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“BREATHING THROUGH OUR WORDS”: REFLECTIONS BY AUTISTIC AUTHORS ON THE POWER AND POTENTIAL OF CREATIVE WRITING

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Abstract

Research within the autistic community suggests that creative writing may have the potential to enhance a sense of belonging, build self-confidence and improve management of distress and overwhelm for some autistic people. This study explores this further, working with three writers from the UK-wide *Beyond the Spectrum* initiative that engages published autistic authors to facilitate creative writing workshops for autistic people. Participants in the study created a piece of ‘free writing’ (i.e. not edited or crafted) to explore how their autism impacts their writing experience, and this was then subjected to ‘poetic transcription’ by the researcher, herself an autistic senior academic. Findings include that these autistic writers value the intensity of their autistic interests as a source of material and of intense focus within their writing, that autism impacts their creation of character, writing supports processing of memories and sensory stimuli and – importantly – is a source of satisfaction, empowerment and joy. Ways that writing, including the use of poetic transcription, may be a valuable source of communication and expression for some autistic people are considered.

Keywords: Autism, creative writing, poetic transcription.

1 INTRODUCTION

This study explores with autistic published writers how they frame their autism within a writing context, how writing may support communication of autistic experience, and how such communication may support autistic wellbeing.

The inclusion of the voices of autistic people in social science autism research is increasingly recognized as important both ethically and epistemologically [1],[2],[3]. Frameworks such as the *Draft Framework for Inclusive Autism Research* [2] identify the importance of autistic involvement in research that purports to benefit the autistic community and recognizes the inclusion of these voices as central to wider understanding of autism.

As autism is a social communication difference, articulating autistic experience through socially constructed, often verbal, exchanges may not support full involvement of all autistic participants. Some autistic people use little or no verbal language [4], [5] or may find spoken communication incomplete, fluent in some situations but not in others, and sufficient only to convey part of what is meant but not all [6].

One way to amplify autistic voice in the sharing of lived experience of autism may be through writing. In their edited book, *Typed words, Loud voices* [7] Amy Sequenzia and Elizabeth J. Grace brought together essays and poems by people who use writing through typing or facilitated communication as their preferred, and sometimes only, method of communication. This writing is compelling and emotionally evocative and, although outside a formal research context, remains a powerful way for otherwise silenced individuals to be ‘heard’.

The ongoing study reported in this paper works with professional autistic writers to explore their experience of writing within autism. By including participants who are published writers, the research works with autistic people who choose the written word as a form of communication, and who have been validated in their competence with it. All the writers in this study also use spoken language, but all communication with them has been through writing.

Of course, writers who are autistic may not frame themselves as ‘Autistic Writers’. To categorize writers by sub-set (‘Black writers’, ‘women writers’, ‘LGBTQIA+ writers’, ‘disabled’ writers...) is to assume a position where the default conceptualization of The Writer is of someone male, white, heterosexual, able-bodied and neurotypical. The writers in this study are autistic but may not write about autism as their subject matter nor see their writing as consciously expounding autistic experience. It is nevertheless the case that as openly autistic people who use writing as a preferred form of communication, they are well

placed to explore interaction as it may occur between writing and autism in their experience. As autistic people who write they inhabit a certain position, as does the autistic researcher who undertook the data gathering, analysis and discussion in this study – and who is using the written word through this paper to share her thoughts and findings.

All participants in this study are, additionally, interested in ways that engaging with writing may have potential to benefit autistic people. They are each workshop facilitators for the initiative *Beyond the Spectrum*, a UK-wide project undertaken by the CIC *Writing East Midlands* to support creative writing workshops delivered by autistic writers with autistic people. There is a considerable body of research suggesting potential health benefits of engagement with creative writing, including promotion of connectedness, empowerment, and identity [8]. Research with autistic participants taking part in creative writing groups suggests that such writing may have the potential to increase social skills development, enhance a sense of belonging, build self-confidence and improve the abilities of writers within this cohort to cope with distress and overwhelm [9]. This current study, therefore, explores this concept in context, asking how the participant writers believe their autism interacts with their writing, and what they perceive as the potential positive impact of creative writing for autistic individuals.

The study uses 'poetic transcription' to create its findings, and as such the method reflects the content. Poetic transcription is a research approach that reconstructs participants' words and phrases into a compact and evocative form through the creation of 'poem-like compositions' from the words of participants [10, p.202]. It may be understood as a 'culturally relevant method for re-telling [stories within] research' [11, p.47], aiming to share participants' ideas in their own words in a concentrated form.

Poetic transcription is a powerful tool ... that creates a deep yet distilled essence of participant and researcher voices. ... Situated within research poetry more broadly, poetic transcription adds to the richness of the available methods as it helps to build relationships with participants, facilitates more personal understanding of the subject, and allows for multiple interpretations of transformative work.

[12, p.53].

1.1 Autism and writing

One way that the concept of 'autistic writing' has been considered historically is through looking back at famous writers and considering whether they could be retrospectively 'diagnosed' as autistic. For example, Fitzgerald [13] suggests that the works of Lewis Carroll and William Butler Yeats reveal classical autistic features. Consideration of these supposedly autistic authors has explored whether an 'autistic way of writing' could be identified [14]. However, this retrospective analysis is largely considered unhelpful, with Roth [15] concluding that 'the notion that autistic art constitutes a unified stylistic genre is ... overly reductive' and may risk 'insulating [autistic writing] from mainstream aesthetic standards' [15, p. 498].

There have been plenty who posit that autistic writing is not only different but deficit. Various interventions have been suggested to support the autistic writer – specifically the autistic student – to write in a 'more effective' (i.e. non-autistic) way. This need for intervention regarding writing by pupils [16] has been identified through linguistic analysis that suggests challenges with personal narrative writing at both the sentence and text level and identifies specifically that autistic writers may have 'greater difficulty getting started and staying on task' [17, p.18].

However, it may be that the concept of deficit in autistic writing lies as much with the non-autistic reader as with the creator. Finn-Kelcey [18] explored the possibility that non-autistic readers (and, in this case, examiners) might fail to appreciate work by autistic pupils. They suggest that autistic students undertaking the creative writing element of the English GCSE may experience penalties from non-autistic examiners, possibly due to the Double Empathy problem [19], and suggest greater strength to the writing of autistic candidates than is given credit. This position is supported in research by Cancer et al. [20] which indicates an 'exceptional originality' in creativity evident in autistic children [20, p.1], and a systematic review and meta-analysis of autism and creativity by Pennisi et al. [21] suggests high levels of detail and originality in the writing of autistic participants. Greater awareness of the potential strength of writing as a form of communication for some autistic people may be of 'broad help to diverse stakeholders, including educators, clinicians, families and autistic individuals themselves' [22 p.1875].

Some writing, and 'creative' writing in particular, has further been suggested to have 'positive effects on autistic symptoms' and may be considered as an 'alternative intervention to traditional treatments' [23 p.1]. Although the highly medicalized language of 'treatments' and 'symptoms' in this research undermines the inclusivity of these ideas, the concept of creativity as a way of impacting some autistic

experience remains an interesting one. Research has explored the use of creative writing to develop the social skills of young autistic adults [24, 25], and a systematic review of creative arts therapies used with autistic children, including creative writing, concluded that many brought benefits and 'a variety of occasions for autistic children to express themselves' [23, p.1].

1.2 Aim of this study

This study aims to explore ways that the professional writer participants suggest that their autism supports their writing, and to consider ways that they believe that their autistic selves may be supported through their writing.

2 METHODOLOGY

Potential participants were recruited from *Writing East Midland's* workshop facilitators. Research ethics approval for the study, including its methodological approaches, anonymization and data storage and sharing, was given by Lincoln Bishop University (then Bishop Grosseteste University) prior to the outset of the project. Three participants chose to take part in this element of the project and were invited to create a piece of 'free writing' (i.e. not edited or crafted) exploring how their autism 'informs, impacts or influences' their writing. Free writing was requested in order to harvest ideas in first draft, un-edited form.

This free writing was then subjected to 'poetic transcription' by the researcher, herself an autistic senior academic. The objective of poetic transcription is to 'distil the original source text into a poetic form which is compact, evocative, and memorable' [26, p.10], through an 'imaginative reconstruction of participants' words, phrases, or paragraphs to fashion a poem' [27, p. 1623]. This 'imaginative appropriation and reconstruction of already existing texts' [28, p. 369] was developed as a way of working with participants' words as research data through the work of scholars such as Glesne, Richardson and Butler-Kisber [10, 29, 30]. During poetic transcription the researcher works with participants' words and revisits and represents them through cuts and edits, changed order and reconsidered line breaks in a process that is 'largely intuitive and reflexive' bringing out 'the essence in participants' narratives in a concentrated fashion' [27, p. 1624]. In this way, the researcher assumes an active role in the editing and so becomes a co-producer of the findings. The process is described in more detail by researcher Butler-Kisber:

As I selected words and phrases from the chained narrative, I experimented with the words to create rhythms, pauses, emphasis, breath-points, syntax, and diction. I played with order and breaks in an attempt to portray the essence of her story while inherently "showing more."

30, p.233.

3 RESULTS

The findings from the data collected and analyzed as described in this study distil into three poems.

3.1 Poem 1

I've been writing for years.
It links to my special interest at the time

I'll want to know everything about my interest
find out about it
understand it
read all about it
live it, breathe it.

When I think I'm getting my head round it
I explain it to someone else
(whether they like it or not),

And when I still lack understanding
I use poetry.
It's an interesting process.

My writing projects are short.
I quite often stop before I'm totally satisfied,
but I've had some great lines of thought
And produced some really interesting work.

And then I switch interests
Every year or so, I switch special interests.
I lose interest.
Almost overnight
And I don't do anything like that again.

3.2 Poem 2

Writing is fast, slow, suspenseful, scary, fun, shocking,
a wild rollercoaster, like the Nemesis ride at Alton Towers.

Along this rollercoaster
there is a slope up high, and it takes a while to get up there.
Sometimes my brain takes a long time to process an idea,
a thought, my emotions,
things that I have seen or heard or touched.
But once I get to the top, then I write.
Then I write intensely.
I focus on the suspense and that moment up high
and the releasing all of what is inside me.

I wouldn't change it.
I get a new lens sometimes and new inspiration
that leads to all sorts of avenues.
I can write from an idea I didn't expect,
and that is like, 'Wow!'.
I always impress myself when this happens
as I look at things from a different perspective.

Sometimes, though, I get too anxious to write.
I forget moments,
or lines,
or thoughts that mean so much.
I am scared to tap into those memories,
those emotions.
Am I ready to process it yet?
And then there's the opinion of others
- even of those I trust.
You never how people are going to be.

I have nearly stopped,
quit writing forever,
hidden many of my works.
I do this to protect myself from the pain...
but I'm hurting myself more by locking it in.

3.3 Poem 3

Every character I create is partly autistic
because every character is part of me
and "me" is all autistic.

I am proud of it,
and it influences every single aspect of "me",
and it influences every single character of mine.

One of them will become a special interest for a while,
and everything I write and dream about will rely on them.

Emotions, I process through these words on this page,
which pour from me unbidden and unhinged.
For a moment I can process,
and my internal monologue can narrow, focus, develop.
Other sounds are quieted, calmed, and I am muted.
For a moment I can exist in myself without a nightmare of navigation
and sound and contrast
and emotion
and story and light and spirit.

I breathe through my words.
They shift in and out of me like the tides,
carrying me along their currents.
I smile through them,
I laugh through them,
and most importantly, they are my screams.
When there is no soundproof room to lock myself in,
when there is no way to yell at the person,
when there is no space to express the anger,
or fear,
or violence,
or complexity I am experiencing,
my words let me scream.

When I use my words to fall in this forest of modern life,
I make a sound.
I am heard. I am seen.

4 CONCLUSIONS

The writers who took part in this study articulate various ways that their autism feeds their writing, and that their autistic selves are nourished through their writing. These include how the intensity of autistic interests can be a source of material, how autism impacts their creation of character, how working creatively facilitates navigation of emotions and enables communication, and how working within fictional contexts can support processing of memories, anxiety and sensory stimuli.

4.1 Intense interests

An element to emerge in this study is how autistic intense interests can be both the source material for writing and how writing can help contain and contextualize that interest. Writing is described as emerging from the interest and as being a way of processing that interest. In this, writing inhabits a similar place to 'autistic monologuing', where an autistic person may be captivated by an interest and think and talk about it without particular attention to whether a listener may share interest: 'I explain it to someone else whether they like it or not'. This monologue is described as being processed by the act of writing, allowing it to 'narrow, focus, develop' as the writer contextualizes it within the written word. One writer suggests that as part of their wish to 'know everything' about their interest, to 'live it, breathe it', they use poetry to provide understanding. Writing is a process and a way of organizing and articulating as much as a means to produce a product. Indeed, the product – the poem or piece of writing – is described as often being abandoned before the writer is 'totally satisfied'. Just as the focus of the interest changes 'almost overnight', so does the attention to the piece of writing switch away: 'I don't do anything like that again'.

As well as emerging from autistic intense interests, writing is reported to nourish these same interests. This is discussed in terms of character creation as autism 'influences every single character' created in these fictions, as all characters emerge from the writer's autistic self. The intensity of the creation of these characters is described as becoming 'a special interest for a while', linking the intensity of the creative process with the intensity of autistic focus.

4.2 Navigating emotions

The participants position writing as a way of navigating emotional intensity. The act of writing is described as 'suspenseful, scary, fun, shocking' and as 'a wild rollercoaster'. Emotions are described as being processed 'through these words on this page', with emotions being potentially 'quieted' and 'calmed' by the writing process. At other times emotional intensity threatens to overwhelm the writer leading to a block in the writing process. The writer shares that this may be through fear, that they may not be ready for the processing of the emotions and memories through writing. Writing is positioned as a means to engage with memories, anxiety and sensory stimuli. One participant shares that their brain 'takes a long time to process an idea' and that writing enables them to 'look at things from a different perspective'. Another suggests that through writing they 'can exist in myself without a nightmare of navigation'.

4.3 Support for communication

Writing as tool to support communication is powerfully conveyed by the participants, who share that they 'breathe' through written words. They convey that writing supports them to smile and laugh, and 'most importantly' writing 'let[s] me scream'. Writing is articulated as a way to express anger, fear, violence and complexity, to find 'space' to 'yell' about what the writer is experiencing.

The freedom to articulate in the written form allows words to pour out 'unbidden' in a process that is described as 'unhinged' as a way of 'releasing all of what is inside me'. This suggests a frustration with other communicative means, and a liberation in being able to express feelings and ideas through the written form. However, there is recognition of the inherent danger in this expression. One writer indicates that they have 'nearly stopped, quit writing forever' on occasions in an act of self-protection, an acceptance that expression of self leaves them vulnerable to others' opinions, even of those they trust. They share, somewhat plaintively, that 'you never how people are going to be'.

The potential of writing as a way to be heard is powerfully expressed, especially by the participant who indicates that they 'use my words to fall in this forest of modern life'. The allusion to the thought-experiment which asks if a tree falls and no one hears it whether it makes a sound, is poignant. This participant confirms their answer, that through writing they do indeed 'make a sound' and are therefore both heard and seen.

4.4 Concluding comments

4.4.1 *Feedback on the poetic transcription approach*

Feedback from the writers on the use of poetic transcription in this study was broadly positive. One described the resulting poems as 'perfect' and another as 'reflect[ing] what I think and what I wrote'. One writer reflected that it is 'really powerful' and 'very well structured and done'.

Perhaps unsurprisingly when writing is their craft, some participants commented on the poetic transcription as poetry, one suggesting that, although it 'does reflect how I feel and thought when I was writing', it is 'not written the way I'd write it'. One commented that 'I kind of feel like it's not my voice yet it's speaking as me'. Although positive regarding how the poetry reflected their ideas and thoughts and did 'speak to my voice', this writer commented on the dichotomy of the poems speaking for them but not in their writing style as 'mak[ing] me quite uneasy'.

The consensus was that the writers would not suggest making any changes, that the poems 'resonate' with them and that broadly the participants 'like the approach'. None commented specifically on the potential for poetic transcription to be a source of expression for other autistic people, nor for it to be a way of enabling the sharing of autistic experience more widely and directly within research literature.

4.4.2 *Limitations and future direction*

The study worked with a very small cohort of participants, so findings are extremely specific. However, the heterogeneity of autistic experience [32] requires that each autistic voice be recognized for its own value; there is not 'one experience' of autism, and articulations of autism and writing as shared here therefore offer valuable personal insights that may nonetheless contribute to wider understanding of autistic lived experience. Similarly, the approach of poetic transcription offers one potential method to capture and share autistic 'voice'. Further use of the approach with autistic participants, and feedback on the findings from the approach from the autistic community, is needed to ascertain whether this is a useful tool to add to approaches within social science autism research.

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