening mental health, particularly increased anxiety related to loss of daily routines. Finally, Amorim et al., (2020) reported worsening behavior in 84% of the sample studied (43 children with autism) in relation to isolation. Anxiety was the most prominent feature.

In relation to the isolation and subsequent alteration of daily routines, the priority is to make the necessary adjustments between the person with autism and the environment where he or she lives in isolation (often times the family home; occasionally a residential resource) (Ameis et al., 2020). These adjustments can involve (1) balancing the routine and anticipatory needs of the person with autism with the un-predictability generated by the pandemic in a natural context; (2) making sure the family and social environment understands the social and sensory needs of the person with autism; and (3) adjusting the possibilities and opportunities offered by the family environment to the learning characteristics of each person. In environments where these adjustments are not sufficiently integrated, increased levels of problematic behaviors, anxiety, stress, or depression are observed (Baribeau et al., 2020).

However, den Houting (2020) mentions some positive effects of isolation on people with autism. He states that less stress and strain on educational and work environments during the pandemic have been manifested by improvement in the behavior and lower levels of stress of individuals with autism. Along these lines, Ameis et al. (2020) highlight some positive experiences in coping with the pandemic: positive use of time, extra family time and time for leisure activities, limitation of social networks and news, exploration of relaxing activities, slower pace of learning, adaptation to social connection, and e-learning. Finally, support to families should be considered as an objective and a priority strategy, providing parents and caregivers with strategies to adapt contexts, enhance emotional well-being, and promote the development of people with autism at home (Lim et al., 2020).

Proposals to encourage continuity in the provision of support to people with autism during a confinement situation

Different articles focused on offering guidelines to support people with autism in isolation and to contribute to keeping specialized intervention uninterrupted and allow to compensate for the added difficulties that this situation generates in the person himself and in his family environment (Altable et al., 2020; Courtenay & Perera, 2020; Echavarría-Ramírez et al., 2020; Narzisi, 2020a; Tarbox et al., 2020; Vermeulen, 2020b; World Health Organization, 2020). These articles suggest certain guidelines in order to potentially support the continuation of provision of health, education, and social services to people with autism and their families.

Delivery of information during isolation

The amount of information surrounding the COVID-19 pandemic underlines the need for effective scientific information. For both families and individuals with autism, one of the challenges at this stage is dealing with the context of conspiracy theories, fake news, and misinformation around COVID-19 (Bavel et al., 2020). The delivery of information during isolation must incorporate considerations both related to the type and way this information is delivered (adapting it to the moment of development) and the delivery of skills that allow the individual to differentiate between true and probably false information. Figure 2 summarizes the suggestions related to the delivery of information during isolation.

Management of daily routine and social relations during isolation

In terms of restructuring routines, several articles suggest a focus on daily living and socialization routines is central, considering that isolation has been associated with an increase in disruptive behaviors in people with autism (Amorim et al., 2020; Grove et al., 2018b; Lai et al., 2020). In this regard, families should be suggested to consider basic aspects such as the need to maintain hygiene, food, and physical activity routines. These articles suggest that daily activities should be carried out together with the person with autism, considering their individual preference, in order to facilitate their fulfillment. In the same way, families are advised to incorporate negotiation, anticipation, and reinforcement strategies to establish routines for both themselves and the person with autism. Time management in the family context must consider

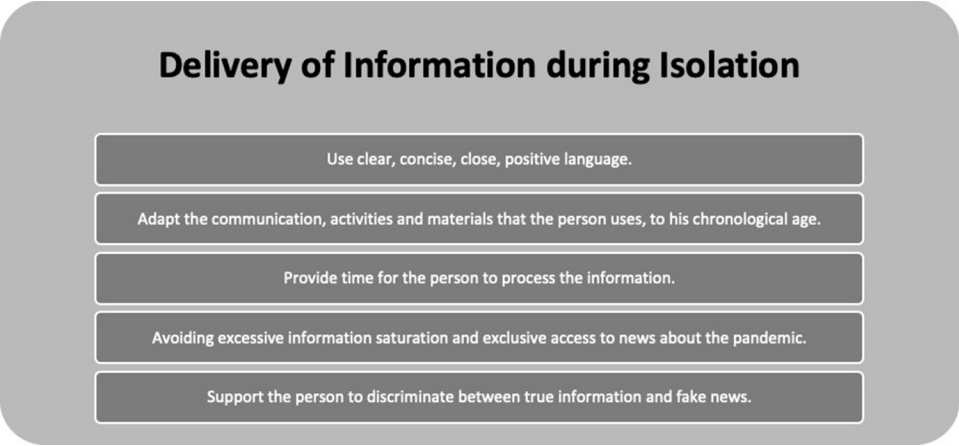


Figure 2. Suggestions for delivering information to people with autism during isolation.

not only the establishment of functioning routines but also the objective of socialization (Amorim et al., 2020; Grove et al., 2018b; Lai et al., 2020). Therefore, situations of the family’s daily life should be used as instances of socialization and promotion of autonomy, as well as facilitating the means for social contact with people outside the family by digital means. Figure 3 summarizes some of these suggestions.

Recognition and emotional expression during isolation

Isolation is correlated with an increase in individual and family stress levels, which are subsequently associated with an increase in disruptive and problematic behaviors in people with autism (Dany & Rodríguez, 2020b; Palacio-Ortiz et al., 2020b). Strategies that facilitate emotional expression may be effective in achieving better emotional regulation in people with autism (Mazefsky et al., 2013b; Vivanti et al., 2019b). As such, further awareness should be facilitated among family members of people with autism about the increased difficulties in emotional expression and regulation, and provide adequate space and time for people with autism to reach emotional regulation when facing stressful situations. Figure 4 summarizes some suggestions based on the aforementioned sources.

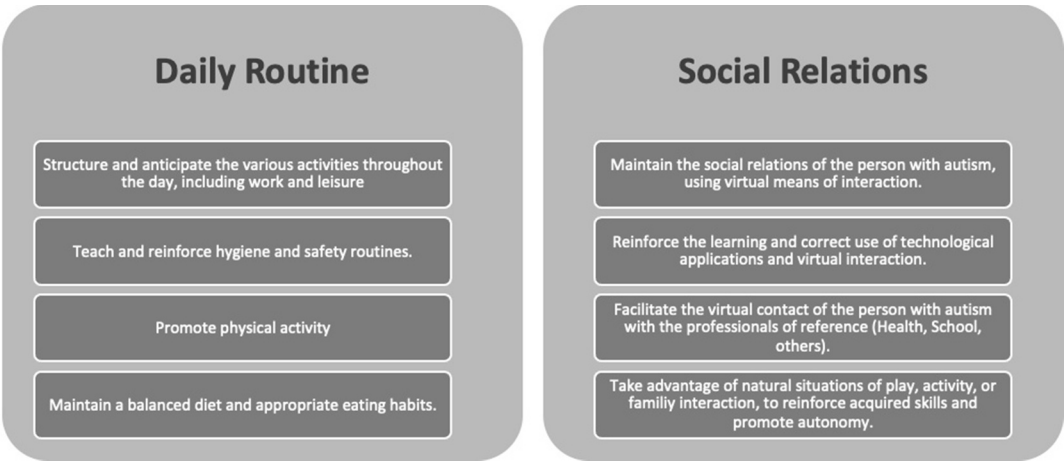


Figure 3. Suggestions to aid time management for people with autism in the family context.

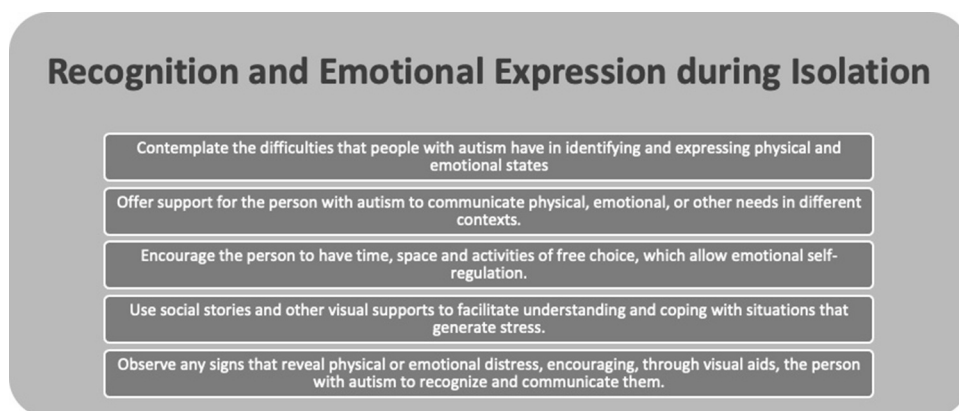


Figure 4. Suggestions to facilitate the recognition and expression of emotions of people with autism during isolation.

Support from service providers

It may be possible to implement remote assessment and support methods for people with autism, which could be replicated in the context of isolation due to the COVID-19 pandemic (Lindgren et al., 2020b; Nevill et al., 2018b; Parsons et al., 2017b). They explain service providers can look to implement strategies that allow for the maintenance of specialized interventions (in health, education, or other areas). An important aspect to consider at work during the isolation is the education of the people with autism about the safety measures to avoid infections. At the same time, the support services should emphasize the need to serve as an emotional support beacon for people with autism and their families. Figure 5 summarizes some suggestions in terms of maintaining contact with service providers.

Discussion

This article sought to explore the effects that the autism community has experienced as a result of the lockdown and isolation due to COVID-19, as well as opportunities for health, educational, and social services providers to support people with autism and their families in isolation in an attempt to ensure that specialized interventions are interrupted as little as possible. To summarize the

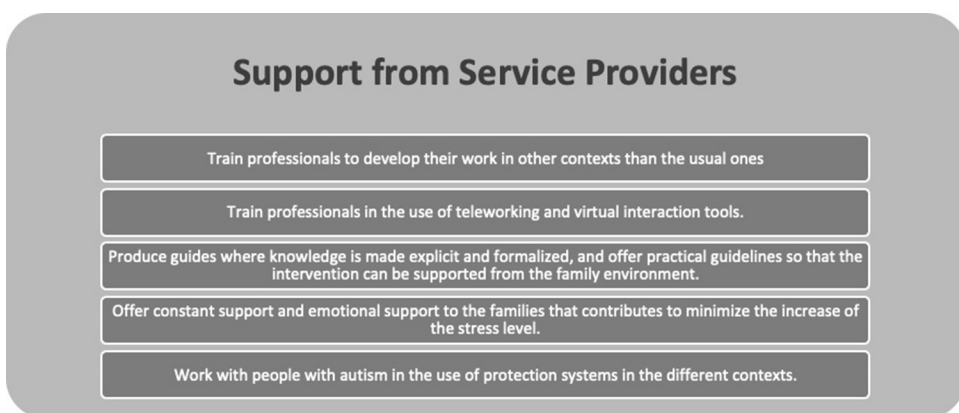


Figure 5. Suggestions for maintaining and improving contact between service providers and people with autism.

findings, people with autism are likely disproportionately affected by the response measures to COVID-19 and health, education, and social support services have to transform to ensure continuity of care.

In particular, in people with autism and their families, the pandemic has highlighted the great needs of this group in the social, educational, and health domains. These needs can be better understood if the differential characteristics of people with autism in terms of their communicative, occupational, social, and emotional development are taken into consideration. Similarly, the needs of this group of people can be better identified if we consider the occupational, mental health, and service provision effects that the COVID-19 pandemic has had on their lives. Service providers – both healthcare and social care – are consistently advised to adapt toward and maintain remote interventions and, at the same time, make recommendations to families so that they support the needs of their family members with autism in aspects such as information delivery, time and routine management, and emotional expression.

Aside from the implications for the autism community, this article also highlights difficulties for families supporting people with autism. In terms of social work, it is important to recognize that the families of people with autism may require additional support as a result of having to increasingly take care of the health and social needs of people with autism. In times of lockdown, families of people with autism are called upon to provide a certain degree of continuity of care and support even though they may lack the formal training to deliver this care. Additionally, family reliability may further magnify existing inequalities, as families from lower socio-economic backgrounds may not have the resources to adequately substitute the required social care (Barron et al., 2021). With health and social care also increasingly adopting digital tools (Kickbusch et al., 2021), the risk of people with autism experiencing increased barriers to health and social care cannot be understated (van Kessel et al., 2021).

This article highlights different factors in how health in vulnerable groups deteriorates as a result of COVID-19. Even though the article specifically looks at the example of autism, the findings of this article may be relevant to other vulnerable groups that experience similar difficulties (e.g. other developmental conditions such as Rett's syndrome, fragile X syndrome, but also conditions that may feature similar deficits, such as schizophrenia (Oliver et al., 2020)). Also, in a larger context, it reinforces the literature that health inequalities are exacerbated and that institutional action is required to prevent further exacerbation and mitigate the gap that has been created as a result of the pandemic (United Nations, 2020).

This article has some methodological limitations that have to be considered. Due to the lack of a systematic search and analysis, the methodology is subjective, and the findings of this article should be interpreted as scoping and are not definitive. They should be used as a means to inspire more thorough and in-depth research in the discussed topics. Additionally, the levels of bias in the included articles have not been assessed, which reinforces the need to interpret the results as exploratory. Due to the nature of the narrative literature review, it is also impossible to explore the complex interactions between the findings. While these limitations affect the reliability of the findings, the goal of the article remains intact: to explore the effects of the pandemic on people with autism and incentivize more in-depth research.

Ultimately, the results of the pandemic have been dire for the autism community. The need to further develop and evolve society's ability to provide various forms of care and support is at an all-time high, both for people with autism, as well as their families.

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Authors' contributions

JLC-G and GG-B contributed equally to this manuscript. JLC-G and GG-B have participated in the conception of the paper. JLC-G, GG-B, and RvK have written the final manuscript. JLC-G, GG-B, VR, AR-U, and RvK have substantially reviewed the final manuscript. All authors read and approved the final manuscript.

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