We are people and so are they: Shared intimacies and the ethics of digital ethnography in autism communities

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Abstract
This paper reflects on the three main ethical challenges we faced when conducting digital ethnography in three autism Brazilian communities on Facebook: how to position oneself as a researcher, how to deal with the identity of participants, and how to manage data when anonymity is not enforced. After careful consideration of these issues and taking into consideration questions of authorship and vulnerability, we concluded that, firstly, as researchers, we wanted to be more than mere observers of our participants so we aimed for a mutual sharing and involvement between participants and researchers. Secondly, we believe that voice and authorship matter, so we gave our interviewees the choice of being anonymised or not. Finally, we had in mind that our participants may not be fully aware of the consequences of academic publishing, therefore sensitive topics as well as data gathered in the communities were always anonymised.

Keywords
Autism, methodology, digital ethnography, Facebook, ethics

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Digital technologies have become increasingly ubiquitous in everyday life. The connections made online cannot be distinguished from 'offline' life, as they are closely entangled and, together, constitute the same reality. Hence, online aspects are part and parcel of human interaction. As other communities, the autism community has found its place online and built a digital culture of its own. When researchers share these online spaces, to make ethical decisions they have to take into consideration how their participation will affect the research process, the research participants, and themselves. As suggested by Goodin (1985), as researchers, we are responsible for those who may be affected by our actions and choices, so we have to consider issues of respect and vulnerability, the consequences of academic publishing, and what can be done within the time frame of the research. Additionally, ethical considerations regarding vulnerable groups should respect the autonomy of participants, which can be diminished by oppressive research relations (Rogers et al., 2012).

Here, we talk about the ethical insights gained in a digital ethnographic study of three Brazilian Facebook communities, investigating social media usage by autistic people and their supporters using a bottom up approach, drawing on participant observation and triangulation through group discussions and in-depth interviews. As the study combines digital ethnography and disability studies, two emergent fields where ethical codes are under development, the most useful considerations are guidelines suggesting a practical view of ethics and putting decisions in the hands of the researcher, based on the specific context and target group of the research (Association of Internet Researchers, 2012; Goodley, 2011). This approach considers the effects of human action, the nature of the research, and how participants can best benefit from the choices made by researchers. The ethical challenges discussed in this paper were the object of ongoing reflection throughout all stages of the research, from research design to data collection and analysis, and they came up as a consequence of our own standpoint in relation to disability, the participation inside the groups, and our desire for a participative research approach.

Before moving on, we first want to mention that we are not autistic people and we thank the opportunity our participants gave us to work with them as researchers and supporters. We also would like to explain our terminology. We use the term 'autism communities' to refer to communities that do not only involve autistic people, but also people connected to autism, such as parents of autistic people, professionals, and caregivers. The term 'autistic communities' designates communities formed by autistic people themselves, usually made for them and by them. Of the three communities we studied, two had more parents of autistic people as members, while the third had more interaction among autistic people themselves. However, all the groups were mixed, so in all cases we observed interactions between autistic people and 'neurotypicals' (people with a mainstream brain). Therefore, we decided to use

the term 'autism community' to embrace all participants in this paper. We also opted to use 'autistic people' instead of 'people with autism' because, as explained by Brown (2011), important voices among the autistic community have been advocating for an 'identity first' language which embraces autism as part of human diversity. Although not all autistic people share this view, and we do acknowledge the importance of describing people as they want to be described, in our research we chose to use this more assertive language based on the view that autism should be considered a positive aspect of one's identity (Kenny et al., 2016).

At the beginning of our participant observation we presented the research to the communities and, although our participants welcomed the project, the deliberate choice of a participative approach entailed a number of ethical decisions. In this paper, we address the three main ethical challenges we came across: (a) how to position oneself as a researcher; (b) how to deal with the identity of participants; and (c) how to manage data when anonymity is not enforced. We were also confronted with the impossibility of collecting consent forms from all members of online communities, so members were only informed about the research through public posts. Drawing on authors who have discussed this subject (Boellstorff, 2012; Willis, 2017), we decided to accept this inevitable limitation in collecting consent forms when researching online communities.

In order to discuss how we dealt with each challenge, we first present our research project by explaining the different perspectives on autism as well as the relation between autism and social media. After that, we move on to discuss each stage of the methodology together with its respective ethical challenges. Obviously, the ethical considerations were safeguarded throughout the research process, but for the sake of clarity we chose to discuss them in relation to the relevant stage of our research. We use Brazil as a case study as that was the context for our research, but we believe that our considerations can be applied to research in other countries as well as with other minorities, in particular in relation to disability. While we do not believe that research ethics is a matter of one size fits all, we do hope that other researchers can draw on our reflections when designing the framework for their own participative research.

Autism and social media in Brazil

The rise of diagnoses in past years has led to increased attention on autism not only within medical science, but also in a wide range of other disciplines, trying to understand the different manifestations of the autistic brain as well as social aspects related to inclusion and acceptance (Runswick-Cole *et al*, 2016). In medical terms, the American Psychiatric Association (2013) characterises autism as a set of impairments in communication and interaction, associated with the presence of restrictive patterns of behaviour and interests. Those aspects can vary along a

spectrum and go from mild to severe, which makes each autistic person unique. However, the medical view of autism, as that of any disability, has been challenged by disability scholars and activists who take a social view and distinguish between disability and impairment, seeing impairment as a physical, sensory or cognitive functional limitation, while considering disability as a consequence of disabling physical and social barriers (Goodley, 2011).

Based on a social view of disability, the term neurodiversity, first used by Singer (1999), presents a different perspective on autism, not focusing on diagnostic criteria but on differences in the autistic brain, which has particular challenges and strengths. The neurodiversity movement affirms that autistic people are mostly limited by the fact that society is tailored by and for the neurotypical, is not inclusive of diversity and creates barriers for people who process the world in different ways (Armstrong, 2011).

The neurodiversity movement does not deny the challenges faced by autistic people, but it does emphasise that most of these could be remedied if a more inclusive environment was offered. This is where the importance of digital technology for autistic people comes in, as one of their difficulties lies in social interaction. Although not all autistic people experience the Internet in the same way or have access to digital media, and some authors have problems with the association between internet usage and mental illness (Romano et al., 2013), most scholars and autistic advocates consider the internet to be an empowering tool as it presents affordances that benefit autistic people (Davidson, 2008; Dekker, 2006; Silberman, 2015). Social media, in particular, is seen as one of the digital platforms that best suits the needs of autistic people.

Social media is a group of internet-based applications based on Web 2.0 technology that allow the creation and exchange of user generated content (Kaplan and Haenlein, 2010). In our project, we focus in particular on social network sites (SNS), currently the most popular form of social media. boyd and Ellison (2008: 211) define social network sites as:

> services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share connection, and (3) view and traverse their list of connections and those made by others within the system.

While social media offer numerous possibilities, for this project we focus on how the autism community in Brazil is using Facebook, taking a bottom up approach to see emerging patterns. Sutcliffe et al. (2011) define 'social affordances' as the features that help in creating and maintaining social interaction. boyd (2011) also emphasises this aspect when discussing the importance of networked publics, which allow social gathering beyond geographical barriers and are shaped by the features of online platforms.

By using social media, autistic people and their supporters are able to create communities that can amplify their voices (Davidson, 2008; Song, 2009), and fight against the ideology of ableism that permeates society and devalues disabled people by considering them as less than human (Campbell, 2009). Scholars have pointed out that social media gives autistic people more control over their environment, facilitates social interaction that can be conducted at their own pace, translates some of the social cues that would be difficult for them to recognise into written text, and offers opportunities to create and sustain relationships (Benford and Standen, 2009; Byrne, 2013). On social media, they can also exchange information and discuss their intimate lives without the mediation of professionals, as they are free to talk on their own terms and present themselves as they prefer.

Social media also bring drawbacks, mainly related to privacy and security issues. These can be even more evident in communities in which there is a high degree of shared intimacy among members (Bazarova, 2012), such as the ones studied in this project. Moreover, participants face a high risk of overexposure and cyberbullying (Carrington et al., 2017).

Despite these risks, social media are of great importance to autistic people, as they do not only offer a platform for community building but can also alleviate communicational challenges. In his treatise about autism, Silberman (2015: 257-258) emphasises that 'computer networks held the potential for not just "augmenting" communication but making it possible, period – minus the stuff that normally made conversation so arduous, such as eye contact, body language, tone, and the necessity of making a good impression'. He adds that the practical constraints of communicating online also require many implicit aspects of social interaction to be made explicit, giving autistic people enough social cues to make communication easier, such as the use of hashtags (e.g. #sarcasm). Thus, while for neurotypicals information technologies provide 'symbol manipulation technologies that allow [them] to extend [their] cognitive and social capabilities and do so in a networked manner' (Tufekci, 2013, p. 34), for autistic people they do not simply extend, but can create new capabilities of interaction, possibly working as an extension of the human brain, as a form of cognitive prosthesis in terms of social functions. It is with these insights in mind that we have developed our project among autism online communities in Brazil, but as mentioned above we believe that these discussions can be applied in other national and ethical contexts.

Digital ethnography and the ethics of online shared spaces

In this section, we want to briefly discuss the methodology we used before moving on to the ethical challenges we faced. Broadly speaking, ethnographic research aims to observe and subsequently interpret the cultural aspects of a certain group

based on theoretical support. Although ethnography was developed with offline communities in mind, it can be transposed to online environments through the concept of cyberculture. To Horst and Miller (2012), the basic characteristic of digital culture is that it can be converted to bits. This definition may look simplistic, but the affordances of bits are the key reason why information can circulate faster and reach people easier than in offline venues. Further associating culture and the digital, Bell (2006) states that cyberculture encompasses forms of representation, concepts and images that are created and replicated through the use of digital media and that can change one's perception of world.

In order to observe cybercultural aspects, digital ethnography was used as a way to combine participant observation with elicitation techniques (Boellstorff, 2012), in particular online group discussions, through participation in the communities and interviews, which were conducted with ten autistic people who were members of the groups. When applied to minority and/or stigmatised groups, digital ethnography can provide an empowering tool as it values interaction and participants' perspectives (Barratt and Maddox, 2016). Along with other forms of participatory and emancipatory research, it is one of the methods that allow for the construction of knowledge based on the interaction between researchers and participants, as opposed to traditional top-down approaches in which the researcher detains all the information while participants are treated as mere subjects. Hence, it creates participatory possibilities for participants, considering them as owners of their own stories and not just as data (McIntyre, 2008). This is even more important when it comes to disability studies, as Goodley (2011) affirms that there is a long tradition of studying stigmatised disabled groups in research that does not consider them as people and does not bring any return to the community or give them a voice. In our research, reflecting about the identities that surround autism and other aspects of social media usage can lead to an engagement with current perceptions of autism and the articulation between identity and socio-political engagement, for instance when neurodiverse identities are more accepted, there is a shift from fights for treatments promoting cure to treatments focusing on accommodation and skills' acquisition. Moreover, observing the benefits and drawbacks of social media for autistic people can make them more aware of how to fully explore these media.

As the interest of our project is to understand culture through a participatory approach, digital ethnography offers both a methodological package to investigate the online culture of autism, and a way to effectively include the communities studied in this research, presenting them as the subjects of their own histories. More concretely, the participants in this project are three Brazilian communities created on Facebook: Sou autista, conheça o meu mundo [I am autistic… know my world] – from now on referred to as SACM; Lagarta vira pupa [caterpillar turns into pupa]; and Grupo Asperger Brasil [Asperger's Group Brazil].[1] These communities were selected after a thorough exploration of online autism communities in Brazil as they

are representative of the diversity of online communities, as well as relevant and data rich. During our initial observations we found many communities where the majority of members were parents of autistic people, but SACM was the richest in terms of data. We did not find many communities made by and for autistic people, but we were aware of restricted groups only allowing the participation of autistic people, which we could not and did not want to intervene in. The first author has been following the communities discussed in this paper since before the start date of the project, but the actual data collection was conducted from October 2014 to September 2016. Data were collected through annotation while representative weekly samples were saved and thematically analysed.

Before discussing the methodological challenges we faced in this research, it is important to sketch a picture of the exchanges in these communities, as we understand that the intimate nature of the discussions was one of the points to take into consideration when dealing with ethical decisions.

In SACM and Lagarta vira pupa, the majority of the discussions are held by parents of autistic people, talking about their daily lives in relation to topics such as inclusion, challenges and daily victories, prejudice and treatment methods. The tone varies between both communities, Lagarta vira pupa providing a more optimistic view of autism while SACM includes both negative and positive views (Antunes and Dhoest, 2018), but their intimate nature is similar. They contain a great many personal narratives, often including pictures, and people provide social support and mostly respond to each other's narratives with empathy. In Grupo Asperger Brasil, there are more autistic people, those with Asperger's, interacting with each other; while they also share their private lives and look for social support, they mainly talk about how autism affects their lives. All three communities have in common the fact that members share their private lives, creating intimate spaces via social media (see Miller et al., 2016) that welcome all the other members, including us as researchers. By joining the three groups, we became part of this intimate space. As participants were sharing their lives with us, we felt that we should give back to them by also sharing our experiences and what we learned when possible. Moreover, being part of those intimate places makes us see people as individuals who should be valued as such. It was the creation of this intimate arena, associated with our field and methodological choices, that permeated our ethical decisions, which we discuss in the following sub-sections.

Considerations concerning online ethics and disability

Ethical codes usually consider disabled people, including autistic people, as a vulnerable group. This makes it more difficult to challenge traditional ethical guidelines for academic research as set by institutional review boards and ethics committees, which stress the need for distance and participant anonymity

(Crowther and Lloyd-Williams, 2012; Svalastog ad Eriksson, 2010), as autistic people are considered to have limited autonomy and to be more susceptible to harm by means of stigma, discrimination, and social exclusion (Braken-Roche et al., 2017). Disability studies scholar Garland-Thomson (2011) adds that, in the case of disability, vulnerability becomes more evident since there is a mismatch between body or mind and the world, which is hostile to disabled people. Parents of autistic people are also included in this category as they carry the 'courtesy stigma' associated with their children (Goffman, 1990).

In terms of ethical consequences, considering autistic people and their parents as part of a vulnerable group entails stricter rules. However, the categorisation as vulnerable itself presents a great challenge for disability studies and its huge efforts toward inclusion and acceptance. To Svalastog and Eriksson (2010), the core problem is that people who are considered more vulnerable than others are often 'reduced to a negative and not fully capable entity' (107). This view confirms the traditional stereotype that diminishes disabled people and defines them as 'more dependent, childlike, passive, sensitive, […] miserable and […] less competent than people who do not have disabilities' (Linton, 1998: 25). Questioning this view on vulnerability opens up the opportunity for increasing agency and autonomy, which can be achieved by proposing acts that engage agency and participation (Mackenzie, 2013; Rogers et al., 2012). In the case of disabled people, one of the ways in which autonomy may be threatened is by the need for caregivers; nonetheless, assistance 'is viewed not as a sign of dependence but as a sort of prosthesis that permits one to be independent' (Kittay, 2011: 50). Obviously other issues, such as intellectual impairment, may limit one's autonomy and should not be forgotten by researchers.

Based on these insights, when setting up our research we realised that we could not straightforwardly apply strict academic rules on anonymity and distance since we aimed to include our participants as much as possible. Apart from considerations from disability studies, we based our decisions on ethical guidelines for social sciences (American Sociological Association, 1999), internet research (Association of Internet Researchers, 2012), and anthropology (American Anthropological Association, 2012), which all stress the need for an approach that takes into consideration the benefits for participants, respecting their rights and dignity.

Entrance and how to position oneself as a researcher

The first challenge we came across was how to get involved as researchers in the communities we were going to study.[2] This relates to the issue of entrance into the communities and how to position ourselves, as required by any ethnographic study, as well as our degree of involvement with participants. Before formal entrance, we had already observed the communities and knew about the intimate

content shared among members. As we were mostly doing disability research because we were allies of the cause, we could not consider ourselves as neutral subjects without any connection to the field. In fact, most research on disability is done by people deeply involved in activism and the disabled community (Linton, 1998). As a consequence, when planning our entrance we decided to present ourselves not only as researchers but also as supporters of autistic and disability rights.

After our entrance into the field, we became strongly involved in the communities during the whole process of data collection, as we were not only gathering samples but also participating and contributing as much as possible. The research touched us emotionally, setting us far from the stereotypical view of the researcher as objective and unaffected (Blakely, 2007). The experience of dealing with sensitive subjects and being immersed in and affected by shared intimacies while conducting academic research is also described by other scholars (Blakely, 2007; Emerald and Carpenter, 2015; Sheftel and Zembrzycki, 2010), confirming that by getting involved with participants on an emotional level, they become more willing to share. For instance, talking specifically about autism, Emerald and Carpenter (2015: 747) shared how they were affected by their research with mothers of autistic children, adding that, although emotional involvement is seen as the opposite of academic rationality, 'our personal experiences can lend understanding to the social / cultural / political context'. Following this line, we deliberately accepted that we were going to take part not only rationally, but also emotionally, in the communities we were participating in, exchanging our intimacies with members, using our own lives to give examples, and discussing the issues related by members of the communities. Our identities were continuously negotiated during the research, as we were researchers, supporters and also simply members of the community exchanging information about the topic.

Data collection via interviews and deliberation over naming

As for the data collection stage, one of the tools we used were in-depth interviews, where anonymity is seen as a basic principle which involves stripping all the information about research participants that could lead to their identification, based on the idea of preventing any harm and risk to the people involved in a study. Grinyer (2002) and Moore (2012) mention that anonymity is usually considered as desired by participants and embedded in most codes of ethical conduct without further consideration, as if naming was a harmful practice per se. Guenther (2009) reinforces this by saying that anonymity became a 'convention within the social sciences; as a general rule, published work only uses real names when respondents are public officials' (411). Hence, the general idea among researchers is to preserve anonymity.

However, the principle of anonymity is increasingly questioned, mainly by those who practice ethnographic and/or participatory and emancipatory research. They contest the benefits gained by participants when they are anonymised and discuss whether participants should have the chance to decide if they want to be anonymised. The core idea behind the dilemma is that ethics cannot be understood as a fixed set of rules, but should be based on a moral judgment that may change according to the social context of the research. As a consequence, it is up to researchers to balance the benefits and drawbacks for their participants (Hair and Clark, 2007; Paoletti, 2014; Tilley & Woodthorpe, 2011).

In the context of our research, as explained before, we found spheres of intimate relations in which members would even refer to each other as family. At no given moment did they treat us as outsiders nor did we have the intention of treating them as mere objects of research. Our shared intimate relations made us reflect on their personal choices and desires, and we did not take anonymity for granted. This decision, however, was not made without the support of other academic literature. For instance, Moore (2012: 332) reminds us that historically, 'anonymity did not protect the vulnerable, but excluded women and others from authorship and ownership of their own words, erasing them from the archive, even from history, and in the process creating vulnerability through rendering people nameless'. Additionally, the anonymity of vulnerable and minority groups, such as disabled people, has often been used to patronize their voices (Moore, 2012; Svalastog and Eriksson, 2010; Trevisan and Reilly, 2014). For instance, in their writing on disability and education in South Africa and Uganda, Nuwagaba and Rule (2015: 265) point out the advantages of naming for advocacy efforts by saying that 'persons with disabilities who were asked to share part of their lives in the study felt that they would cause positive change among people with disabilities and non-disabled if their names were used in reporting'.

As we wanted to act as sharers of an intimate space and not only as lurkers, with the aim of bringing benefits to our participants, we saw the practice of anonymity based on the concept of vulnerability as a problem, because vulnerability may not be part of who autistic people are, but a consequence of a biased society which can even be reinforced through exclusionary academic principles. Anonymity does not always bring benefits for research participants, but is often used as a guideline without further consideration, while naming can be valuable to give otherwise disempowered people a sense of authorship, a voice to represent a group, and to show respect for their perspectives (Paoletti, 2014; Vainio, 2013). Lake and Zitcer (2012) add that when researchers omit their informants, they also turn them into just data and overshadow the presence of participants. Hence, for our research design and purposes the best choice was to let participants we interviewed decide whether they wanted to be named or not.

Of course, there are many concerns about the interpretation of data when people are named. Vainio (2013) argues that when participants are named, the researcher cannot independently interpret data without taking into consideration participants' opinions. He adds that it becomes more difficult to formulate general arguments as it is anonymisation that turns participants' views into data, arguments and examples. Even though naming may entail these challenges, we believe that participants' perspectives are worth considering so they have the right to decide how information will be presented. Moreover, if a research project about disabled people cannot serve the aims of disabled people, it cannot be considered as grounded in a social perspective (Goodley, 2011). It is also worth noticing that even Vainio (2013), in his strong criticism of naming, considers that there may be good reasons to embrace non-anonymity in participatory research. We also understand that denying our participants this possibility would show a lack of respect for the people we are researching, since they have struggled to have their voices heard, even in organisations that claim to work for them.

Presentation of results and anonymity

At the end of data collection, we analysed our data thematically and proceeded to present the results. At this time, we had to deal with data collected from the communities, as well as from the interviews. Although we did allow our interviewees to choose whether they would like to be named or not, as researchers we had to review the nature of what we were going to present and the possibility of causing harm to our participants. Hence, to ensure that all participants were protected, we created a list of sensitive topics, based on the reflection that participants might not be fully aware of the implications of academic publishing, even after reading the consent form presenting all relevant information about the research. This list of sensitive topics was based on the dataset and took into consideration the fact that many of the topics were of an intimate nature and could compromise the privacy of the participant outside the context of the community, such as details of their professional lives or where they live, and extremely emotional content. When we raised the question in the communities of which topics they would consider sensitive, members did not want to have their names associated with information that could complicate their professional lives. They did not mention issues of emotional fragility themselves, but as researchers we opted not to name participants in instances in which they showed emotional disturbance. In our papers and reports, such topics are always anonymised through the use of a pseudonym and without direct quotation, independent of the choice of the participant. By doing this, we intended to preserve both the right of authorship and advocacy, and the integrity of participants. Nevertheless, there is no way of avoiding any possible link to the general context as the names of the communities are mentioned – a concern always

present in ethnographic research, as anonymity, even when requested, cannot be fully guaranteed (Van den Hoonaard, 2003).

Moreover, during participant observation, we also collected data in the communities. These data were collected after getting consent from the owners of the communities and publicly presenting the research to all the members through posts. As there was no way of circulating consent forms among all members, these data were anonymised in the same way as those of the participants who asked for a pseudonym. In addition, when quoting from the dataset collected in the community, no names are mentioned. Our choice for anonymising information collected from the groups is based on the distinction between public and private in online environments as related to the expectations of participants (Association of Internet Researchers, 2012). Although the posts were made public to the group, we acknowledged that participants allowed their information to circulate in that given context on a basis of trust; thus, we did not want to expose them beyond the limits of the group. The choices we made when deciding how to deal with issues of anonymity were always based on what would be best for the participants in our research as, in the end, it was still our responsibility as researchers to guarantee their safety as participants and also to be aware of ethics in academic research. Although we may not have achieved a fully inclusive system, we did attempt to include members of the communities in our research while preserving them from any harm.

Conclusion

When we decided to merge disability studies and internet studies using a digital ethnographic approach, we already knew that we would have to make some hard ethical choices. We started from the perspective that our participants were valued people who deserved to have their authorship and voices respected. We also considered that, as they are people as are we, we could not participate in the communities without giving something back in return, as participants were sharing their lives with us. Thus, the three issues discussed in this paper emerged from the fact that researchers and participants were sharing an intimate space and should first and foremost be considered as people, rather than researchers or subjects of research.

In conclusion, regarding the first issue, some scholars argue that keeping the researcher detached from participants is necessary to better evaluate data. However, during our research, it became clear that sharing should be mutual, and being a member of a group connected to disability comes with the expectation that one is also an advocate, as many disability studies scholars stress (Goodley, 2011; Linton, 1998). Moreover, the mediation of a digital platform makes communication somewhat more intimate as people do not have the same barriers as they do in

face-to-face communication. Hence, researchers share a degree of intimacy with people they will probably never meet in person.

As for the second issue, the common academic belief is that naming is, per se, a harmful practice. For instance, Moore (2012) notes that a great many documents affirm that information must be anonymised without further explanation. The issue gets complicated for minority groups, such as disabled people, as anonymity has often been used to patronise their voices (Trevisan and Reilly, 2014). With this in mind, we gave our interviewees the choice of being named or not, explaining the process of academic publishing to guide them. As many of our participants were active advocates, it was important for them to have their authorship guaranteed and publicly stand for what they believe. We acknowledge that by naming participants we give them authorship but do not necessarily give them voice, which would imply extensive quotations in their own words. Nonetheless, we do believe that the mere fact of naming can be powerful because, referring back to Moore (2012), some groups have been erased from history because of enforced anonymity, which robbed them of ownership of their ideas. The question of naming brings us to the third issue: as it may be hard for anyone to assess the impact of being named in academic writing, a list of sensitive topics was created and discussion of those topics was always anonymised through the use of pseudonyms and avoiding direct quotation, regardless of the choice of the participant.

By the end of our data collection, as we conducted a digital ethnography study, there was another issue that we want to briefly highlight here. In traditional ethnographic studies, researchers generally have to leave the field site in which they carry out their project. However, as we grew attached to our participants and shared their advocacy claims, we did not leave the communities. Instead, we kept participating as allies of the autistic cause, which is still fighting for inclusion, better services and acceptance, as the neurodiversity movement is slowly emerging in Brazil. We also believe that we can contribute to the growing discussions about the social perspective of autism among non-scholars and, thus, collaborate with the participants who were so helpful during the research process by sharing the insights gained in academic research not just in academic circles.

Our choice to adopt a practical approach to ethics forced us to reflect extensively on the intentions of the research and the position of participants. However, if participants are not merely considered as sources of data but as people who can help to build knowledge, it is worth spending time reviewing best practices to fit their needs instead of simply following general academic guidelines.

We understand that the final aim of inclusive research in disability studies is that it should be emancipatory and we acknowledge that, as much as we try to respect the voice and authorship of our participants, our research was mostly participatory. Other scholars interested in this field may want to consider the full participation of disabled people in the research design, from the development of the research

questions to the publication of results. However, we want to point out that it is not an easy road, as the constraints of academia, such as finding funding, may not align with the desires of the researcher to guarantee participation and emancipation. In our case, the project was submitted for ethical approval to the university ethics board before contact with participants, so they were not involved from the very beginning. Moreover, much as we wanted to continue participating in the communities, we acknowledge that, because of time constraints, it was more difficult to remain active while working on data analysis and the dissemination of results, although we are still advocates of the cause and try to contribute as often as possible. Hence, we want to conclude by saying that, despite the best intentions of any researcher, it is not always possible to align all research interests with advocacy matters, but the benefits to participants should be taken into consideration as much as possible.

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Notes

1. The term Asperger's is used to describe a mild form of autism. As a diagnosis, Asperger Syndrome was included in the autism spectrum in DSM-V. However, the use of the term 'Asperger's', as well as the labels 'high functioning' and 'low functioning' autism, is debated by those who promote neurodiversity (Squenzia, 2013).
2. Although participant observation was carried out by the main author, we chose to use the pronoun 'we' as the second author was closely involved with every stage of the research, from design to analysis.

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