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Not Doing it Properly? (Re)producing and Resisting Knowledge Through Narratives of Autistic Sexualities

Hanna Bertilsdotter Rosqvist¹ · David Jackson-Perry²

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Abstract

Autism is conceptualized in much scientific literature as being associated with restricted and repetitive interests, characterized by an ‘empathy deficit’, and negatively impacting social communication. Meanwhile, ‘good and healthy’ sexuality is largely considered to be a social endeavor: asexuality and sexualities defined by acts rather than by partner gender—for example kink or BDSM—are broadly pathologized. Perhaps, therefore, first-hand autistic experiences of sexuality challenge existing assumptions about ‘good and healthy’ sexualities within couplehood. As a theoretical starting point to explore this potential, we revisit Gayle Rubin’s notion of ‘sex within the charmed circle’ to ask whether autistic sexuality can ever truly ‘fit’ within this (neurotypically defined) virtuous sexual arena. We further consider the ways in which the intersection of autism and sexuality is understood and experienced in first-hand autistic accounts of sexuality within a specific context, through analysis of a Swedish online discussion forum in which autistic people discuss sexuality. In doing so we seek both to better understand autistic sexual experience, and to track and deconstruct potentially restrictive assumptions of (non-autistic) couple sexuality more generally. We also consider ways in which assumptions of deficit concerning both non-normative sexualities and autism may have a deleterious effect on autistic people and on research more broadly, limiting theoretical and conceptual understandings of autism and autistic ways of (sexual) being by a default comparison to sexual and neurological norms.

Keywords Sweden · Autism · Sexuality · Epistemological community · Online forum · Autistic self advocacy

A Note Regarding Language

The language best used to describe autism is ‘currently the subject of intense and passionate debate’ [1, p. viii]. While there is no single consensus either across or within stakeholders as to whether identity-first language (IFL) (‘an autistic person’) or ‘person-first

✉ Hanna Bertilsdotter Rosqvist
hanna.bertilsdotterrosqvist@sh.se

¹ School of Social Sciences, Södertörn University, Huddinge, Sweden

² School of Social Sciences, Education and Social Work, Queen’s University Belfast, Belfast, Northern Ireland, UK

language' (PFL) ('a person with autism') should be used, available research indicates that the term most strongly endorsed by autistic people and advocates themselves is IFL [2, 3] reflecting a conceptualisation of autism as an intrinsic, 'all-encompassing part of a person's identity' [2: 17]. In recognition of this, and amidst suggestions that PFL may increase stigma [4], many authors across disciplines predominantly or exclusively use IFL [5–7], and specialist autism journals increasingly state in their author guidelines that IFL can or indeed *should* be used [8, 9]. Importantly, we further noted a preference for IFL when referring to themselves by many (although not all) of those cited in the research drawn upon for this article.

We are aware of this journal's preference for PFL, which is issue from early disability rights activism [1] and is often preferred by professionals working in the field [2]. Seeking to conform to the journal's preference while also respecting differing perspectives and also, crucially we feel, the choice of the people we are citing, we use both IFL and PFL throughout the article. We hope that this compromise, while not perfect, will be acceptable to readers.

Introduction

The diagnostic criteria for autism laid out in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) revolve around deficits in social communication and interaction, and restricted, repetitive patterns of behavior, interests, or activities [10], with '(O)bservation of aberrant behaviour' as the basis for diagnosis [11]. The literature concerned with autism largely follows a similar focus, taking as its basis a study of 'negatively valued deviations from behavioral norms' [12], and leaving the assumption of deficit in the areas detailed by the DSM largely unquestioned.

This assumption permits the extrapolation of a variety of social deficits attributable to autistic people, including traits which may be considered as positively-valued should they be manifested by non-autistic people. Izuma et al. [13], for example, found that their non-autistic control group donated larger amounts, and more frequently to charity when in the presence of an observer than when alone. Autistic participants donated at the same rate and equally generously when they were not observed, which may, for example, permit a hypothesis of increased altruism in autistic people. The authors concluded however that people with autism 'have a specific deficit in taking into account their reputation in the eyes of others' [13, p. 17302].

Conclusional leaps of this nature are conceivably made possible only by assuming the presence of deficit which is taken to apply to all the actions of a specific group of people, whereby neutral or even, as in the above example, positively valued acts may be read as offering support for a deficit reading of that group's behavior. One logical assumption that may follow this line of reasoning is that any 'deficit' that may be apparent is one-sided, the responsibility of the studied group rather than the 'healthy control' group. In this way, the lack of empathy and dysfunction in Theory of Mind (ToM: the ability of an individual to understand other peoples' thoughts and feelings) attributed to autistic people is often stated as fact in autism literature [14]. There has been ongoing questioning of the robustness of ToM [15], and increasing research indicating that misunderstandings between autistic and non-autistic people are 'mutual' rather than one-sided [16–18]. Despite this, an assumption of deficit on the part of autistic people to 'read' non-autistic minds, or their

‘mind-blindness’ [19] is wide-spread, and broadly and ‘tacitly accepted as useful in scientific discourse on autism’ [20, p. 110].

Observation of aberrant behavior is also a recurrent theme in literature on sexuality, with certain practices considered to be ‘normal’, and therefore healthy, and others to be aberrant or deviant paraphilias [21]. Even in the absence of any distress caused to others or the ‘paraphilic individual’, paraphilias are included in the DSM, and the definition given above supports the statement ‘that to be normal, sexuality should be genitally organized’ [21].

Illustrating ways in which ‘particular knowledges, practices, identities, and texts, are validated at the expense of others’ [22, p. 1144], Rubin [23] uses the metaphor of the charmed circle, at the centre of which sit ‘high status’ sexual happenings. For Rubin, these are heterosexual acts, happening in private without the use of sexual aids, between two people of similar ages in a long-term monogamous relationship with, ultimately, the aim of reproduction, or at least that of maintaining an intact and stable couple. The further away from high-status sex individuals move, the further they are pushed to the outer reaches of this charmed circle. At the outer rim of the circle are sexual acts that do not conform to religious, psychiatric, or social norms, which may be tarified sex, BDSM, sex with multiple partners, gay/lesbian or intergenerational sex. The ‘imaginary line between good and bad sex’ [23, p. 151] that is drawn in this way therefore renders some practices dangerous, including for the individuals who in practicing them places themselves at risk of not attaining the holy grail of a ‘stable intimate relationship’, with the social sanctions that may be incurred.

In what follows we consider, through analysis of a Swedish online forum on which autistic people discuss sexuality, ways in which autistic people in that particular context discuss and make sense of their sexuality. This needs to be considered against the backdrop of the body of literature which, as discussed above, explores both sexuality and autism from a position of ‘comparison to the norm’. We are particularly concerned here with sexual identification or conduct that is not primarily directed towards other people or does not have a primary social goal such as couple bonding.

We consider the online forum as constituting an epistemological community, leaning on feminist theorist Lynn Hankinson Nelson’s [24] conceptualization of epistemological communities as ‘agents of epistemology’, where ‘agents or subjects of epistemology’, here, Swedish autistic people communicating online, are ‘embodied and situated in specific social and historical contexts’ [24, p. 121]. As such, Nelson suggests that members of these communities contribute to constructing knowledge about their own lives. This community shares knowledge from other sources of information, evaluates the value given to these sources of knowledge, and community members both ‘construct and acquire knowledge’ [24, 124]. They are therefore both recipients of knowledge about their lives and co-constructors of this same knowledge.

However, the process of the evaluation of knowledge requires decision-making by members of these epistemological communities as to what knowledge is credible, and this process can be understood as depending on ‘epistemic authority’. Epistemic authority is defined by Oikkonen [25, p. 284] as ‘the belief that the proposed account is the most accurate one’. In a condition as highly medicalized as autism, whose parameters are laid out in medical practitioners’ diagnostic manuals, it follows that the testimony which may be assumed to be the most accurate, which holds the highest level of credibility when discussing autism, and which is the most commonly published [26], issues from medical science [27]. Therefore, the sources on which this particular community bases its co-construction, the starting point for discussion, is likely to lean heavily on a medical ‘story’, which in turn

takes an assumption of deficit as its starting point. These sources include published literature, which are used by contributors to validate their opinions, while also perhaps restricting those same contributors to a deficit reading of their own sexual lives.

While a medical narrative of autism currently dominates, and while the story of autism it recounts might be ‘a story...it is not *the* story’ [28, p. 27]. There are, for example, increasing calls to consider autism through a lens of neurodiversity, whereby in place of a medical deficit reading of the condition, autism is read as a naturally occurring variation in human cognition, essential for the survival of the species [29, 30]. Some contributors to the forum indeed make reference to neurodiversity rather than deficit. Thus, different participants in debates around autism can be said to be engaging in ‘epistemic struggles’, in competing for epistemic authority and defining what may be considered the most ‘accurate’ account of autism in particular epistemological communities.

These struggles for authority on the forum manifest themselves as debate between different competing meanings—each of them seeking epistemic authority—illustrated by different ‘epistemic tensions’ between different knowledges [31]. Throughout this article we discuss ways in which contributors to the forum make up an epistemological community, whereby autism is ‘understood, acted upon and experienced’ in particular local contexts [32, p. 167], and explore how the production of knowledge is both made possible and limited by the contexts in which members of an epistemological community evolve. We further consider the epistemic tensions that are (re)produced within this community, relying as it does to a large extent on a sometimes uneasy combination of individual experiences and external sources considered to hold epistemic authority outside of the community.

Methods

Materials

This paper is based on analysis of forum threads on a Swedish-speaking discussion forum. The forum is primarily a discussion space for autistic people, but also welcomes ‘everybody interested in the subject’ of autism to participate in the discussions. This results in a space largely, although not exclusively, used by people on the autistic spectrum. At the time of writing, the forum consists of just over 10,000 members, and includes a total of more than 35,000 discussion threads on which more than 1.3 million comments have been posted. The forum started in 2005 and is currently the largest and most well-known forum aimed at autistic people in Sweden.

Procedure

For this article, threads concerned with sexuality were identified by the first author through searches on the forum (search word in Swedish: *sexualitet*) in March 2018. The potential sample pool consists of 786 threads. This pool was reduced in number through several steps. Firstly, all threads concerning dating/initiating a relationship/emotions and love with a non-sexual focus and sexual violence were removed. In the next step, threads concerning issues of gender/trans or threads not directly concerning the participants’ sexuality but rather general issues around sexuality and attitudes toward sexuality in society were removed. Finally, threads not directly focused on sexual attraction/behaviors/fantasies were

removed. In this way we reduced the data to 186 posts on the general subject of sexuality made by 102 contributors between October 2007 and April 2017.

Analysis

The analysis of the posts was inspired by rhetorical and discourse psychological analysis [33]. Important concepts in this type of analysis are those of interpretative repertoires and ideological dilemmas. Interpretative repertoires can be defined as culturally available resources or ‘storylines’ from which members from a specific society ‘both draw on and resist in order to produce their own accounts’ [34, p. 2]. Here, we understand and refer to this concept as sometimes competing ‘meanings’ within ambivalent discourses, produced within specific, localized, epistemological communities, as discussed throughout this article. Billig et al. [35] used the concept of ideological dilemmas in order to analyse dilemmas such as democracy versus authority, equality versus expert, and individualism versus human beings as social actors. In this analysis we link the concept of ideological dilemmas to epistemic tensions, whereby ideological dilemmas arise in the competition for epistemic authority within an epistemological community between different knowledges; such as ‘professional’ or ‘scientific’ knowledge versus experience-based knowledge.

Ethics

The data used here issue from publicly available threads on a discussion forum, to which access was not restricted to forum members or contributors. However personal the information provided may be, discussion forums of this type, like blogs, are clearly situated in the public domain: as such, consent from contributors is not considered necessary. Similarly, ethics approval is not necessary for this type of research in Sweden, where the first author is based. However, we have treated data with caution to avoid harm or embarrassment to the contributors or the forum. To safeguard the contributors’ anonymity, we have deleted information which could track comments to individual contributors, even when only online ‘pseudos’ are used. Therefore, only the date for the contribution and a code name (assigned by the authors) are given here.

There is a further ethical question in analyzing this online material, however public it may be. As Milton and Sims [36] pointed out in their analysis of articles from the magazine *Asperger United*, there is concern amongst autistic communities that academics might misrepresent data of this nature [37, 38]. While we have made every effort to frame this analysis within our readings and understandings of autistic experience more generally, we accept that misrepresentation is clearly a risk here, as indeed in any form of data analysis. Therefore, again following Milton and Sims [36], we apologize if we have unwittingly misrepresented contributors or caused them offence in any other way through our analysis.

Findings: The Trouble with Autistic Sex

Two competing primary meanings around ‘autistic sexuality’ emerge from the forum. The first is manifested through discussion of what we will call *autistic specificity*, whereby autistic sociality, emotionality and bodily/sensory perceptions—and accordingly, sexuality—are conceptualized as being profoundly influenced by autism.

This specificity in turn takes two forms. The first revolves around meanings of autism as a neurological deficit [32], or a set of social and emotional impairments. The second meaning of specificity is based on the conceptualisation of autism as a spectrum of neurological difference [30, 38] or alternative, meaningful ways of experiencing sensory stimuli, and of loving and relating to other people without an a priori reference to deficit. Both versions are invoked by contributors on the forum to argue for the occurrence of a particular ‘autistic sexuality’, whereby autistic sexuality is considered to be qualitatively different to non-autistic sexuality (c.f. [39]).

The second major meaning of autistic sexuality on the forum takes an opposing view. Here, sexuality among autistic people is argued not to be specific to autistic experience, but rather to be part of a wider spectrum of *human sexuality*. This meaning holds that the sexuality of people with autism does not differ significantly from that of people without autism. Instead, any difference is considered to be a matter of different individuals’ experiences of sexuality rather than different *autistic* individuals’ experiences of sexuality.

The debate between these two broad competing meanings of sexuality and autism is apparent within three different discussion themes in this data: *the sexual intensity spectrum*, which includes discussion of asexuality, hyper-sexuality, and ‘interest-driven’ sexuality; *non-normative sexuality* which speaks to the perception that ‘unusual’ or non-heteronormative sexual identity and behavior may be more highly endorsed by autistic people than by their non-autistic counter-parts; and *non-social sex* which we understand as sexual identification or conduct that is not primarily directed towards other people or which does not have a primarily social aim. In the following we explore each of these debates in the forum in turn.

Sexual Intensity Spectrum

Intensity in sexual activity and sexual desire, including discussion of people with autism as being either hypersexual or having a low, or a lack of, sexual drive is a recurrent theme for debate on the forum.¹ From the specificity-perspective, an imagined non-autistic sexuality is positioned as following a ‘normal’ relational developmental pace while autistic sexuality is represented as resulting from either an underly or overly intense interest. One contributor compares sexual interest among autistic people with how autistic people may be considered to function in other areas as well;

‘It’s probably the same as Aspergers is in other ways. Either very interested or not interested at all.’²

Sometimes a sexual interest starts as an intensive sexual interest which turns into lack of or low sexual interest.³ Among those considering sex as representing an intensive interest (corresponding to DSM criteria of restricted or repetitive interests), some represent it as being sexually attracted to one’s ‘special interest’⁴ or having sex as a special interest in itself.⁵

¹ A13 (2007-10-13 20:53:04); C13 (2007-10-13 23:48:27).

² A8 (2013-07-21 20:08:10).

³ C4 (2008-04-12 5:03:36).

⁴ A44 (2013-04-06 22:00:14).

⁵ C13 (2007-10-13 21:58:21); B11 (2013-04-06 22:56:20).

This is true to the extent that for some contributors, strong focus and intensity⁶ is a necessary condition for sexual desire. For example (as part of a debate between contributors about living with an autistic person, largely discussed in a tongue in cheek fashion), a contributor writes:

‘But joking aside, sex is another area where aspies can be extreme, one way or the other. Some are not at all interested in sex or body contact while for others sex seems to become something of a special interest. I also understand that ‘deviant’ sexuality is relatively common among aspies, as are paraphilias. (...) And it is clear that an aspie who NEVER wants to have sex or who wants to have sex entirely on their own terms can be a problem in a relationship, in the same way as an extremely intense sexual or unusual sexual interest may be. Again - we aspies are bad at being ‘moderate’. And when it comes to sex, this may either be great for the partner (if he/she finds the ‘right’ aspie), or on the contrary be an insurmountable problem.’⁷

These narratives of intensity may also conversely be understood in relation to common external views associating autism with asexuality, pointing toward the sexual intensity spectrum as an epistemic tension on the forum. Challenging the non-autistic assumptions of autistic (a)sexuality, one contributor (ironically) notes that:

‘Aspergers live in their parents’ basement and read train timetables, so they only have sex with themselves.’⁸

Among contributors challenging assumptions of autistic asexuality, some refer to sexuality as among the basic human needs,⁹ a source of pleasure, and something which creates closeness to the person one loves,¹⁰ a strategy for managing anxiety,¹¹ or a strong need associated with well-being.¹² Some contributors stress the connection between sexuality and longing for children, excluding asexuals from possibilities of parenthood.¹³ A low sexual interest is associated with inner or external barriers, for example difficulties with certain bodily contact,¹⁴ mental illness,¹⁵ social isolation,¹⁶ medication,¹⁷ bad self-esteem,¹⁸ ‘deviant sexuality’¹⁹ and social/emotional difficulties with relationships.²⁰ In line with this,

⁶ A6 (2010-11-17 0:56:52); B18 (2010-11-17 1:44:08); B15 (2010-11-17 10:55:31); B18 (2010-11-17 13:25:41); C14 (2010-11-25 20:44:07); C11 (2010-11-25 20:46:58).

⁷ B7 (2013-01-08 16:53:37).

⁸ A43 (2013-05-25 15:11:43).

⁹ A30 (2008-04-12 16:10:57); B20 (2010-11-18 0:04:07).

¹⁰ A30 (2008-04-12 16:10:57).

¹¹ A7 (2009-10-23 14:35:50); C10 (2010-09-19 19:51:51).

¹² C7 (2010-09-21 0:02:31); A40 (2010-11-17 16:46:51); C11 (2010-11-17 17:44:15); B5 (2010-11-17 20:08:39); B4 (2010-11-18 19:16:29); B5 (2010-11-18 19:38:46); B4 (2010-11-18 20:17:50).

¹³ C18 (2008-04-12 11:02:40); A42 (2013-02-20 19:30:59).

¹⁴ A21 (2010-11-17 2:14:14).

¹⁵ C18 (2008-04-11 23:58:56); A59 (2008-04-12 0:11:33); C4 (2008-04-12 3:18:19); A7 (2009-10-23 14:35:50); C18 (2010-11-17 7:19:24); C18 (2010-11-28 21:37:13).

¹⁶ A7 (2009-10-23 14:35:50).

¹⁷ A23 (2009-10-23 14:52:50); A51 (2010-09-21 10:27:56); B15 (2010-09-21 15:23:03); A21 (2010-11-17 2:14:14); C18 (2010-11-17 7:19:24); C18 (2010-11-28 21:37:13).

¹⁸ C1 (2011-07-01 17:20:56).

¹⁹ C18 (2010-11-17 7:19:24).

²⁰ C18 (2007-10-13 22:55:29); A57 (2010-09-21 4:45:49); C10 (2010-09-19 21:07:50); B6 (2010-11-17 7:03:53); C18 (2010-11-17 7:19:24); B20 (2010-11-18 4:09:44); A49 (2014-01-05 16:04:33);.

some contributors stress their ('normal' levels of) sexuality as conditioned by well-being, with being in a loving couple relationship²¹ and in general being more social.²²

Confirming the views on an association between autism and asexuality, having a low or non-existent sexual drive is represented by some contributors as common among autistic people.²³ Further, and in opposition to the association of a low sex drive with internal or external barriers as discussed above, some contributors who state that they do not have an interest in sex stress asexuality as a valid sexual orientation similar to other sexual orientations, as an inborn lack of sexual drive,²⁴ which does not exclude parenthood.²⁵

Some contributors stress an openly asexual position as being radical, challenging assumptions of an active sexuality²⁶ and expectations of how 'real life' should look.²⁷ On this latter basis, an asexual position may be something some asexual people try to hide²⁸ or cure through medication.²⁹ Others take a pragmatic approach to their asexuality, seeing sex and strong attractions as something 'impractical which prevents one focussing on something useful'³⁰ or something risky,³¹ using up energy that they would rather focus on their (nonsexual) special interests³² or invest in their strong non-sexual feelings with another person.³³

While some statements do stress that levels of sex drive have nothing to do with autism but is rather something which is present in all populations of humans,³⁴ there is little in this data to challenge the autism specificity meaning. Indeed, in line with a deficit-oriented view of autism as a collection of social and communication difficulties, intensity in sexual activity and sexual desire is also associated with 'degrees' of autism. From this perspective, people with 'more severe autism' are assumed to be less sexual than those with 'less severe autism' and people without autism.³⁵

Non-normative Sexuality

In relation to diagnostic criteria stressing restricted and repetitive behaviors as part of the diagnosis, external assumptions of sexuality among autistic people as being limited or restricted pose an epistemic tension on the forum. Invoking the specificity-perspective, an imagined non-autistic sexuality is represented as 'normal sexuality' including a normal sexual variance, where—similarly to the sexual intensity spectrum—autistic people

²¹ C12 (2010-09-24 9:37:52); C13 (2010-11-17 1:22:24); B2 (2010-11-17 18:31:19); A5 (2010-11-25 14:32:36).

²² A48 (2010-11-17 2:37:39).

²³ C13 (2007-10-13 21:58:21); C6 (2007-10-13 22:04:06); C18 (2008-04-14 15:22:58); C18 (2013-04-06 21:22:35); B7 (2013-04-07 0:54:52); C18 (2017-04-16 15:34:04); C18 (2017-04-16 21:50:06).

²⁴ C17 (2007-10-14 10:39:07); C18 (2008-04-12 15:04:36).

²⁵ C15 (2008-04-13 21:27:04); C15 (2008-04-14 14:17:43).

²⁶ C15 (2008-04-14 10:05:22); C17 (2008-04-14 15:40:52); C15 (2008-04-16 0:49:31).

²⁷ C15 (2008-04-14 17:07:49).

²⁸ A53 (2012-11-26 18:52:16).

²⁹ B17 (2015-07-14 16:20:48); B17 (2017-03-31 17:15:19).

³⁰ A36 (2007-10-14 10:51:13).

³¹ B22 (2008-04-13 4:17:11).

³² B12 (2008-04-12 15:57:28); C4 (2008-04-12 16:22:52); B12 (2008-04-12 17:07:37).

³³ A9 (2008-04-12 23:15:13).

³⁴ C17 (2008-04-14 15:34:36).

³⁵ A60 (2010-11-26 14:58:56).

are associated with either a greater or lesser sexual variance than non-autistic people. For example in a forum thread discussing ‘Are aspergers just like others when it comes to sex?’, a contributor notes:

I do not think so. According to my personal observations, Aspies are more extreme either the nearness poor or the obscene perverse. This is especially true of women.³⁶

This variance may be reflected by a high level of identification amongst autistic people as being other than heterosexual, or through sexual acts that do not conform to couple-based, genitally organized sex as discussed in the introduction.

From the perspective of *autistic specificity*, some sexual expressions are represented as unusual or deviant are represented as more common among people with autism,³⁷ while non-autistic people’s sexuality is represented as more restricted/limited than autistics people’s sexuality.³⁸ Contributors arguing for a greater sexual variance among autistic people in comparison to non-autistic people frequently do so in relation to different external sources.³⁹ For example, a high frequency of people with autism identified as LGBTQ on the forum (measured through different polls on the forum or through different contributors posting in different discussion threads) is invoked to challenge the assumptions of limited or restricted sexual interest among autistic people on Wikipedia.⁴⁰ An alternative way of thinking, and qualitatively different forms of expression to most ‘normal’ people, it is argued by a contributor, may result in autistic people choosing other ways to have sex than according to the norm⁴¹

Questioning the idea of difference between autistic and non-autistic people’s sexuality, thus stressing the *human sexuality-perspective*, a contributor (again ironically) notes that:

‘Clearly we are not like others! A clear sign of aspergers is that we all have to wear socks during intercourse and mumble the alphabet backwards, and of course staring crazily at the ceiling, or maybe some furniture or onto the pillow but we do not fucking looking into someone’s eyes. After sex we cry because we do not tolerate sweatiness or stickiness and rub ourselves with steel wool in either an ice cold or a scalding hot shower while we swing to calm ourselves. Or is it just me who does that?’⁴²

In relation to meanings of autistic people’s sexuality as ‘extreme’ in relation to non-autistic sexuality, some contributors stress the similarity between autistic and non-autistic people’s sexuality, stressing differences as individual (human) differences rather than group differences based on differences in neurofunctionality,⁴³ or as one contributor expresses this:

³⁶ In the original citation in Swedish, the contributor is using a homemade word, “närhetsfattig” which is hard to translate into English, but which we here has chosen to interpret literally as “nearness poor”. A10 (2013-07-27 2:33:17).

³⁷ C18 (2010-11-18 7:54:15); C18 (2010-11-20 21:29:55); A60 (2010-11-26 14:58:56); B16 (2013-04-02 2:04:50); C18 (2017-04-16 15:34:04); C16 (2017-04-16 22:45:53); C16 (2017-04-16 23:07:44); C16 (2017-04-16 23:57:51); C16 (2017-04-17 1:22:49); C16 (2017-04-17 3:31:26); C18 (2017-04-17 9:54:35).

³⁸ C18 (2010-11-20 21:29:55).

³⁹ C18 (2010-11-18 7:54:15); A10 (2013-07-27 2:33:17); C18 (2013-07-27 10:58:23).

⁴⁰ A45 (2013-04-02 1:40:04).

⁴¹ A16 (2015-06-13 8:20:56).

⁴² A56 (2013-07-22 1:41:20).

⁴³ B9 (2010-09-21 10:35:57); C2 (2013-07-21 19:44:00); C2 (2013-07-21 20:11:18); A62 (2013-07-21 23:42:26); C9 (2017-04-16 22:09:00); C9 (2017-04-16 22:52:35); C17 (2017-04-16 23:24:43); C17 (2017-04-17 0:18:52); C17 (2017-04-17 2:25:38); C9 (2017-04-17 16:47:15).

'No one is 'like everyone else' in terms of sex, that is just pretence. People have fetishes, addictions, they are interested in some things and not in others, and all have different orientations. Even though today it is more permissible to be 'deviant' and open, there is still that sense of a 'standard everyone else'.⁴⁴

Stressing similarities between autistic and non-autistic sexuality as both love-based and nothing out of the ordinary, a contributor says:

'I love closeness! And I love sex but no strange things. Ordinary spontaneous playful and loving sex is absolutely wonderful!'⁴⁵

A possibly higher proportion of autistic people identifying as LGBTQ is explained either through differences between autistic and non-autistic sexualities,⁴⁶ or with different ways of talking about or practicing sexuality in relation to different social norms. Autistic people may have difficulties with hiding non-conformative sexualities, don't think that it may be inappropriate to talk about it in certain contexts,⁴⁷ or are less likely to suppress 'deviant' sexual preferences as a result of social pressure than non-autistic people.⁴⁸ Thus, it may appear that autistic people are more likely to express alternative sexual behaviors and identities,⁴⁹ whereas here non-conformative sexual identities and behavior are presented as being due not to any essential difference in the way people with or without autism function sexually, but rather that autistic people are less likely to conform to social pressures to 'behave' a certain way sexually.

Non-social Sex

Most contributors on the forum represent sex and sexual attractions based on love as normal,⁵⁰ better,⁵¹ interesting⁵² and perhaps also more fulfilling.⁵³ This *love-based sexuality* is also associated by some contributors with wellbeing/something which make you feel good⁵⁴ or something you practice when you are feeling well.⁵⁵ In line with the ideal of love-based sexuality, sexuality for some contributors is even experienced as conditional on being in love and feeling safe in a relationship while being single is associated with asexuality.⁵⁶ Through sharing sex with a loved partner, the relationship is confirmed, and

⁴⁴ C17 (2013-05-24 23:07:51).

⁴⁵ B10 (2013-07-27 14:16:46). See also B21 (2010-06-16 14:03:34).

⁴⁶ A63 (2014-01-06 14:54:52).

⁴⁷ A26 (2013-07-27 14:52:23); B3 (2014-01-06 15:13:55); A63 (2014-01-06 14:54:52).

⁴⁸ A7 (2009-10-23 14:35:50).

⁴⁹ B3 (2014-01-06 15:13:55).

⁵⁰ A42 (2013-02-20 19:30:59).

⁵¹ A25 (2010-11-25 20:26:36); C11 (2010-11-25 20:38:12); B8 (2010-11-28 3:54:35); A1 (2011-01-18 11:42:57); A4 (2013-07-27 1:16:21);.

⁵² A46 (2011-01-18 4:27:32).

⁵³ B8 (2010-11-27 15:21:01).

⁵⁴ C14 (2010-11-27 15:29:54).

⁵⁵ B6 (2010-11-06 3:03:54).

⁵⁶ B10 (2013-07-27 0:59:53). See also B2 (2010-09-19 19:14:38); B9 (2010-09-19 19:20:50); A2 (2010-09-20 13:11:05); B13 (2010-09-20 14:24:33); A33 (2010-09-21 10:22:20); A28 (2010-09-29 10:48:05);

the loving connection strengthened.⁵⁷ In relation to the ideal, *non love-based sexuality* such as one-night stands is associated with ‘only sex’,⁵⁸ a ‘temporary’ solution,⁵⁹ or even pointless.⁶⁰

The primacy of love-based sexuality is challenged though, from alternative perspectives of sexuality; *pleasure-based sexuality*, *asexuality* and *solitary sex*. From the perspective of pleasure-based sexuality, some contributors stress that they love sex and have a strong sexual drive,⁶¹ or find it complicated to mix sex with feelings.⁶² From the perspective of asexuality, some contributors represent sex as an obligation within a relationship.⁶³ For one contributor falling in love, romance and physical intimacy such as kisses, hugs and caressing is very important, but not genital sexual activities.⁶⁴ Similarly, another contributor stresses that s/he wants to find ‘real genuine love’ and finds sex overestimated.⁶⁵ Some contributors stress that they prefer solitary sex to couple sex.⁶⁶ Others refer to low sexual activity within a long-term relationship as ‘natural autistic behaviour’,⁶⁷ as a sign of being ‘aspie social’⁶⁸ in relation to ‘NTs who see sex in a relationship confirming that they are still good (in principle),⁶⁹ and further that ‘It is common among aspies not to see sex as something ‘holding relationships together’ but as reproduction.’⁷⁰

When debating meanings of a specific autistic sexuality in the context of non-social sex, most contributors invoke a deficit-oriented view of autism as a set of social and communication difficulties.⁷¹ Stressing sex as a social practice or as having an important social function,⁷² several contributors associate social and communication difficulties⁷³ in combination with low self-esteem⁷⁴ among autistic people, with difficulties in taking the right steps toward a sexual encounter, leading to no sex at all.⁷⁵ However, once the steps

Footnote 56 (continued)

A52 (2010-09-29 13:57:34); C14 (2010-11-17 2:23:10); A54 (2010-11-17 13:40:57); A41 (2011-06-28 4:06:27); A29 (2012-12-13 20:53:59).

⁵⁷ A19 (2010-09-30 11:38:20); A3 (2013-08-04 0:45:14).

⁵⁸ B8 (2010-11-28 3:54:35).

⁵⁹ B8 (2010-11-28 3:54:35).

⁶⁰ A1 (2011-01-18 11:42:57).

⁶¹ C10 (2010-09-19 18:46:14).

⁶² C10 (2010-09-19 18:46:14); A18 (2010-09-24 3:16:43); B14 (2010-09-25 2:27:48); A11 (2010-09-30 17:54:10); B14 (2010-11-17 10:47:36); C6 (2010-11-17 11:34:20).

⁶³ B22 (2008-04-12 14:33:34); C17 (2008-04-13 15:42:20); C12 (2010-09-19 19:23:25); C12 (2010-09-19 20:10:31); A34 (2010-11-20 20:08:03).

⁶⁴ B12 (2008-04-12 17:07:37); A32 (2011-01-25 13:34:09).

⁶⁵ A35 (2010-11-23 10:03:06).

⁶⁶ A38 (2010-11-18 9:39:50).

⁶⁷ C18 (2010-11-29 18:45:20).

⁶⁸ C18 (2010-11-29 18:45:20).

⁶⁹ C18 (2010-11-29 18:45:20).

⁷⁰ C18 (2010-11-28 21:37:13).

⁷¹ A24 (2013-04-10 2:50:19).

⁷² A31 (2010-11-23 16:56:19); B19 (2010-11-24 3:09:37); B11 (2013-02-20 20:04:36).

⁷³ A55 (2009-10-23 22:14:06); B7 (2013-02-22 12:49:50); A3 (2013-08-04 0:45:14); C17 (2015-07-14 10:55:29); A27 (2015-07-15 13:54:29); A47 (2015-07-18 0:42:15); A37 (2015-07-18 5:07:32).

⁷⁴ A55 (2009-10-23 22:14:06).

⁷⁵ C6 (2007-10-13 22:04:06); C14 (2010-11-25 19:18:29); B16 (2010-11-25 19:31:53); A39 (2010-11-25 19:41:17); C7 (2015-07-18 18:39:39); C6 (2017-04-16 18:44:54); B3 (2017-04-16 18:52:54); C18 (2017-04-16 21:50:06);.

have been taken, some contributors note that ‘the sex can be at least as good as the sex of NT’s’,⁷⁶ whereby it ‘hardly requires the social genome to have really good sex’.⁷⁷

External sources are commonly invoked when stressing the impact of social difficulties on autistic people’s sexuality. These consist, firstly, of popular international resources aimed at practioners, parents and to some extent autistic adults, which have been translated into Swedish, such as certain books by Tony Attwood, and secondly of Swedish sources, such as books by Swedish author and autistic activist Gunilla Gerland. Gerland has among many other books written a book on autism, relationships and sexuality in Swedish. The book was published for the first time 2004, is aimed at professionals, parents and adults with autism, and has been widely read in those groups. Thirdly, scientific literature is invoked, such as research papers published in international research journals in English. These external sources may also be challenged from an experienced-based perspective. For example, summarizing the argument of one such external source, one contributor notes that autistic people may have the same sexual desire and need as ‘most others’, but their difficulties with social codes and communication lead them to misunderstand or being misunderstood by others in intimate contexts.⁷⁸ After the summary, the same contributor, argues that he can’t actually remember experiencing such misunderstanding, but asks other members of the forum whether they have experienced them in their intimate lives.⁷⁹

Although the ideal of a love-based sexuality is challenged from alternative perspectives of sexuality, most often it is the less sociable forms of sexuality that are being problematized (and sometimes even mocked⁸⁰) on the forum. Sex for pleasure is considered by some contributors as a consequence of social and communication difficulties, for example difficulties with connecting sexual practices with feelings, which leads people to ‘only focus on sexual pleasure’.⁸¹ Similarly, solitary sex is represented as consequence of difficulties in forming relationships.⁸² Some contributors refer to solitary sex as not real sex, but ‘a rather unsightly substitute’.⁸³

Discussion

Autistic sexual specificity is partly defined as being interest-driven on the forum. This means that an interest can either be directed to sexuality, resulting in an overly intense interest and intensity in sexual practices and desires, or an underly intense interest for sexual practices. Conversely, non-autistic sexuality is represented as being social-driven; as following a ‘normal’ relational developmental pace. The notion of autistic sexuality as interest-driven, rather than socially driven, sits uncomfortably with contributions aiming at challenging non-autistic peoples’ assumptions of autistic people as asexual, or as non-social, perhaps illustrating an epistemic tension on the forum between two competing demands of epistemic authority. On the one hand, epistemic authority is demanded based

⁷⁶ C14 (2010-11-25 20:26:18).

⁷⁷ B16 (2010-11-25 19:31:53).

⁷⁸ C3 (2013-04-10 0:49:30).

⁷⁹ C3 (2013-04-10 0:49:30).

⁸⁰ A43 (2013-05-25 15:11:43).

⁸¹ C10 (2010-09-19 21:07:50).

⁸² C13 (2007-10-14 13:13:31); A15 (2011-06-22 13:54:10).

⁸³ C7 (2011-06-23 3:00:23).

on a critical perspective of notions of autistic deficits, stressing autism as difference. This perspective draws on deficit-charged notions of autistic people as essentially uninterested in sexual practices due to a lack of interest in social interaction or being less likely to form peer relationship due to severity in social interaction deficits are questioned. This leads to questioning the frequency of authentic or naturally asexual autistic people, describing asexuality as predominantly a consequence of individual and social barriers, and perceptibly supporting Przybylo's use of the term 'compulsory sexuality' to refer to 'the social expectation that sexuality is a universal norm, that everyone should be sexual and desire sex, and that not to be sexual is inherently wrong and in need of fixing' [40, p. 182].

On the other hand, epistemic authority is also claimed based on critical perspective of notions of asexuality, stressing asexuality or a low sexual drive as a common and radical position to take among autistic people, a resistance to the above expectations. Davidson and Tamas [41, p. 64] note the pressure that may be felt by autistic people identifying on the asexual spectrum, who may 'worry about the political implications of their personal preferences, about the risk of undermining the long struggle by people with disabilities against being stereotyped as asexual and non-reproductive.' The tension on the forum echoes tensions around this subject within disability studies more broadly: on the one hand 'individuals with disabilities have long been working to have their sexuality recognized and given legitimacy' [42, p. 124], and the notion of asexuality has been seen as anti-thetical to this position; on the other hand, asexuality is increasing conceptualised as a valid sexual orientation, not 'a dysfunction in need of correction, but as a variation in sexual subjectivity' [43, p. 3]. It is possible that acceptance of self-identified (rather than imposed) disabled asexuality may be contingent on changing attitudes around asexuality more broadly.

In line with notions of autistic sexuality as interest-driven rather than social-driven, some contributors also see asexuality or a low sexual drive as an expression of lack of sexual interest. Invoking ideas of autistic people as interest-driven in their motivations, some contributors stress that sexual practices are impractical and may prevent a person from focussing on something either more useful or more interesting to that individual. Meanings of sexuality as essential for social bonding (couple bonding) are challenged and the possibility of relationships based on shared non-sexual feelings for each other is stressed. In opposition to the specificity-meaning of autistic sexuality, where the notion of an interest-driven sexuality is central, contributors bring forth autistic sexuality as not particularly interest-driven; as neither intensely interesting or uninteresting, and where level of sex drive has nothing to do with autism.

The epistemic tension on the forum between the different meanings of sex could be understood to be part of a wider discussion within the community around autistic emotionality and sociality, where stressing sex for love may be understood as resistance to notions of autistic people as not able to or interested in forming close relationships (see also 40). This is only discussed from the sexual specificity-perspective. Unlike other assumptions of autistic people's sexuality which are more challenged there seems to be a consensus on the forum regarding autism as a collection of social and emotional difficulties and discussing the (negative) impact of these on autistic people's sexuality, with just a few critical or questioning voices in the debates. Together this speaks to what we have chosen to refer to as 'sociable sex' or sex as a social practice, with its counter-position of *non-sociable sex* which we understand as sexual identification or conduct that is not primarily directed towards other people or which does not have a primarily social aim.

Meanings of more sociable forms of sexuality seem to speak to a further epistemic tension on the forum. While less sociable forms of sex are sometimes criticized, and more sociable forms of sex idealized, some contributors also bring forward the argument of

interest-driven sexuality as normal for autistic people, arguing for different functions of sex for autistic and non-autistic people. From this position, sex for people with autism is represented as more individual-functioning (interest-driven, reproduction, as ways of managing anxiety), while sex may have more social functions for people without autism (such as confirming roles in the relationship/holding the relationship together). ‘Good sexuality’ in the sense of Rubin’s charmed circle may mirror the non-autistic social functions of sex; as a way of maintaining an intact and stable couple, in the case of the contributors of the forum, not entirely signing up for this aim of sex, may rather be placed or pushed to the outer reaches of the charmed circle (similar to representations of bisexuals as merely ‘selfish’ in their sexual desires and practices, 41)

Conclusion

The history of autism is also the history of a group of people characterized in the vast majority of scientific literature as ‘the disordered and damaged other’ [38, p. 5]. While calls to change this, notably through the meaningful participation of autistic people in research processes [7] are multiplying, it is rare to find literature discussing autism other than from a perspective of deficit, of aberrant deviation from the norm. On the forum there are ongoing debates regarding whether autism has any impact on the sexuality of people with autism or not. This debate must then be understood in relation to wider discourses present in research, practice and politics concerning different meanings of autism and diagnostic criteria of autism; stressing intensity (related to diagnostic criteria of restricted-limited/intense interests), non-normativity (related to rigidity/lack of flexibility), and social- and emotional communication impairments. The way of debating at the forum can be referred to as ‘talking back to power’, in this case ‘talking back’ to bio-medical conceptualisations of autism, where a subordinated group within the walls of one’s own community, is enabled to fight for epistemological credibility over bio-medical language of diagnosis which at least initially have a high level of epistemic authority [25, p. 284]. All these have the effect of othering autistic people’s experiences in relation to non-autistic people’s experiences, centering neurotypicality and producing neurotypical experiences as ordinary and autistic experiences as extraordinary. (c.f. [44]).

Within the context of a body of autism literature which is generally deficit-driven, is it then possible for autistic people to imagine themselves and their intimate experience other than through deficit? Findings from the forum appear to indicate that, at the very least, this is a complex undertaking. In line with Nelson’s ideas of knowing as collective, we argue that what can be narrated on the forum is dependent on what narratives are available, either by ascribing to them, or by resisting them. Given that the study of autism is largely the study of ‘...negatively valued deviations from behavioral norms’ [12, p. 3], it follows that discussion of autism is largely limited to a comparison to those norms. Therefore, as we have seen, both the contributors who position their sexuality as ‘different to’ and those who consider it to be ‘the same as’ non-autistic sexuality have little choice but to use ‘neurotypical sexuality’ as a starting point. Thus, the ‘others’, who are ‘not doing it properly’, are positioned in opposition to the imagined cognitive normal counterpart, the one who is ‘doing it right’.

This leaves us with some considerable ideological dilemma of our own: how do we value ‘lived experience’ and its narratives, when we are arguing for this narration as being itself, in a sense, the result of a discourse that individuals may have limited power

to resist? How do we separate a person's 'lived experience' from that same person's 'epistemic infection' by a body of (collective) knowledge that defines their actions as being the product of deficit? The answer, perhaps, is that we cannot.

We can, however, observe how people discuss different aspects of their sexuality on the forum, and try to draw a parallel between their narratives and the foundations on which those narratives may stand. For example, when discussing non-social sex and asexuality we have seen the extent to which contributors draw on the diagnostic criteria to support their thoughts and opinions, and more particularly on the proposition that autistic people have social and communication 'deficits...failure...abnormalities' [45] that negatively impact their sexual possibilities. To move beyond this, and therefore, perhaps, move closer to the reality of embodied autistic (and indeed non-autistic) sexual experience, two possibilities emerge.

The first is the epistemic interest of being creative in how we explore sexual experience. While a discussion of sensory experience on the forum is beyond the scope of this article, we were struck by ways in which sensory sensitivities are discussed on the forum. Discussion in this area seems largely to avoid reliance on deficit, leaning rather on comparison and points in common *between* contributors, rather than as opposed to a perceived norm. This is interesting in the context of our discussion in that, while sensory questions are now included in the diagnostic criteria [45], the language used is less resolutely limited to deficit. For example, what is considered as 'abnormal' when applied to social behavior is described as 'unusual' in discussion of sensory experience, and this less 'judgement-driven' tone is maintained throughout the description of the sensory criteria, in marked opposition to descriptions of social criteria. Perhaps exploring 'sensoriality' rather than 'sexuality' could broaden discussion, positioning people discussing their intimate experience not at the inner or outer areas of the charmed circle of sex discussed in the introduction, but providing a second circle, a circle in which the inner and outer limits do not demark moral judgement but sensory experience: in this second circle, 'pleasant' or 'unpleasant' would thereby replace 'good' or 'bad' sexual and intimate experience.

The second possibility is to reposition autistic voices closer to the centre of the literature around autism. Here this would mean producing qualitative research into autistic peoples' sexual and intimate lives without taking as a starting point an assumption of deficit, or certain non-autistic expectations of what counts as 'sexual'. This call for qualitative research soliciting the views and experiences of autistic people has been made for decades [46, 47]. With the increasing interest in studying sexuality generally [48], and a growing understanding that the complexity of human sexuality and gender identity is not currently captured by traditional research methods and categories [40, 49, 50] perhaps the time is now ripe to carry out this research. Or are we all stuck in the same tension, the 'epistemic hamster-wheel' that is manifested on the forum: is deficit so much a part of meanings of both sexual and neurological difference that we are unable to untangle the validity of our own sexual experience from the stories we have been told about it?

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Compliance with Ethical Standards

Conflict of interest Author Bertilsdotter Rosqvist declares that she has no conflict of interest. Author Jackson-Perry declares that he has no conflict of interest.

Ethical Approval This article does not contain any studies with human participants performed by any of the authors.

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