Autistic adults' personal experiences of navigating a social world prior to and during Covid-19 lockdown in Spain

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ABSTRACT

Background: The SARS-CoV-2 coronavirus pandemic brought significant movement restrictions and national lockdowns. These drastic changes impacted routines, social life and support networks for the autistic community.
Aims: This study investigated the lived experiences of autistic adults with social expectations before and during the first Covid-19 lockdown in Spain.
Methods: A qualitative Reflexive Thematic Analysis was applied to 10 Photo Elicitation Interviews using images provided by five autistic adults. Interviews were conducted at two time points, before the pandemic and during the first lockdown.
Findings: Three themes before the pandemic were identified: (1) everyday interactions, (2) finding sense of belonging, and (3) fractured wellbeing, which revealed the participants' eagerness to fit in socially whilst experiencing rejection, weakening their mental health. During the first Covid-19 lockdown, two master themes were identified: (1) daily, positive experiences, and (2) surfacing failures, which emphasised an increased lived stigma as well as an ineffective autism support network, contributing to a heightened anxiety.
Conclusions: The current study provides further support to the recent findings highlighting lack of appropriate mental health support for the autistic communities during the pandemic, across the world. Future research should aim to provide more data on the experiences and needs of autistic communities when sudden societal changes are imposed.

What this paper adds

This study contributes to the increasing body of research about experiences of camouflaging, identity development, diagnosis, stigma, mental health and autism support received before and during the pandemic. The purpose was to learn how autistic adults adapt to new social constructs imposed during the first Covid-19 lockdown in Spain in comparison to their lived experiences with social expectations and norms before the pandemic. Our second aim was to identify the costs and benefits of navigating a social world during both timeframes. The outcomes from this study can form a platform for the development of better and more individualised autism

support during the lived pandemic and any future life-changing events. Participants had negative lived experiences with social expectations and norms both before the pandemic and during the first Covid-19 lockdown. During the second period, autistic adults experienced an increased anxiety and social unacceptance while perceiving a worsening in the quality of the autism support network. The lockdown measures amplified experiences of lived stigma and social rejection towards the autistic community, making autistic individuals feel more isolated and socially detached. In line with our findings, the international warning highlighting the importance and the need for ensuring a high-quality autism support during the pandemic failed to be registered by the Public Health services in Spain.

1. Introduction

The SARS-CoV-2 coronavirus (Covid-19) outbreak brought a number of significant adjustments around the globe. Spain was one of the first European countries forced to impose societal measures to reduce infection and death rates. Some of the measures included the declaration of the State of Alarm, which included movement restrictions, closing schools and public areas such as parks, and hygiene protocols. Whilst the State of Alarm in Spain specified the restriction of movements for the general population, it also allowed people "with disabilities, those diagnosed with autism spectrum or with disruptive behaviour, to circulate on public roads" during lockdown based on a 'force majeure' or situation of need (Royal Decree 463/2020, Official State Bulletin, 2020).

The impact of the sudden restrictions on societies has shown to induce stress, anxieties and other mental health difficulties in some individuals diagnosed with neurodevelopmental conditions (Chung, 2020; Kong, 2020; Oomen, Nijhof, & Wiersema, 2021). Kong (2020) concluded that having to reorganise lives and routines presented "additional challenges" for autistic children, and Chung (2020) emphasised the adverse effects on mental health for autistic adults (see also, Dimitriou, Adams, & Halstead, 2020). Several reports also revealed that the medical and mental health needs of autistic people have not been adequately addressed during the pandemic (Narzisi, 2020; Pavlopoulou, Wood, & Papadopoulos, 2020). Canal-Bedia, Magán Maganto, Amaral, and Vries (2020) pointed out that there is an urgent need for improving the cooperation between families, society, researchers, support providers and the autistic community in Spain. In fact, autistic population in Australia reported some positive experiences during the confinement, such as having more flexibility, time and space for themselves as well as for their family (Pellicano et al., 2020).

During these uncertain times, Oakley, Amaral, and Vries (2020) emphasised the importance of exploring the wellbeing of the autistic community. The traditional and well-engraved social norms changed as new measures and social expectations were imposed by the governments during the first lockdown period. We do not know how autistic people navigate through imposed changes. A myriad of studies has shown that autistic people tend to mask and compensate for autistic traits to fit in a social world to avoid ostracism and attacks (Bargiela, Steward, & Mandy, 2016; Livingston, Colvert, Social Relationships Study Team, Bolton, & Happé, 2019; Mandy, 2019). These behaviours and strategies known as camouflaging can be consciously or unconsciously implemented during social interactions to mask, hide, or reduce the salience of autistic features to appear more socially skilled (Hull et al., 2017). Other research has shown that navigating a social world can have a negative impact in autistic individuals' mental health (Cage & Troxell-Whitman, 2019; Cassidy, Bradley, Shaw, & Baron-Cohen, 2018; Hull et al., 2017), and it has also been linked to trauma, family relationships, experiences at school, and bullying (Leedham, Thompson, Smith, & Freeth, 2020). Less perceived acceptance from social agents (i.e., society, family, and friends) has been associated with greater levels of depression, where stress was found directly affected by a perceived external acceptance (Cage, Di Monaco, & Newell, 2018). Cassidy et al. (2018) found a direct link between camouflaging in autistic individuals and suicidality markers, whilst another study reported that more than half of the female autistic participants lived with moderate or severe depression, stress and risk of suicide (Beck, Lundwall, Gabrielsen, Cox, & South, 2020).

To enhance our knowledge of how autistic adults adapt to new social constructs and sudden changes, such as those imposed by lockdowns, the current study aimed to unravel potential impacts of sudden changes to societal norms which may help us to plan and create better strategies for such situations as pandemics. This study begun prior to Covid-19 pandemic, with an intended examination of the lived experiences of autistic adults with societal norms and expectations. Due to changes to societal norms during the pandemic and the first lockdown, we took an exploratory approach by gathering data from the same group to examine and contrast autistic adults' lived experiences before the pandemic in Spain, and during the first Covid-19 lockdown period, which lasted from 16th March to 21st June. We were also interested to identify the factors relating to the costs and benefits of navigating a social world during the two timeframes.

2. Methods

Photo Elicitation Interviews (PEI, Banks, 2001) are a form of qualitative method using photos to prompt conversations about participant's views and experiences (Collier, 1967). Participants' self-selected images contribute to their own narratives, create a positive space for discussion (Epstein, Stevens, McKeever, & Baruchel, 2006; Hazel, 1996) and more comprehensive interviews (Harper, 2002), where photos or any other image promote the active involvement from participants. In the recent years, PEI have been successfully used in studies which explored adults' lives (Bignante, 2010; Collier & Collier, 1986; Harper, 1997, 2002), identity development (Hatten, Forin, & Adams, 2013), as well as narratives from people experiencing profound, life-changing experiences (Oliffe & Bottorff, 2007; Padgett et al., 2013).

Prior to the study commencing, ethical approval was obtained from the University College London Research Ethics Committee. All personal data have been anonymised and kept according to General Data Protection Regulation (Data Protection Act, 2018).

2.1. Participants

Ten interviews in total were conducted with five autistic adults (3 females, 1 male and 1 non-binary, mean age = 30.2 years, *SD* = 5.06, range = 23–37). Each participant then completed two interviews at two different time points, before and during the first Covid-19 lockdown. At the first interview, all the participants verbally confirmed that they had no intellectual disability, and all were officially diagnosed with autism using standardised diagnostic tools, stating whether this was obtained from a clinical psychologist at the Public Health Services of Spain or at a private clinic. All participants but one reported having received their diagnoses during adulthood and according to DSM-5 criteria. Verbally confirmed diagnoses were accepted, in line with the current research where self-diagnosed autistic adults are not excluded as their lived experiences have shown to allow "healthcare professionals to have an insight" (Lewis, 2016) into their lives and wellbeing. Thus, promoting acceptance and recognising them as valuable members of the human community (Sarrett, 2016). Most participants had at least a Higher Education Degree and lived with their relatives. See demographic details in Table 1.

2.2. Procedure

All participants were approached using a snowballing sampling technique, specifying inclusion criteria through online platforms and social media, where participants suggested other potential participants of their network. Participants willing to take part received information sheets and consent forms via university's email account. All participants returned their Consent forms. All participants' data were anonymised and given aliases so that no personal information was made identifiable, and all personal data were kept following data protection regulations (Data Protection Act, 2018).

Each participant was asked before the pandemic and then again during the first lockdown period to reflect on their lived experiences navigating a world full of social conventions and rules agreed by non-autistic people, focusing on their relationships with friends, family, and societal expectations in general, allowing for "unexpected" topics to surface (Smith & Osborn, 2007). For the first interview before the Covid-19 pandemic, each participant was given two weeks to take and select a maximum of 15 photos related to their lived experiences with societal norms. For the second interview, as the first Covid-19 lockdown had a limited duration, participants were asked to select up to 8 images related to their lived experiences with societal expectations during this time. Participants were prompted to depict images that were completely or vaguely related to their own thoughts and lived experiences with societal norms, friends and family life. An example of a verbal instruction offered was: "you may choose to take a photo of *a watch to describe your own experiences of feeling the need for being on time and comply with others' expectations*." Once the images were selected, the participants were asked to send these through email at least 15 min prior to their interview to prompt the subsequent conversation. The interview questions generated from participants' photos and attributed meanings, promoting "deeper and more elaborated accounts of subjective experiences" (Hong & Goh, 2019). Each interview had a participant-driven nature and there was no limited time specified beforehand.

During the interviews, participants were asked to elaborate on the reasons why each photo was chosen and what meaning these had for them associated to their daily lives. As photos prompted participants' narratives about their personal lives, topics of conversation started to arise. Clarifying questions (e.g., *"Could you elaborate on what you just said about this photo?", "Would you explain further?", "Could you please tell me how you relate with friends?", "To what extent has your diagnosis impacted the way you feel about yourself?"*) were used to explore arising topics, such as those related to camouflaging, diagnosis, identity, family relationships, social rejection and detachment, anxiety, lockdown, or autism support received throughout their lives.

The interviews were considered semi-structured as photos were linked to ideas about a central topic which was the lived experiences with a social world and expectations (Bates, McCann, Kaye, & Taylor, 2017). Interviews were carried out by the first author via phone call or video-call through Microsoft Teams. The average duration of the first interviews about lived experiences before the pandemic was one hour and 30 min, whilst those interviews about experiences during the first Covid-19 lockdown averaged 45 min. Interviews were audio recorded, transcribed verbatim, translated, and analysed by the first author following a Reflexive Thematic Analysis (Braun & Clarke, 2006, 2019). Arising themes and sub-themes were contrasted by first and third authors in order to avoid biases.

Table 1
Demographic information of participants (*n* = 5).

ALIAS	AGE	AGE OF DIAGNOSIS	GENDER	ETHNIC GROUP	RELIGION	LIVING SITUATION	EMPLOYMENT STATUS	EDUCATION
Elena	30	25	Female	Spanish	Agnostic	Sharing household with partner	Unemployed	Master's Degree
Javier	32	29	Male	Spanish	Christian	Sharing household with partner	Unemployed	Bachelor's Degree
Carmen	37	32	Female	Spanish	None	Living with partner and children	Employed	Master's Degree
Brais	23	8	Non-binary	Spanish	None	Single	Employed	Secondary
Marina	29	22	Female	Spanish	Christian	Living with children	Self-employed	Bachelor's Degree

2.3. Data analysis

Data were analysed using Reflexive Thematic Analysis (Braun & Clarke, 2019) as this process allowed us to identify codes and propose themes through a thoughtful engagement between the first author and participants' narratives. The subjective and interpretive process, where themes represent an in-depth organic analysis, is characterised by its high flexibility and variability according to the continuous engagement between our theoretical approach and the identified patterns of meaning. The methods chosen aimed to uncover autistic adults' own experiences during both timeframes and explore factors related to the participants' wellbeing. A sample of
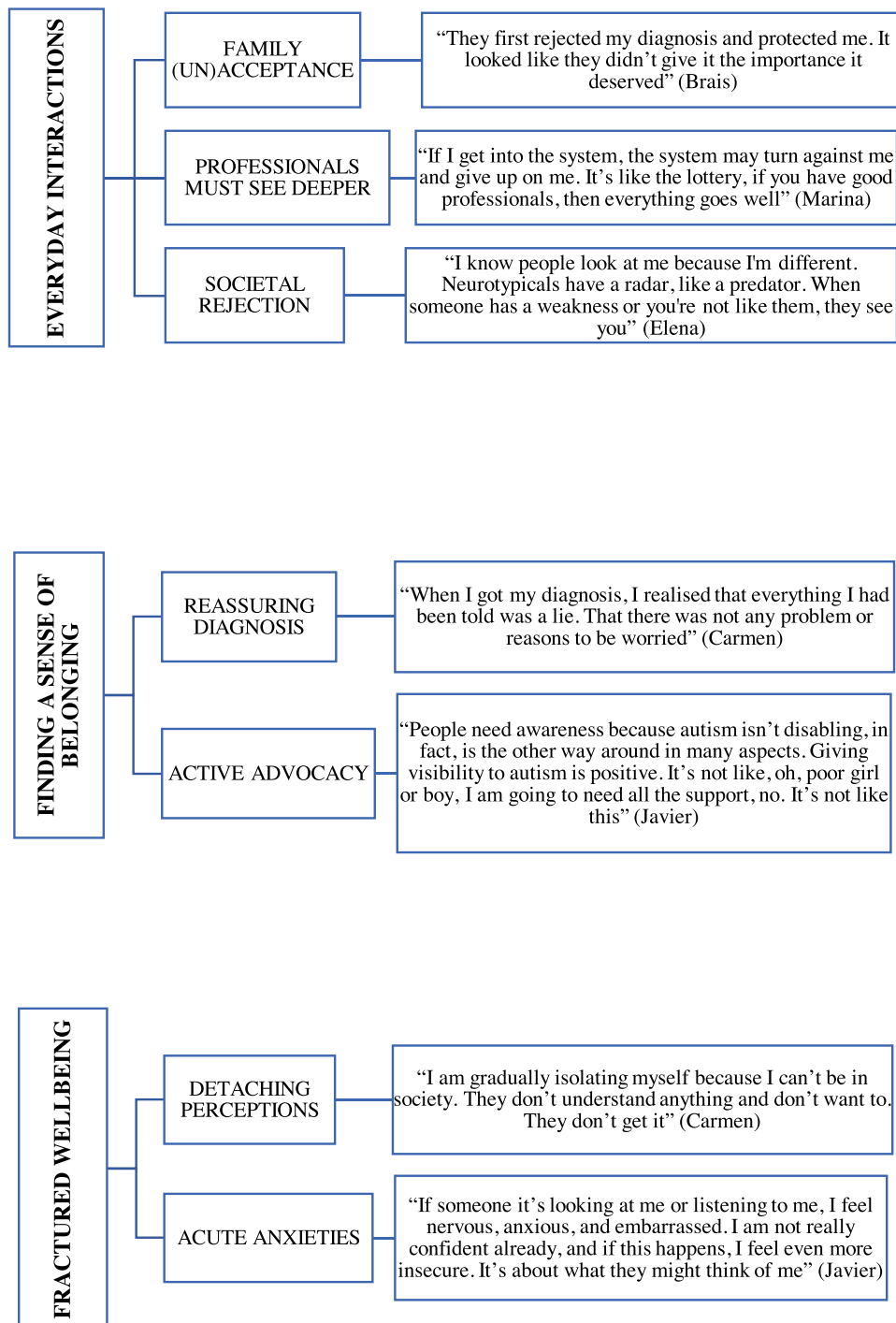

Fig. 1. Master themes, sub-themes and sample quotes from participants prior to the pandemic.

the Reflexive Thematic Analysis process from Carmen's quote "*What it's working and what it's not working. Test error, test error. So, I would carry on with what is working,*" was coded as "copying, putting the best version", and then identified as belonging to the master theme "Everyday Interactions." Braun and Clarke (2021) recommend being cautious when considering data saturation while conducting a Reflexive Thematic Analysis. In the current interpretative process, data saturation was achieved after completing ten interviews, accessing participants' meaningfulness of experiences before and during the first lockdown by identifying patterns of meaning which conformed the master themes.

3. Results

This section is divided into two parts, (A) Navigating a social world before the Covid-19 pandemic, and (B) Autistic lived experiences with societal norms and expectations during the first Covid-19 lockdown.

3.1. Navigating a social world before the COVID-19

Three master themes generated from a pre-Covid interview emphasising participants' eagerness to fit in a rejecting society, their journey into knowing and accepting themselves, as well as described mental health consequences. Fig. 1 provides an outline of the master themes and sub-themes.

3.1.1. Everyday interactions

In this master theme, participants referred to navigating a social world as the need to please others when interacting within the society through the use of camouflaging techniques. In order to succeed, if Elena "*did not see that the social interaction had not been optimal enough, then I punished myself.*" However, Brais stated:

I like to think that I always choose the better option. It's a never-ending election. I have forced myself to go out, face that number of stimuli in order to fulfil my part of the deal.

Narratives reveal that participants live in an endless camouflaging performance where Carmen is "*always putting the best version for everybody, not even the best version of myself,*" to which she relates to the negative consequences of this constant play:

I've put everything on my part and now I am broken. It hasn't worked. That is the proof that if only autistics do 100 % of the walk, it does not work. Someone else would have to walk at least 50 % of the walk.

3.1.1.1. Family (un)acceptance.
Most autistic adults revealed that they felt lack of understanding by their families. Elena shared that "*when my mother read about Asperger, she was left only with the 'challenge to authority' trait.*" Similarly, Marina said that her family felt that:

They had the worst of a boy and a girl. They reacted badly to my diagnosis and there is no mention of the subject. They think I have self-esteem issues, like I'm not mature enough to make my own decisions.

3.1.1.2. Professionals must see deeper.
All participants said that they have been overlooked by their local community. Carmen indicated that "*a clinician diagnosed me with OCD and depression and prescribed medicines which made feel horrible.*" Elena had similar experiences when her psychiatrist "*saw a little under the mask and told me that she could not work with such negativity. They don't understand. They're not capable because they haven't felt it, they haven't lived it.*" Brais stated that at school:

My teachers asked me to interact with someone who was bullying me. We are like an easy target. That time I was diagnosed, and my parents hid it from me until I was 14. They rejected it.

Unfortunately, Javier "*never found a teacher or a doctor that had enough knowledge about autism. No one did ever tell me I might be autistic.*"

3.1.1.3. Societal rejection.
Participants revealed feeling a societal stigma towards their "autism". Bullying was common, as Brais reveals, "*I was being physically bullied; they used my autism to hurt me.*" For Elena:

The problem is when you're a walking enigma and they don't understand anything about you. I've stopped trying to make friends.

3.1.2. Finding a sense of belonging

Participants referred to struggling with, and developing, their own identity. Javier wondered about his own self as he "*was making a collage of many things.*" Echoing these words, Elena stated:

There were as many identities as there were people who related to me. There wasn't even a real identity. Not one of them was really me. There were portions, covers.

3.1.2.1. Reassuring diagnosis.
Participants wished they had known their autism diagnosis earlier as it bolstered their identity. Marina said, "*it has helped me to get to know myself and I think knowing before would have helped me a lot,*" whereas Elena pointed out negative

consequences of a late diagnosis:

> *The fact that I was not diagnosed as a child made my own expectations of myself and those that others had, very high because I saw no limitations in me.*

3.1.2.2. Active advocacy. Some felt that the diagnosis-identity interactions gave them a sense of belonging to a greater community which contributed to agency towards an active advocacy. Javier shared that:

> *Autism has to be shared and given visibility. I honestly think autistic people can do some things better than non-autistic people. I feel proud of being autistic.*

3.1.3. Fractured wellbeing

This master theme gathers narratives related to the social expectations to be accepted in society and outcomes of poor mental health and insecurities. In this regard, Carmen revealed:

> *I have always felt that I could not do what others thought wrong, like wearing this or that. That made me be on character all my life. It's not the reality and affects my mental health.*

3.1.3.1. Detaching perceptions. All participants referred to feeling detached from society. Elena specified:

> *I am a spectator, and I can never aspire to have a life of my own. I'm looking out of the window at everybody's life, and my life is static. It doesn't happen. Like a sense of alienation. Always a sense of strangeness.*

3.1.3.2. Acute anxieties. Autistic adults reported living on the edge with acute anxieties, where daily social interactions are dreaded. Javier has *"come to avoid meeting people, pretend I haven't seen them."* Carmen revealed having difficult times at work because *"how are they going to accept that I am going to have an anxiety crisis in a meeting just because they come and sit down next to me?"* Similarly, Brais said:
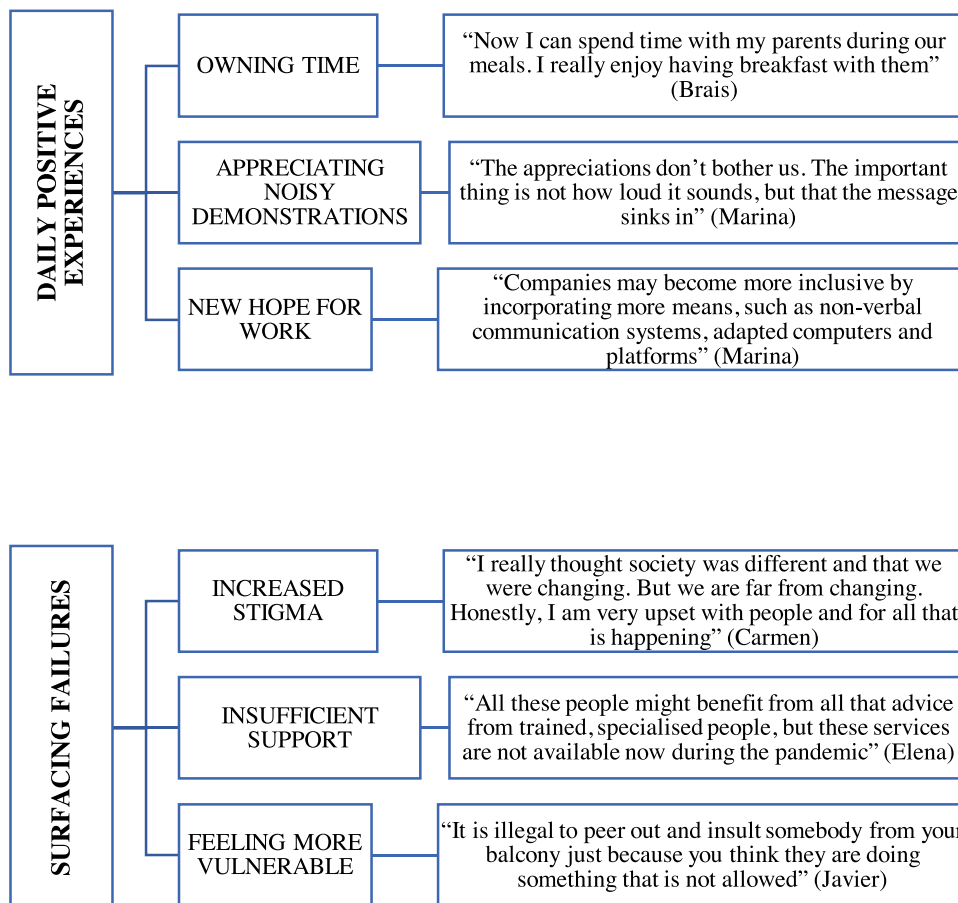

Fig. 2. Master themes, sub-themes and participants' sample quotes referring to their experiences during the first Covid-19 lockdown.

Trying to be perfect leads to frustration. I was depressed. It wasn't me. I was rather a scared chick than a human being. I lacked resources of my own. I used to tremble all the time. Now I live with generalised anxiety.

3.2. Lived experiences during the first COVID-19 lockdown

The participants had many positive responses to the Covid lockdown and measures associated with it. However, they also emphasised negative experiences living uncertain times and difficulties to access autism support, as well as suffering negative general population responses to the pandemic. Fig. 2 provides an outline of master themes and sub-themes.

3.2.1. Daily positive experiences
In this master theme, positive accounts of experiences during lockdown were gathered. Marina did *"not miss everyday life as it is,"* referring to being at home as *"pleasant,"* while for Carmen it was not "*a big deal."* Also, Brais stated:

I was kind of expecting all the repetitive and stimming behaviours to be back, the obsessions and pressures. But it has not happened.

3.2.1.1. Owning time. Autistic adults appreciated having time to catch up with their interests and their families. Brais spent his time *"drawing, watching TV shows, or movies I wanted to watch."* Javier stated:

I am taking the time to practise with my guitar and get better at it. I am also taking the time to deepen into economy, philosophy and politics.

3.2.1.2. Appreciating noisy demonstrations. Participants supported the noisy appreciations for healthcare workers. Marina said that she was *"out with my family to applaud, thinking of everyone out there working,"* whereas Brais shared his experience as:

It is very positive for our society. Seen from psychological and anthropological point of view, people are joining in to carry out the same action with a shared objective.

3.2.1.3. New hope for work. The participants talked about the new work opportunities. Marina highlighted:

Others are doing well because they're finally working remotely. I think people are going to be more aware that you often can work remotely. They may be putting more means, such as adapted computer systems.
Brais felt reassured when he was *"given the guarantees to go back to work once the situation is passed."*

3.2.2. Surfacing failures
Uncertain times during the lockdown made participants feel that when difficulties appear, the failures in society are more salient. Discrimination towards the autistics and difficulties to find support increased their feelings of vulnerability. Javier reflected on *"how little is needed for our values and pillars to collapse"* emphasising:

When things go wrong, we see the best and the worst of people. Everything looks very stable and balanced and it just needs a little push to be knocked down. I wonder, aren't we doing something wrong here?

3.2.2.1. Increased stigma. Participants highlighted an increased stigma towards autism because of being legally allowed to have daily walks, as they were verbally attacked by the general population while being outdoors. Marina pointed out the *"scary social response with people insulting us from their windows."* These reactions were seen as "*a root problem*," coming from "selfishness." For Elena:

The view of autism has worsened during the coronavirus and we live in a pressure cooker.
As a consequence, a perceived stigma intensified when a public campaign advised *"that autistic people should be visible by wearing something blue so that we are not attacked."* Elena and Brais compared these experiences with "*II World War and Nazi camps."* For Carmen: "*It's nonsense. It is very sad".*

3.2.2.2. Insufficient support. Autistic adults discussed the general lack of autism support. Elena revealed that:

Everyone has been told that we cannot call the healthcare numbers so that we don't overuse all the telephone lines. Currently, anything that has nothing to do with the coronavirus has not preference.
Some participants opted to "*spread the word about autism and our needs with people on the spectrum and charities.*" (Brais). Also, Elena noted *"if clinicians don't listen to us, how are we going to expect the rest of society to do it?"*

3.2.2.3. Feeling more vulnerable. Participants revealed feeling more vulnerable due to their stigmatising experiences by the society and the lack of support experienced during lockdown. As Carmen puts it: "*anything could make me have a meltdown."* Participants lived with daily noisy appreciations for the healthcare workers, change of routines and uncertainty, as for Elena "*each police officer may interpret our diagnosis differently."* Brais *"would not be able to go out for more than* 10 s,*"* trying to *"do things at my pace to avoid getting stressed and frustrated."* Elena felt that her anxiety was intensifying:

There is misinformation and bad news. I feel more nervous and worried because I have no idea of how to live daily.

4. Discussion

This study aimed to examine the personal accounts of autistic adults about their lived experiences navigating a social world prior to the pandemic and during the first Covid-19 lockdown in Spain. Our findings reveal a clear contrast in social experiences between these two timeframes. Among the benefits of experiencing a lockdown, the findings show that the negative consequences linked to camouflaging strategies which were emphasised by participants before the pandemic, disappeared during the lockdown period as it was no longer necessary to maintain social interactions. The narratives show that participants also benefitted from having time to dedicate to their family. Contrastingly, whereas anxiety levels were perceived similar before the pandemic and during the first lockdown, in general, the costs for their mental health overran the benefits during the confinement period. During the first Covid-19 lockdown in Spain participants experienced a lack of specialised autism support, whilst feeling an increase in the stigma towards the autistic community, amplifying their feelings of vulnerability. Considering the two timeframes, the figures below include a visual summary of different personal responses and lived experiences with the societal norms.

4.1. Reduced social camouflaging during the lockdown

Prior to the lockdown, participants pursued social acceptance by complying with others' expectations when interacting, performing camouflaging techniques to provide a best version of themselves to conform to social expectations from other people. These findings support previous research (Cage & Troxell-Whitman, 2019) which revealed that autistic adults camouflage to cope, in both formal and relational settings (Allely, 2019; Hull et al., 2017; Lai et al., 2017; Livingston, Shah, Milner, & Happé, 2020).

The imposed measures during the first Covid-19 lockdown restricted social interactions which were seen by autistic people as positive at times, which echoes recent research (Pellicano et al., 2020). Finding a balance between the removal of the felt societal obligations to interact and the movement restrictions appeared to positively impact the mental health of autistic people. These findings also support recent literature on camouflaging being mentally and physically exhausting for autistic people (Cage & Troxell-Whitman, 2019; Livingston et al., 2019; Perry, Mandy, Hull, & Cage, 2020).

4.2. Societal rejection was intensified during the lockdown

Prior to the first Covid-19 lockdown, autistic adults provided accounts of experiencing rejection from relatives, local community and the general population. They also felt trapped in the social cycle of wanting to fit in society, thus spending a huge amount of energy to succeed. Consequently, participants felt rejected which often resolved in self-blaming and questioning own actions which made them feel socially detached (see Fig. 3). These findings are in line with previous research that revealed negative experiences in autistic individuals due to a lived stigma (Bargiela et al., 2016; Botha & Frost, 2018; Perry et al., 2020). The perceived societal rejection was intensified during the period of lockdown, making participants feel discriminated. These findings emphasise the need to reduce the social stigma and make changes in the environment to improve the experiences of autistic people (Botha & Frost, 2018; Leedham et al., 2020; Mandy, 2019; Perry et al., 2020).
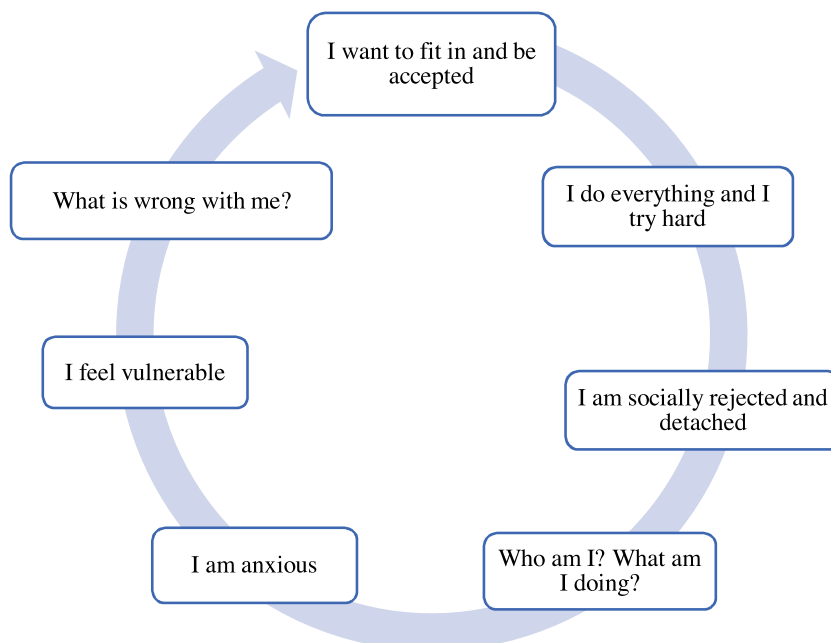

Fig. 3. Lived social cycle experienced by participants prior to the Covid-19 pandemic.

4.3. Identity confirmed by diagnosis before the pandemic was negatively affected by an increased lived stigma during the first Covid-19 lockdown

Prior to the pandemic, participants felt as they were positively developing their autistic identity. Diagnosis was reported to enable self-acceptance, boosting self-esteem and a sense of belonging to a greater community, partly in line with findings where autistic individuals pursued diagnosis for self-confirmation (Crane et al., 2018). Autistic identity also contributed to feelings of pride and commitment (Cassidy et al., 2018; Leedham et al., 2020). However, in Spain, the lockdown measures had a very negative impact on the autistic individuals as they were subjected to discrimination by the general population, who questioned their diagnosis and identity, asking them to identify themselves to others. This Covid-19 social rule uncovered an increased stigma towards autistic people.

4.4. Mental health difficulties before and during the Covid-19 lockdown

The perceived social unacceptance contributed to participants' questioning of their own identity, their contribution to society as well as how to deal with their mental health difficulties. Prior to the first Covid-19 lockdown, camouflaging was a one way of achieving some of the "norms" driven by the society albeit at high costs such as an increasing stress, anxiety, depression, or even risk of suicide (Cassidy et al., 2018; Hull et al., 2017; Lai et al., 2017; Perry et al., 2020). The lived experiences during the lockdown period amplified feelings of social detachment due to a heightened uncertainty, anxiety and fears of having a meltdown, which emphasised the "additional challenges" due to having to reorganise lives and routines during the pandemic, aligning with recent research (Kong, 2020; Oomen et al., 2021).

The interactions with support providers and professionals deteriorated during lockdown as autistic adults perceived a lack of mental health support (see Fig. 4). These findings echo recent reports (Dimitriou et al., 2020; Pavlopoulou et al., 2020), which revealed an absence of autism specific support during the lockdown period, as well as lack of cooperation (Canal-Bedia et al., 2020), emphasising the importance of exploring the wellbeing of the autistic community during the Covid-19 pandemic (Oakley et al., 2020). In line with the above-mentioned studies, the current findings suggest that, during the pandemic, support networks and autism specific guidance were not appropriate. This is also despite the autism research recommendations (Fletcher-Watson et al., 2019) and governmental initiatives to address the priorities of the autistic population (Canal-Bedia et al., 2020; Oakley et al., 2020; Oakley et al., 2020). It is thus recommended here to develop evidence-based strategies to address and deliver the autism provisions for potential national and international crisis such as pandemic.

The current findings emphasise that participants experienced a positive reduction of their social requirements and camouflaging experiences due to the movement restrictions. However, they also perceived an increased stigma towards autism during the confinement, amplifying their mental health difficulties, and contributing to feelings of social detachment. The participants' perceptions of a stigma and social unacceptance towards the autistic community produced a great impact in their lives, aligning with recent findings (Botha, Dibb, & Frost, 2020; Cage et al., 2018). Extending our understanding about lived unacceptance, how it is experienced by the autistic community as well as how it is reproduced by society, could help pinpoint its nature and contribute to its future reduction.

Additionally, the international warnings about the importance of ensuring a high-quality autism support during the first lockdown failed to be registered by support providers, which calls the attention towards the need for reviewing how these networks are organised
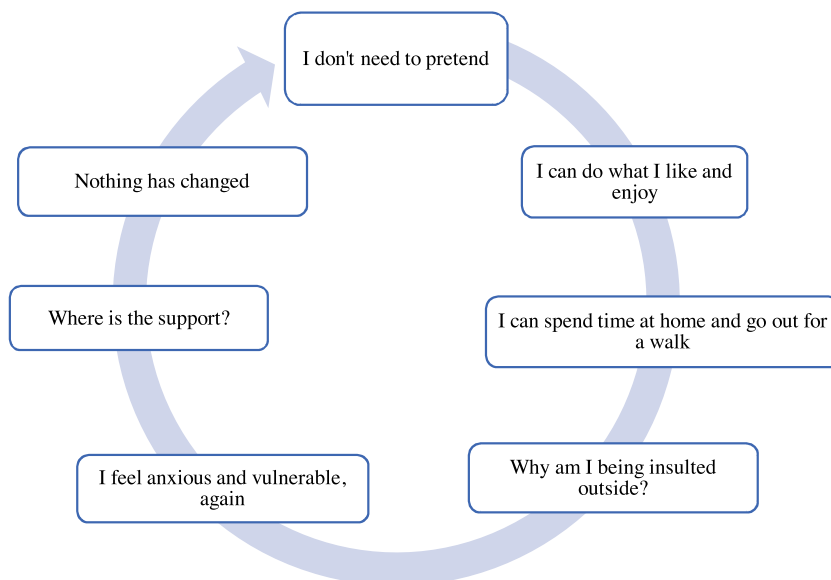

Fig. 4. Lived social cycle experienced by participants during the first Covid-19 lockdown.

and what training is provided for professionals. The current study also highlights the need to gain data from autistic adults about their lived experiences as a central point to inform future support provision and professional training.

4.5. Limitations and future studies

The current study is not without limitations. A snowballing sampling technique was used, all the participants were self-selected, reported no intellectual disability, and belonged to the same ethnic group, which may not represent the diversity of the autistic population in Spain. Additionally, all the participants except one received their autism diagnosis through adulthood.

Although we bear in mind the importance and depth of all the narratives, our sample included five autistic adults, which may seem a small representation. However, although all the participants referred to similar main topics (i.e., camouflaging, social rejection, support, anxiety), autistic individuals described meaningful experiences which were lived with different intensities. Through their narratives, all the participants identified profoundly personal and particular reactions and emotions lived during their experiences with societal norms and expectations. Having two timeframes allowed for the contrast of those differently lived intensities and how they were experienced before the pandemic and during the first Covid-19 lockdown, adding heterogeneity to this study. Therefore, whilst we recognise the importance and depth of the personal experiences explored in the present study, our sample may not generalise to the wider autistic population in Spain. Further research ought to examine whether similar themes emerge amongst a broader sample of autistic adults. Furthermore, it is important to explore autistic experiences and whether the healthcare services and specialised support provision improve across the time by learning from the initial sudden changes in order to adapt to the arising new situations.

CRediT authorship contribution statement

ML and DD designed the study. ML carried out the data collection and the data analyses, GP contributed to methods and oversaw the results section. DD, WM contributed to introduction and discussion sections. All authors contributed towards the article. This article has been submitted solely to this journal and is not published, in press or submitted elsewhere.

Declaration of Competing Interest

No competing financial interests exist.

Acknowledgments

References

Allely, C. S. (2019). Understanding and recognising the female phenotype of autism spectrum disorder and the "camouflage" hypothesis: A systematic PRISMA review. *Advances in Autism, 5*(1), 14–37.
Banks, M. (2001). *Visual methods in social research.* London: Sage.
Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism Spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders, 46*(10), 3281–3294. https://doi.org/10.1007/s10803-016-2872-8.
Bates, E. A., McCann, J. J., Kaye, L. K., & Taylor, J. C. (2017). "Beyond words": A researcher's guide to using photo elicitation in psychology. *Qualitative Research in Psychology, 14*(4), 459–481.
Beck, J. S., Lundwall, R. A., Gabrielsen, T., Cox, J. C., & South, M. (2020). Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. *Autism: the International Journal of Research and Practice, 24*(4), 809–821. https://doi.org/10.1177/1362361320912147.
Bignante, E. (2010). The use of photo-elicitation in field research. *EchoGéo,* (11). EchoGéo, 2010-02-24 (11).
Botha, M., & Frost, D. M. (2018). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health, 10*(1), 20–34.
Botha, M., Dibb, B., & Frost, D. M. (2020). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society.* https://doi.org/10.1080/09687599.2020.1822782.
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.
Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597.
Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health, 13*(2), 201–216.
Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899–1911. https://doi.org/10.1007/s10803-018-03878-x.
Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders, 48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7.
Canal-Bedia, Magán Maganto, Amaral, D. G., & Vries, P. J. (2020). COVID-19 and autism research: Perspectives from around the globe. *Autism Research, 13*(6), 844–869.
Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism, 9*, 42. https://doi.org/10.1186/s13229-018-0226-4.
Chung, W. (2020). *COVID-19 and its impact on autistic adults in the SPARK community* (October 20) Retrieved from. Spark For Autism https://sparkforautism.org/discover_article/covid-19-and-its-impact-on-autistic-adults/.
Collier, J. (1967). Visual anthropology's contributions to the field of anthropology. *Visual Anthropology, 1*(37-46), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5.
Collier, J., & Collier, M. (1986). *Visual anthropology.* Albuquerque: University of New Mexico Press.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders, 48*(11), 3761–3772.

Data Protection Act 2018, c. 12 Available at http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted (Accessed: 3 March 2019).

Dimitriou, D., Adams, J., & Halstead, E. J. (2020). *Autistic adults are in a silent crisis in COVID-19 lockdown.* Available for download: ASD Wales https://www.asdinfowales.co.uk/home.php?_dds=true&fileID=6388.

Epstein, I., Stevens, B., McKeever, P., & Baruchel, S. (2006). Photo elicitation interview (PEI): Using photos to elicit children's perspectives. *International Journal of Qualitative Methods*, 1–11. https://doi.org/10.1177/160940690600500301.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., et al. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism: The International Journal of Research and Practice, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721.

Harper, D. (1997). Visualizing structure: Reading surfaces of social life. *Qualitative Sociology, 20*(1), 57–77.

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies (Abingdon, England), 17*(1), 13–26.

Hatten, K., Forin, T. R., & Adams, R. (2013). A picture elicits a thousand meanings: Photo elicitation as a method for investigating cross-disciplinary identity development. *ASEE Annual Conference and Exposition, Conference Proceedings*.

Hazel, N. (1996). *Eliciting techniques with young people.* Guildford, UK: University of Surrey Press.

Hong, R. T. Y., & Goh, E. C. L. (2019). Using photo elicitation interviewing to access the subjective well-being of children from poor families within an affluent Asian society: Insights for service delivery. *Children and Youth Services Review, 96*, 430–438.

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., et al. (2017). "Putting on My Best Normal": social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47*(8).

Kong, M. (2020). What COVID-19 means for non-neurotypical children and their families. *Pediatric Research*, 1–3. https://doi.org/10.1038/s41390-020-0913-0917.

Lai, M. C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., et al. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism, 21*(6), 690–702.

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism, 24*(1), 135–146. https://doi.org/10.1177/1362361319853442.

Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism Spectrum disorder in adults. *Archives of Psychiatric Nursing, 30*(5), 575–580.

Livingston, L. A., Colvert, E., Social Relationships Study Team, Bolton, P., & Happé, F. (2019). Good social skills despite poor theory of mind: Exploring compensation in autism spectrum disorder. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 60*(1), 102–110. https://doi.org/10.1111/jcpp.12886.

Livingston, L. A., Shah, P., Milner, V., & Happé, F. (2020). Quantifying compensatory strategies in adults with and without diagnosed autism. *Molecular Autism, 11*(1), 15. https://doi.org/10.1186/s13229-019-0308-y.

Mandy, W. (2019). Social camouflaging in autism: Is it time to lose the mask? *Autism: the International Journal of Research and Practice, 23*(8), 1879–1881. https://doi.org/10.1177/1362361319878559.

Narzisi, A. (2020). Handle the autism spectrum condition during Coronavirus (COVID-19) stay at home period: Ten tips for helping parents and caregivers of young children. *Brain Science, 10*(4), 207. https://doi.org/10.3390/brainfascmi1i0li0e4s02w0h7o.

Oakley, Amaral, D. G., & Vries, P. J. (2020). COVID-19 and autism research: Perspectives from around the globe. *Autism Research, 13*(6), 844–869.

Official State Bulletin. (2020). *Royal Decree 463/2020, March 14, declaring the state of alarm for the management of the health crisis situation caused by COVID-19.* Spain.

Oliffe, J. L., & Bottorff, J. L. (2007). Further than the eye can see? Photo elicitation and research with men. *Qualitative Health Research, 17*(6), 850–858.

Oomen, D., Nijhof, A. D., & Wiersema, J. R. (2021). The psychological impact of the COVID-19 pandemic on adults with autism: A survey study across three countries. *Molecular Autism, 12*(1), 21.

Padgett, D. K., Smith, B. T., Derejko, K. S., Henwood, B. F., & Tiderington, E. (2013). A picture is worth…? Photo elicitation interviewing with formerly homeless adults. *Qualitative Health Research, 23*(11), 1435–1444. https://doi.org/10.1177/1049732313507752.

Pavlopoulou, G., Wood, R., & Papadopoulos, C. (2020). *Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK.* London, UK: UCL Institute of Education.

Pellicano, E., Brett, S., den Houting, J., Heyworth, M., Magiati, I., Steward, R., et al. (2020). *"I want to see my friends": The everyday experiences of autistic people and their families during COVID-19.* Sydney, Australia.

Perry, E., Mandy, W., Hull, L., & Cage, E. (2020). *Understanding camouflaging as a response to autism-related stigma: A Social Identity Theory approach [Unpublished manuscript].* Division of Psychology, Faculty of Natural Sciences, University of Stirling.

Sarrett, J. C. (2016). Biocertification and neurodiversity: The role and implications of self-diagnosis in autistic communities. *Neuroethics, 9*(1), 23–36.

Smith, J. A., & Osborn, M. (2007). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 53–80). London: Sage.