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An analysis of Twitter discourse regarding identifying language for people on the autism spectrum.

Abstract

Person-first language, to refer to a person with autism, has been dominant within peer-reviewed literature, however there are autistic people who prefer identity-first language. This is a shift from the language championed within mental health nursing, therefore important to understand the meaning and actions within identifying language. This analysis of 29,606 words of Twitter discourse explored the political struggle between the modes of language. Differences within the conceptualisation of autism and disability underpinned varied subject positions and the rearticulation of autism and expertise was identified. Contextually driven adoption of identifying language requires awareness of the potential benefits and consequences.

Introduction

Person-first language (PFL) is posited to place emphasis on a person, their individuality and their humanity rather than their disability. This use of *person with a disability* rather than *disabled person* has been adopted within health and human services policy and literature as exemplified by the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007). However, not all individuals adopt or prefer PFL. Identity-first language (IFL), at times called disability-first language is championed in some settings where proponents elect to be identified as a disabled person, blind or Deaf (Dunn & Andrews, 2015). This antagonism, the clash between the two modes of identifying language is present within discussions related to autism spectrum disorder (ASD) and remains largely understudied. The use of IFL, to refer to a client as autistic may present a challenge for mental health nurses who consider PFL an important step towards the reduction of stigma.

Terms such as ‘autist’ and ‘autistic’ that align with IFL have been associated with the neurodiversity movement (Runswick-Cole, 2014). The neurodiversity model was suggested to focus on the notion of difference rather than disorder, that this difference represented the atypical way of being experienced by autistic individuals (Graf, Miller, Epstein, & Rapin, 2017). Neurodiversity advocates positioned autistic people as a minority group, largely disabled by a society built around the “neurotypical” population with the focus of change within society rather than the individual (Graby, 2015).

The identifying terminology of *on the autism spectrum* used within this publication was selected specifically to avoid use of a term that aligned with PFL or IFL. Furthermore *on the autism spectrum* was utilised by the Autism Cooperative Research Centre (Autism CRC, 2019) at the time of data collection. *On the autism spectrum* has also been endorsed by significant numbers of participants within a study of terminology preference by Kenny et al. (2016).

A review of the peer-reviewed literature published in English from 2010 to February 2018 identified a paucity of research related to identifying language for people on the autism spectrum (Shakes & Cashin, 2019). One single study retrieved explored identifying language preference, however presented with limitations and as a convenience sampled online survey that cannot be considered representative (Kenny et al., 2016). The other articles retrieved discussed identifying language, however not as the focus of study.

There was evidence that some autistic people prefer IFL, with a possible relationship to the neurodiversity model and/or the perceived reclamation of agency and power (Shakes & Cashin, 2019). Like PFL, this preference is not universal. This raises the need for mental health nurses to attempt to understand the potential meaning and action behind the two modes of identifying language, *autistic* and *a person with autism*. If PFL was championed to surface

the human rights of people with a disability or mental health condition, then understanding any shift in this would be central for mental health nurses to reconcile this language dilemma.

Both subject positions, that is the stances of IFL or PFL are suggested to encapsulate an intent to reduce stigma and surface the humanity of individuals, however they may represent different pathways to implementation. The shifting discourse related to identifying language preferences for people on the autism spectrum reflects the instability of language which includes the principal that language is fluid and meaning is never fixed (Jørgensen & Phillips, 2002). Drawing upon the work of philosopher Michael Foucault, knowledge is produced through discursive practices therefore conflict arises when competing discourses aim to become the hegemonic, the dominant knowledge construct (Foucault, 1989, p. 183).

This research study attempted to uncover potential meanings through a systematic analysis of the discourse regarding identifying language for people on the autism spectrum focused around two research questions. What are the subject positions and antagonisms present in the discursive struggle regarding identifying language for people on the autism spectrum? What are the potential consequences with a hegemonic adoption of one mode of identifying language?

Method

A discourse analysis guided by Laclau and Mouffe's (2014) discourse theory was undertaken on data extracted from Twitter during Autism Awareness/ Acceptance Month, April 2018. Laclau and Mouffe's discourse theory considers that social phenomena is never fixed, that knowledge, identity and social relations are all contingent, shaped by communication (Laclau & Mouffe, 2014). Laclau and Mouffe's poststructuralist theory positions the aim of discourse analysis to explore how one construction of meaning and

reality undergoes a discursive struggle to become dominant and thus provided a theoretical construct for this research study.

The Twitter advanced search platform was used to locate tweets written in English, posted from 1/4/18 to 30/4/18 with search terms “person first” (field: this exact phrase) and autism, Asperger’s and autistic (field: any of these words). These terms were selected after a trial of several different combinations of terms which included identify first. The layout of the advanced search platform meant that inclusion of both *person* and *identity first* restricted retrievals to Tweets that included both terms only. When these terms were entered into other fields such as ‘any of these words’ the search was too broad and the majority retrieved posts did not focus on identifying language. A Boolean string was attempted in the ‘quick’ search area, however this limited findings to posts that contained both person-first and identify first. The trials demonstrated that the single term “person first” did retrieve both Tweets in support of PFL and IFL and therefore was considered suitable for the purpose of this research, that being to analyse the nature of the discourse rather than the frequency. This search was undertaken at intervals of up to four days throughout the month due to Twitter’s restriction of tweets accessible after five days. All identified tweets dated from 1/4/18 to 30/4/18 were copied and pasted into an Excel spreadsheet with exclusion of identification markers. If the tweet formed a reply or part of a conversation the tweet and subsequent conversation was concurrently pasted into a Word document with a tracking number that aligned with the spreadsheet, images were similarly recorded in this manner with the exclusion of photos of people. The analysis focussed on the Word document of entire conversations. The aim of this study sought to explore varying subject positions rather than address the concerns regarding representation, therefore an online mode for data collection appeared well positioned.

Immersion in the data occurred through a process of separate reading and discussion followed by further focussed reading on points of difference and identified the subject

positions, the body of thought and meaning. Further identified was the nodal point, the central sign which shaped the articulation of all other signs. Laclau and Mouffe describe articulation as the process that connects the signs, through which their meanings are shaped (Laclau & Mouffe, 2014, p. 153). The totality of this is referred to as discourse. Floating signifiers, signs in which meaning is partially fixed within a discourse, helped to establish the relationship with other signs, such as the master signifier, a sign related to identity (Jørgensen & Phillips, 2002). This identification of the key signifiers and their articulated relationships surfaced the antagonisms within the data, this is where the discourses collided. Within discourse theory a discourse seeks to override antagonisms through hegemonic interventions, a discursive use of force in an attempt to make a subject position (Jørgensen & Phillips, 2002).

The dominant, hegemonic subject position is said to become naturalised when it is accepted without thought and challenge, although as a social construct the dominant meaning always remains open to being challenged discursively in the future. Laclau and Mouffe's discourse theory positioned identity and group formation to be constructed within what is said, that the discourse designates the positions for people to form a social imaginary, a group built around the nodal point (Laclau & Mouffe, 2014). A spreadsheet of key signifiers was constructed with colour coded quotations to exemplify findings. Identification of the social imaginaries within the data provided a foundation for exploration of the political struggle. Jørgensen and Phillips (2002) described politics to regard the organisation of society in a way that excludes other possibilities. Therefore, a political struggle identified within discourse analysis is a concept in which social actors seek to action the reorganisation of society through discursive processes. An identified political struggle allowed the exploration of potential consequences with a hegemonic adoption of one form of identifying language. While the analysis of discourse is inherently subjective and within a social constructionist

framework there is no objective truth to discover, discourse analysis facilitates a systematic and replicable process to explore discourse. With a commitment to being open and reflexive to the data the authors, with different views at the study outset collaboratively produced the published construction through a circular process of drafts and discussion in alignment with the methodology and method until consensus was reached.

Ethics approval for the research was granted by a university Human Research Ethics Committee. Internet related research raises specific ethical considerations related to whether data obtained exists within the public or private domain, respecting confidentiality and valid consent (British Psychological Society, 2013). Data was collected from a large public online social media platform where users are informed of the public domain upon sign up. Due to the topic, inability to gain informed consent and potential for inclusion of youth, data was treated as sensitive and de-identified. Manual extraction of data provided a further attempt towards participant anonymity by avoiding metadata captured by software extraction. While participants could not consent or opt out of the research, they maintain ability to edit their social media account in the unlikely event of deductive identification.

Results

The search of tweets identified 254 individual tweets that when replies and conversation were extracted produced a document of 29,606 words.

Subject positions

Familiarisation with the data set lead to the identification of two key subject positions, the bodies of thought and meaning. These included support for PFL. “April is Autism Awareness Month- Person first language is VERY important. It's not "autistic people" but instead "people with autism". The competing key subject position was support of IFL. “I don't have autism, I'm not with autism, I don't live with autism. I'm autistic. Or I'm an autistic

person. Being autistic isn't a bad thing. It's just part of who I am.” Two further distinct yet minor subject positions also presented within the data. One minor subject position challenged the importance of identifying language. “But actually, I think the whole debate's irrelevant. I'd wager a majority of people simply DO NOT CARE about trivial labels in the first place.” The other minor position aligned with the right for each individual to adopt the identifying language of their choice. At times this latter subject position of individual choice also featured within a tweet aligning with clear support for PFL or IFL. “The majority of autistic people prefer identity first language (autistic person not person with autism). People should respect individual preferences but when referring to autistic people in general or as a group, avoid person first language.”

Key signifiers

The nodal point, the central signifier identified within the data, was autism. There were notable differences in the articulation of autism within the competing subject positions that supported adoption of either person-first or identity-first language. The different meanings partially fixed to autism influenced the meanings of the other signs within the discourses and therefore positioned autism as a nodal point. Within discourses supporting PFL autism was presented as something that impacts a person, a “disability”, “ASD” and a diagnosis. “I tend to work with younger kids and typically others that are greatly impacted. So for perspective, person-first is more appropriate for what I do!”

Discourses that supported IFL articulated autism in a manner unlike the discourses supporting PFL or ASD as presented within the DSM-5. This rearticulation moved towards a conceptualisation of autism as a difference in neurology that offered an atypical way of being. “It is a different neurotype to be accepted”. This difference was positioned as something other than a medical condition. “The non-autistic pros are like ‘buhhh they're not

their diagnosis.’ To which we reply, diagnosing is something you do for a medical condition. Autism is a difference in neurology, a unique way of thinking & seeing.” Within this subject position autism offered a person membership to a marginalised group “Ableist language keeps us as marginalized second class citizens”. Group members were said to face challenges consequential to societal organisation. “Autism is unique in that it's only a problem due to an ablest, allistic society.” Several discourses sought to shape experiences that are considered core traits of ASD as misunderstandings about autism. “Autistic people aren't just obsessed with certain topics. It isn't negative to their health. But they do have large investments in their interests, just like neurotypical people, that may appear obsessive because of communicative style or knowledge”.

These varying meanings of autism within the competing subject positions were also highlighted through the use of chains of equivalence. Discourses in support of IFL attempted to discursively align autism with other markers that relate to identity and included height, gender, sexuality, race and religion. “You don't say "has gayness" or "has blackness”.” This contrasted the equivalence to cancer offered by one participant who sought to naturalise PFL. “We don't refer to people with cancer as “cancerous people””. In an exemplar of a hegemonic process in which rules were placed around what equivalences could be included in the debate, while not a reply to that particular tweet, the issue of equivalence was denounced as demeaning by another participant. “Comparing that label to one like "cancerous" is offensive and demeaning”.

The differing meanings partially fixed to the nodal point of autism appeared to both influence and be shaped by different meanings attached to the floating signifier of disability. The discourses which supported PFL often positioned disability as something that should not define a person. “Use person-first language when referring to an individual with #disabilities. For example, instead of #Autistic #Students, they are students with #Autism.

Their #Disability does not define them.” References to dehumanisation presented several times within discourses supporting PFL. “When you're talking about someone who has a disability, make sure to refer to them in a way that does not dehumanize them by defining them by their disabilities.” This notion of dehumanisation through defining a person by their disability appeared to be interpreted by IFL proponents as though disability or autism and personhood were antagonistic. “Person-first language implies that autism and personhood are incompatible.” A further participant challenged the notion of humanisation through the use of PFL by drawing upon the meaning of autism as membership to a marginalised group along with equivalences to infuse autistic as an identity marker. “But I think that people in the real world generally need a basis for identity in addition to just ‘being human.’ I think that’s a nice ideal, but “human” is often defined in terms of the dominant group... When people take pride in being gay, autistic, black, etc., I think it’s a way of asserting that those are identities are “human” too.”

This meaning of disability as an identity was adopted within discourse supporting IFL. “I urge you to look up identity first language... It explains how some of us see disability as an identity”. Similarly, autistic as an identity presented frequently within the discourses that adopted hegemonic interventions, discursive force to naturalise IFL. “Try to remember that most #ActuallyAutistic people have made it crystal clear that they hate person-first language and that if you are not autistic yourself you can SHUT THE FUCK UP about it and MIND YOUR OWN FUCKING BUSINESS about how we describe ourselves #AutismAcceptance”. To construct this notion of autistic as identity participants often drew upon a distinction between autism as something separate to oneself, as distinct from disease or a challenge to the meaning of having something. “I don't live with autism. I don't suffer from autism. Autism isn't a disease or an illness. It's not something I have. You can't separate me from it. I am autistic. Not broken. And not in need of fixing or a cure.

#AutismAcceptance #AutismAwarenessWeek”. While some participants positioned identity around autism and disability, other participants challenged the conceptualisation of autism as disability by positioning autism as something separate from disability. “The community of people with disabilities prefer person-first language. That is fine. The autistic community overwhelmingly prefer identity-first language.”

Group formation

Within the data a social imaginary, a group division rested upon a divide between those considered on the autism spectrum and those not. Thus, diagnosis with autism or identification as autistic acts as the logic of equivalence, the concept that connects the group beyond all the individual differences and other identities that the individual may hold. References to “they”, “them”, “us” and “we” are present within each subject position despite the differences within meanings attached to the signs. Terms to refer to people without a diagnosis of autism were “neurotypical”, “NT”, “non-autistic” and “allistic”. A further grouping that presented frequently within the data is that of the “autistic community” at times presented as an “autistic voice” with assumed unity. “Nope. Never person-first. Us Autistics prefer to be referred to by our identity of Autistic. Not person with Autism.” While the presentation of an objective totality with a united voice was challenged, the social imaginary of the group of the autistic community was accepted with the caveat that it is not spoken for with a single voice “The autistic community is not a monolith.” A small number of participants sought to reduce the priority of identifying language with emphasis on other political interventions that they prioritise, attempting to form group solidarity and alignment through positions related to treatment. “We don't have to agree about "autistic" vs "with autism" to fight for our lives together, to oppose electric shock, to demand real education instead of ABA, to fight eugenics, and all the rest of those things.”

The politics within the discourse

Differences were identified within and between the subject positions regarding expertise and authority which hold significance for the organisation of society. Within discourses that supported individual choice, the individual was deemed to hold authority over how they wish to be identified. Discourses in support of PFL appeared to position “guidelines”, professions and education as authority for use. “As a teacher, I’ve always been taught and practiced the importance of using person-first language, though.” Images were offered which demonstrated organisational commitment to PFL, such a screenshot of a publication from the Centre for Disease Control and Prevention promoting PFL. The experience of being an individual with autism was also used as authority for supporting PFL. “I am a person first. I identify that way. I expressed MY issue with identity first language being misused.” Similarly, being a family member of a person with autism was positioned as authority for support of PFL. “I try not to refer to my daughter as autistic. She’s a person first, not an autistic or an autistic person. She is a young woman who has autism.” Discourses supporting IFL also sought to position lived experience as authority to select identifying language. “Like most autistic people, I prefer identity-first language since my autism is an intrinsic part of how and who I am.” However, the lived experience of being a family member of a person with autism or professional was discredited as a marker of authority for a preference of identifying language. “Now please learn from autistic people. Not their caretakers, doctors, parents etc. Please use identity first language.”

The coupling of autistic expertise and the social imaginary of the autistic community presented the base for hegemonic interventions aimed to naturalise IFL with many discourses also referring to “polls” or “studies” and linking to blogs to represent evidence. “Countless polls have been run, and 75-97% of autistic people consistently choose IFL over PFL. It matters what we want, not what NTs want for us.” Three Twitter polls were present within

the data set, embedded in tweets extracted. One poll enquired whether participants (n=248) prefer to be called ‘disabled’ or a ‘person with a disability’, with 80% selecting disabled. Two other Twitter polls enquired about a preference between ‘autistic’ and ‘person with autism’ and requested responses only from “#actuallyautistic” people. One poll demonstrated strong preference for ‘autistic’ with 86% of 617 votes with the final poll still underway at the time of data extraction. While Twitter polls were offered as support and evidence for the adoption of IFL there was no discussion of the significant limitations of this method of surveying such as how inclusion of the #actuallyautistic hashtag within the poll targeted people who know of and use the IFL based hashtag. Some discourses also referred to studies as evidence for the adoption of IFL. “Studies have show[n] that person first language leads to discrimination, lack of accommodation, and is detrimental to mental health.” Participants provided links to the National Autistic Society page which discussed the study by Kenny et al. (2016) and an editorial which proposed that PFL may actually accentuate stigma despite the original intention (Gernsbacher, 2017).

Attempts to naturalise IFL also often presented PFL as something of which is harmful to autistic people, described as “gas lighting and abuse”, “insulting”, “act of violence”, “ablest”, “offensive” and “ignorant”. Participants in support of IFL positioned the use of PFL as a sign that the person or organisation was “out of touch”, “not listening” and “disingenuous”. “Some organisations say ‘We do listen and act on the voices of people with autism’ Eh? Listen to #ActuallyAutistic voices? but still say ‘people with autism’ Who’s pulling whose leg then? Discontinuity here you need to examine”. The hegemonic interventions that attempted to naturalise IFL similarly sought to shape the organisation of authority and expertise beyond identifying language through a critique of the quality of an organisation or event based upon the level of consultation with autistic people. “Neither [name] and [name] are autistic led. (I am guessing about [name]. Their name gives it away).

They can give input but every show about autism needs autistic input. Both ethically and for accuracy.”

Discussion

This study utilised discourse analysis to explore the subject positions and antagonisms, that is the bodies of thought and meaning and where these collided within Twitter discussions related to identifying language for people on the autism spectrum. The two key subject positions which competed to become dominant, support for person-first or identity-first language rested upon different articulations of both autism and disability. Discourses in support of PFL appeared to conceptualise autism similar to the DSM-5 presentation of ASD as a neurodevelopmental disorder characterised by impairment in social communication and the presence of restricted and repetitive behaviours, interests and activities (American Psychiatric Association, 2013). Discourses that supported IFL rearticulated autism away from that of a disorder, towards the notion of a neurological difference which offers membership to a marginalised group and in which disability is reinterpreted and at times minimised. This conceptualisation was similar to that presented within discussion papers regarding neurodiversity (Graby, 2015; Runswick-Cole, 2014).

This relationship between neurodiversity and IFL aligns with the findings by Kapp et al. (2013) that participants with an awareness of, and perhaps more correctly stated an allegiance to neurodiversity were more likely to prefer *autistic* over *person with autism*. IFL offered membership to autistic communities which were found by Tan (2018) to provide more fulfilling networks and social relationships. Membership was not based on formal diagnosis but rather identifying with an autistic way of being or identifying. An online survey exploring mental health and autism identity by Cooper et al. (2017) found positive associations between the identification with a positive autism identity and wellbeing. This

rearticulation of autism and autistic challenges the deficit nature presented by professionals and diagnosis that can pose a challenge to building a positive identity of the self (Brownlow & Thompson, 2018; Mattys et al., 2018). The suggestions by Parsloe (2015) that the process of naming as ‘Aspie’ forged space for a reclamation of agency, symptoms and normalcy aligns with this reconceptualization, however the term ‘Aspie’ was presented as controversial within the findings of this study. These differences may relate to the evolution of terms and language that occurred between the two studies. One antagonism present is the shift towards medicalised terminology of ‘autistic’ while simultaneously challenging the pathologisation of presentations. For many proponents of IFL, the use of PFL signified disrespect or abuse, which is in direct opposition to the championed intent. This is significant given the use of PFL may create barriers for autistic people who are seeking support from mental health clinicians. The use of PFL may deter some IFL proponents away from seeking support.

The rearticulation of autism attempted to shape how the lived experience of autism is understood. An example was the denial of obsessions and subsequent detriment to health, instead what was offered was description of special interests that are misunderstood due to a different communicative style. This disjunct between the interpretations of behaviours was discussed by Mackay and Parry (2015) who employed phenomenology to explore the experience of autism of ten young participants. The authors discussed parental reports of obsessive and ritualistic behaviours to be highly restrictive while the children rarely reported such behaviours. The authors posited this to be the parents’ pathologisation of behaviour that was functional for the children. The notion of function underlying behaviour is largely accepted and the assessment of function forms a key step for behavioural interventions (Horner, Carr, Strain, Todd, & Reed, 2002). While function to the person isn’t denied, obsessions and rituals that fall within the category of restrictive and repetitive behaviours, are

a core feature of ASD that may present as impairment through challenges for development and daily living.

Rearticulation of symptoms as difference may align with strengths based models, however consideration of the potential consequences of this requires review. Mackay and Parry (2015) rearticulated parental perspectives of their children's limited diets to be preference based rather than restricted. A literature review found children on the autism spectrum to be at a greater risk of nutritional deficiencies related to their restricted eating patterns (Kral, Eriksen, Souders, & Pinto-Martin, 2013). This presents a challenge within the reconciliation of difference and choice and potential impacts on health.

This challenge to reconcile the notion of difference and choice and deny impairment is further exemplified in other repetitive and restricted behaviours. The function of hoarding and collective behaviours were suggested to build a sense of self within a case study and model development of three people with Asperger's syndrome, however distress and anxiety was also triggered when the behaviour was compromised (Skirrow, Jackson, Perry, & Hare, 2015). A parental survey of 58 children with ASD found that 71% became "locked in" with repetitive and restricted behaviours that resulted in a loss of adaptation with their environment, this interfered with school attendance for 51% of the sample (Cashin & Yorke, 2018). It is plausible that restrictive and repetitive behaviours hold some relationship with the disparity of health and employment outcomes for people on the autism spectrum compared to the typically developing population.

Further research regarding repetitive and restricted behaviours could lead to the development of supports to improve health outcomes and assist people on the autism spectrum within education and employment (Cashin & Yorke, 2018). These areas align with the priorities identified within a mixed methods study exploring the research priorities of the

UK autism community (Pellicano, Dinsmore, & Charman, 2014). A reshaped conceptualisation of obsessions as special interests that do not constitute impairment or do not have an impact on health may consequently lead to barriers towards research and support through funding from fiscally constrained governments. The current Australian National Disability Insurance Scheme entry guidelines exemplify this. While a diagnosis of ASD level 2 of 3 was considered to allow automatic entry to the support scheme, a level 1 diagnosis prompts a functional assessment that is assessed alongside the eligibility criteria that specifically uses the term of impairment (Department of Human Services, 2019). To shift the conceptualisation away from impairment while access to support is governed by impairment warrants consideration. This concern of changes to the conceptualisation of autism and potential impact on services was also presented within the study by Kenny et al. (2016).

This rearticulation of a core feature of ASD may relate to the differences in interpretation of behaviours or may offer one perspective of autism. ASD is heterogeneous in presentation therefore experienced by individuals in individual ways. Furthermore there may also be sex based differences in presentation and experience (Ratto et al., 2018). While an official diagnosis represents delineation between the diagnosed and the not diagnosed, a cultural conceptualisation of autism is not bound to diagnostic delineation, however in this case the origins of the nomenclature used add a layer of increased complexity. Self-identified autistic people who do not hold an official diagnosis are at times welcomed in the community and research (Sarrett, 2016). This has been described as an accommodation for barriers presented within pursuit of an adult diagnosis, such as service availability and cost (Kapp et al., 2013). This holds relevance regarding both the rearticulation of autism and representation. An Australian online and paper based survey study of 313 adults who identified as having “high functioning” autism found differences in the demographics of people with an autism diagnosis and people who self-identified as being on the autism spectrum without an official

diagnosis (Autism Spectrum Australia, 2011). The people without a diagnosis were identified as more likely to be older, have higher educational attainment, be married, have children and be employed. It is plausible that a proportion of participants within this discourse analysis may fall at the margins, or indeed out of the margins of the current diagnostic criteria for ASD and that these people may experience autism differently to those within the shifting margins. Similar assertions about representation and potential issues of whose voices were contributing to the discourse were also identified by Kapp et al. (2013) and also relate to the study by Kenny et al. (2016).

This consideration of representation also presents in relation to the identified positioning of the autistic as expert through lived experience. A commitment to the inclusion of the autistic voice to allow for the coproduction of knowledge along with the shaping of service delivery and research priorities may allow for progress in the field of autism that is meaningful for people on the autism spectrum (O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow, & Orsini, 2016). However sensitivity to the heterogeneity and individual experience of autism must be maintained. The lived experience of any one person remains inherently subjective therefore policy and guidelines should be guided by rigorous research.

Within the framework of social constructionism the diagnosis of ASD within the DSM-5 is also discursively constructed and open to challenge, exemplified by the many changes to diagnostic criteria and understandings over the decades (Verhoeff, 2013). Every shift within the construct of ASD will consequently shift service and support funding and provision. The debate related to identifying language while superficially seeming perhaps of little consequence has potential implications for how we construct our understanding of autism in society and the origins of the experienced impairment. This understanding flows through to contemporary understanding of the supports required and how they are funded.

Limitations

The search terms used for this study likely impacted the centrality of the term autism, furthermore may have limited the complexity of conversation around identify first language, despite this being heavily represented within the extracted data. Further limitations relate to data extraction from Twitter at intervals of 24 hours to four days throughout the month, therefore any further replies after extraction were not included. The study design restricted participation to people with capability and access to the internet and who were motivated to engage in the research topic. Results must be interpreted with awareness that a researcher cannot produce an analysis from a position outside of the discursive structures being analysed, therefore subjectivity is inherent to the process of discourse analysis despite the collaboration of two authors and use of data to supplement the results.

Conclusion

This study has illuminated differences within meanings of autism and disability which underpin the political struggle to position either person-first or identify-first language as dominant and universal. In the field of mental health nursing, where PFL has been championed, it is important to recognise that both PFL and IFL for people on the autism spectrum are associated with the aim to improve the life of people on the autism spectrum. However, both modes of identifying language also have the potential to be interpreted negatively. These differences in conceptualisation may relate to the heterogeneity of autism and the inherent differences in the experience of autism. The findings of this study supports the contention that adoption of identifying language should be contextually driven with awareness of the potential benefits and consequences of either person-first or identity-first language. In the clinical setting, mental health nurses should be guided by the preference of the person who they are supporting, in line with person-centred care. Further research that

addresses the limitations of representation, the identified potential consequences and ways to mitigate any potentially negative consequences of a hegemonic adoption of either mode of identifying language is required. Research that explores any potential differences within demographics of the people who present in support for PFL or IFL is also recommended.

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References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Autism CRC. (2019). *Welcome to Autism CRC Knowledge Centre*. Retrieved from <https://www.autismcrc.com.au/knowledge-centre>
- Autism Spectrum Australia. (2011). *We Belong*. Retrieved from <https://www.autismspectrum.org.au/content/we-belong>
- British Psychological Society. (2013). *Ethics guide for internet related research* (INF206/1.2013). Leicester. Retrieved from <http://www.bps.org.uk/system/files/Public%20files/inf206-guidelinesfor-internet-mediated-research.pdf>
- Brownlow, C., & Thompson, D. (2018). The construction of difference: the impact of neurodiverse communities within the cyber and physical worlds. In K. Sheehy & A. Holliman (Eds.), *Education and new technologies* (1 ed., pp. 103-121). New York City, New York: Routledge. Retrieved from <http://ebookcentral.proquest.com/lib/scu/detail.action?docID=5205858>.
- Cashin, A., & Yorke, J. (2018). The relationship between anxiety, external structure, behavioral history and becoming locked into restricted and repetitive behaviors in autism spectrum disorder. *Issues in Mental Health Nursing*, 39(6), 533-537. doi:10.1080/01612840.2017.1418035

- Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844-854. doi:10.1002/ejsp.2297
- Department of Human Services. (2019). *Access to the NDIS: Access Criteria*. Retrieved from <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-table-contents/access-ndis-access-criteria>
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. doi:10.1037/a0038636
- Fein, E. (2015). Making meaningful worlds: role-playing subcultures and the autism spectrum. *Culture, Medicine and Psychiatry*, 39(2), 299-321. doi:10.1007/s11013-015-9443-x
- Foucault, M. (1989). *The archaeology of knowledge*. London: UK: Tavistock Publications Limited.
- Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859-861. doi:10.1111/jcpp.12706
- Graby, S. (2015). Neurodiversity: bridging the gap between the disabled people's movement and the mental health system survivors' movement? In H. Spandler, J. Anderson, & B. Sapey (Eds.), *Madness, distress and the politics of disablement* (pp. 231-244). Bristol, England: Policy Press.
- Graf, W. D., Miller, G., Epstein, L. G., & Rapin, I. (2017). The autism "epidemic": Ethical, legal, and social issues in a developmental spectrum disorder. *Neurology*, 88(14), 1371-1380. doi:10.1212/WNL.0000000000003791
- Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W., & Reed, H. K. (2002). Problem behavior interventions for young children with autism: a research synthesis. *Journal of Autism and Developmental Disorders*, 32(5), 423-446.
- Jørgensen, M., & Phillips, L. (2002). *Discourse analysis as theory and method*. London, England: SAGE Publications Ltd.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59-71.

- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. doi:10.1177/1362361315588200
- Kral, T. V., Eriksen, W. T., Souders, M. C., & Pinto-Martin, J. A. (2013). Eating behaviors, diet quality, and gastrointestinal symptoms in children with autism spectrum disorders: a brief review. *J Pediatr Nurs*, 28(6), 548-556. doi:10.1016/j.pedn.2013.01.008
- Laclau, E., & Mouffe, C. (2014). *Hegemony and socialist strategy* (2nd ed.). London: England: Verso.
- Mackay, S. J., & Parry, O. (2015). Two world views: perspectives on autistic behaviours. *Journal of Health Psychology*, 20(11), 1416-1426. doi:10.1177/1359105313512515
- Mattys, L., Noens, I., Evers, K., & Baeyens, D. (2018). "Hold me tight so I can go it alone": Developmental themes for young adults with autism spectrum disorder. *Qualitative Health Research*, 28(2), 321-333. doi:10.1177/1049732317730329
- O'Dell, L., Bertilsdotter Rosqvist, H., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, 31(2), 166-179. doi:10.1080/09687599.2016.1164026
- Parsloe, S. M. (2015). Discourses of disability, narratives of community: reclaiming an autistic identity online. *Journal of Applied Communication Research*, 43(3), 336-356. doi:10.1080/00909882.2015.1052829
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756-770. doi:10.1177/1362361314529627
- Ratto, A.B., Kenworthy, L., Yerys, B.E., Bascom, J., Trubanova Wieckowski, A., White, S.W., Wallace, G.L., Pugliese, R.T., Ollendick, T.H., Scarpa, A., Seese, S., Register-Brown, K., Martian, A. & Gutermuth Anthony, L. (2018). What about the girls? Sex-based differences in autistic traits and adaptive skills. *Journal of Autism and Developmental Disorders*, 48(5), 1698-1711, doi: 10.1007/s10803-017-3413-9
- Rios, C., & Costa Andrada, B. (2015). The changing face of autism in Brazil. *Culture, Medicine and Psychiatry*, 39(2), 213-234. doi:10.1007/s11013-015-9448-
- Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability and Society*, 29(7), 1117-1129. doi:10.1080/09687599.2014.910107

- Sarrett, J. C. (2016). Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics*, 9(1), 23-36. doi:10.1007/s12152-016-9247-x
- Shakes, P. & Cashin, A. (2019). Identifying language for people on the autism spectrum: a scoping review, *Issues in Mental Health Nursing*, 40(4), 317-325. doi: 10.1080/01612840.2018.1522400
- Skirrow, P., Jackson, P., Perry, E., & Hare, D. J. (2015). I collect therefore I am- autonoetic consciousness and hoarding in Asperger syndrome. *Clinical Psychology and Psychotherapy*, 22(3), 278-284. doi:10.1002/cpp.1889
- Tan, C. D. (2018). "I'm a normal autistic person, not an abnormal neurotypical": autism spectrum disorder diagnosis as biographical illumination. *Social Science and Medicine*, 197, 161-167. doi:10.1016/j.socscimed.2017.12.008
- UN General Assembly. (2007). *Conventions on the rights of persons with disabilities*. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Verhoeff, B. (2013). Autism in flux: A history of the concept from Leo Kanner to DSM-5. *History of Psychiatry*, 24(4), 442-458. doi:10.1177/0957154X13500584