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Comics as communication: developing more awareness and understanding of high-functioning autistic individuals, through depiction of their lived experience.

Keywords: Autism Spectrum Disorder, Autism, ASD, Aspergers, Comics

Introduction

This project aimed to utilise the medium of comics to present a more holistic and variable depiction of the high functioning autism spectrum disorder (HFA) individual's lived experience. Additionally, the other intention is to also prove that comics are a medium capable of educating and informing audiences, despite their low status (Domsch et al., 2021; Eisner, 2008a; Eisner, 2008b; Kukkonen, 2013; Lyons & Williams, 2010; McCloud, 2000; McCloud, 2008; Pizzino, 2015; Stein & Thon, 2015). The objectives of this research are:

- To demonstrate that comics are a medium capable of communicating serious topics—to inform and educate the public.
- To provide a humanising and authentic depiction of the HFA individual
- To encourage more awareness and empathy of the HFA individual's experience
- To challenge preconceived notions of what constitutes reality for the HFA individual
- To contribute to research supporting neurodiversity and the autism rights movement (ARM).

All these aims, and objectives are adhered to, in a bid to address this research question: What role could graphic narrative play in enhancing a deeper understanding of the lived experience of high-functioning autistic individuals?

The research interest in comics is as a creative means of address that can be implemented in educating and informing audiences. In expanding upon this, it is apparent that much more research is needed into this field of inquiry as well as its capabilities, past questions of status (Gavaler, 2017; Kukkonen, 2013; McCloud,

2008; Pizzino, 2015; Stein & Thon, 2015). This project investigated the gaps deliberated, to address the aims and objectives outlined. Elaborating further, the ultimate motivation regarding this research's significance is one rooted in contributing new knowledge to these fields - the fields of autism spectrum disorder (ASD) and graphic narrative research (comics), respectively. The work aimed to depict a more holistic depiction of the consciousness of HFA individual(s), as demonstrated through the narrative vehicle of one character and his interactions with others, with or without the condition, in his everyday life. These elements amalgamate all strings of research within this project: the literature review (secondary research), and data gathered in the field (primary research). This exploration intends to dig deeper into the question of what makes an individual truly an individual, past their labels or diagnoses. In positioning this, such a proclamation is led by the motive of highlighting the humane aspect of the HFA individual. This is through an example of creatively demonstrating how the HFA individual's existence is presented through their own consciousness. This is in opposition to the common notion that clinical and stereotypical depictions alone are definitive of the HFA individual's identity.

Literature review

A literature review was conducted to inform the creative synthesis of the comic, as well as provide a basis of significance to the research. The literature review is instrumental in two identifiable ways: 1) as a means of creative synthesis, to inform the creation of the means of address, and 2) it is also triangulated against resulting data from phase III (testing the comic). The analysis of literature focused on the designation, definition, and constituents of both ASD as well as comics.

The literature of "comics" and "ASD", respectively, reveal gaps in the research pertaining to each discipline. These were ultimately explored: the designations, the constituents, and the definitions of ASD and comics, separately. Within the literature review for comics, it was revealed that there are gaps within representation of the medium for academic use. This is due to its history and correlation to 'juvenile' reading; the medium is still seen in a relatively poor light (Domsch et al., 2021; Eisner, 2008a; Eisner, 2008b; Kukkonen, 2013; Lyons & Williams, 2010; McCloud, 2000; McCloud, 2008; Pizzino, 2015; Stein & Thon, 2015). Despite this pre-existing notion, the review revealed that comics as a medium show considerable strength in communicating serious topics. Therefore, more contribution to the academic use of comics is required to bridge this gap in knowledge.

The ASD literature review provided a basis of knowledge to supplement the creative outcome and inform its representation (how this literature informed the creation of the comic, will be explored in "Creative synthesis: creation of the comic" within this paper), as well as depiction. The review also revealed that negative stereotypes of ASD prevail within mass-media representations (Barrio et al., 2021; Draaisma, 2019; Fontes & Pino-Juste, 2021; Garner et al., 2015; Gillespie-Lynch et al., 2015; John et al., 2015; Jones & Harwood, 2009; Loftis, 2015; Nordahl Hansen et al., 2017a; Nordahl Hansen et al., 2017b; Stern & Barnes, 2019). This strongly suggests that more positive contributions to ASD representation within mass-media are still required. This, paired with comics strong potential in communicating and informing audiences on serious topics, suggests that the two facets of knowledge could work together to generate new knowledge. That is, the medium of comics can be used to bring more awareness and understanding of the lived experience of the high-functioning autistic individual.

Methodology and research design

The research was informed by qualitative research, ontologically, epistemologically, and methodologically (Leavy, 2017). The overarching research paradigm which guided the development of the research project was interpretive/constructivist in its alignment. The primary theoretical and philosophical schools of thought were conducted through the methodology of phenomenology (both pure and heuristic conventions), along with the subsidiary methodology of arts-based research (ABR) (Given, 2008; Patton, 2015). Surveys and interviews were conducted in a set of three phases: Phase I surveyed participants for public perception of ASD; Phase II gathered data on the lived experience of ASD (high functioning) by interviewing diagnosed individuals; and Phase III tested whether the comic that was created, as informed by the earlier phases and the subsequent literature review, did indeed address the research topic and question.

As for the creative synthesis of the project, this was informed through the basis of ABR (Given, 2008). This, as described by Leavy & Mcniff (2018) "...is the artistic process of inquiry that can be used to explore art, as well as the totality of human experience" (p. 24). In further explanation, ABR is a methodology which adapts the creative arts with social research, and its aim is to create research, which is thereupon widely accessible, suggestive, and engaging (Eisner & Barone, 2011; Leavy, 2020). In question of the framework's rigor, the tenets of ABR are informed by many offshoots of social science, as well as the discipline of the creative arts. For

this research, the medium of comics – a modality of a visual nature, is utilised as a means of addressing both the topic and the research question posed. Do note that before each phase was conducted ethical clearance was granted by the researcher's university to ensure that participants were respectfully engaged with.

Ultimately, an overarching qualitative approach to a constructivism/interpretive research paradigm was chosen for the research design of this project. These, in essence, are the justifications as to why:

- To allow participants in surveys and interviews the liberty to describe their experiences in detail and to collect a rich data sample with language being at the forefront (Leavy, 2018).
- "Researchers... value people's subjective interpretation and understanding of their experiences and circumstances" (Leavy, 2018, p.13).
- "Constructivism, as an underpinning philosophy, points to methods or techniques that most effectively elicit data which represent a person's constructed sense of reality" (Denicolo et al, 2016, p.4).
- "...constructivists seek to understand a person's internal experiences from that person's personal perspective, not the researcher's own perspective" (Denicolo et al 2016, 5).
- "A constructivist's task is to seek understanding about how people make their own sense of their personal world... [the] emphasis on research participants' personal meanings is central to the constructivist's philosophy and practice" (Denicolo et al 2016, p.5).
- Research paradigm aligns with research question through: "The most frequent articulation of research topic expressed generically is 'an exploration of individual or group perspectives/viewpoints/beliefs about, or experiences of, particular objects, events, or people' (Denicolo et al 2016, p.6)".

Data evaluation: Phase I, surveying public perception of ASD

For the first phase of data gathering within this research, the online questionnaire was designed to gather insight into the general public's perception of autism spectrum disorder (ASD) and what it personally means to them. A total of 88 participants took part in the survey. The following areas were assessed:

What is a public perception of autism spectrum disorder?

- How do they perceive the condition and those diagnosed?
- Does this perception of autism spectrum disorder support the research topic?

The findings from the survey demonstrated that a large majority of the public believe that there is more about the condition that they could learn about. Participants in this survey actively reflected on their understanding and perception of the condition through the course of the survey. The main findings were that there is a need for better societal awareness of, as well as understanding toward, ASD – and, ultimately, that the public has a lack of understanding and knowledge about the condition and those who are diagnosed with it. This is indicated through 87.5% of participants stating that they felt as if there was still little they knew about the condition. Ultimately, in summary, there is a need for better understanding of ASD and the subsequent communication mechanisms to achieve it.

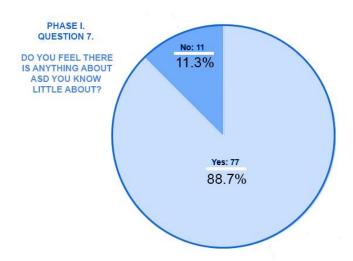


Figure 1: Percentage of participants who felt as if there was more they could know about ASD.

Data evaluation: Phase II, interviewing ASD individuals.

Semi-structured interviews were conducted for 'Phase II' to gather data on the lived experience of high-functioning ASD individuals. This phase was conducted to produce real data on the lived experience of ASD, for the purpose of creatively synthesising it into the comic. A smaller sample of 4 participants was chosen to support the depth of case-oriented analysis that was conducted for this phase. Also, in further explanation, a smaller sample size was fundamental to gathering richer qualitative data, based on lived experience. This was to address the following:

- What is the phenomenon of ASD? How do people who live with the condition describe it? How do they believe the public perceive them, and their condition?
- How can the comic cohesively depict ASD through the creative synthesis of data produced through interviews of those formally diagnosed with ASD?
- How can we creatively synthesise this data into the comic to address the outlined aims and objectives?

The resulting data was parsed in a bid to determine codes and themes to support creative synthesis. The main findings demonstrated that participants had a unanimous view that society's view of ASD individuals was quite poor. One participant explicitly made this misunderstanding clear, with their reply to a question: "Absolutely under no circumstances is there anything wrong with being autistic and I feel like society really needs to... learn that..."

The collective negative experiences and misunderstanding by society among this sample is also demonstrated through Phase I's results. A set of HFA traits, characteristics, and lived experience of the condition for use in creative synthesis was the result of this phase. Triangulation of this data against the literature review further supported and determined the validity of the participants' accounts of their lived experience. This, as well as testing conducted in Phase I, would inform and support Phase II's results to produce a set of characteristics and traits.

The identified traits were compared with clinical rubrics and definitions from the literature review of this research (DSM-5 2013; ICD-11, 2018). In summary of what inspired and influenced the synthesis of the comic... these traits were noted in participants, and for that reason were utilised to synthesise the main character in the comic. All traits were neutral in their representation, sourced from the transcript of each participant in the sample – both characteristics that were positive and negative were deemed equally as important. This was crucial to ensure that the representation of the character was realistic. Traits included:

- Insistence on sameness
- Sensory reactivity
- Insomnia
- Sensitivity to light

- Stimming
- Systematic thinking
- Social masking
- Difficulties in communication
- Substance abuse to find relief
- Hyperfocus
- Comorbid conditions of depression, and anxiety
- Possesses cognitive empathy, although may not have affective empathy
- Hypervigilance
- Mind blind/socially oblivious
- Prone to meltdowns and shutdowns
- Bluntness/radical honesty
- Suicidal ideations
- Executive functioning issues

With Phase I and Phase II stages of testing concluded, the next section describes the creative synthesis of the comic – that is, the method of creating the work and the justification for the elements it synthesised.

Creative synthesis (Phase III): creation of the comic

After Phase I and Phase II concluded, the creation and production of the creative means of address of this research inquiry, the comic, began. The resulting creative outcome contains 60 pages of narrative, drawn predominantly in black and white monochrome, with small additions of red and blue. The comic was also designed to be fluid between print and digital modalities, to increase its accessibility for readers. Included in this was the work being published online for free. The comic in full can be found online at www.merylkeioskie.com.

The comic was intended to be mature in its themes and presentation, due to it being aimed at an audience of 18 and older (the target demographic being between the ages of 18–30).

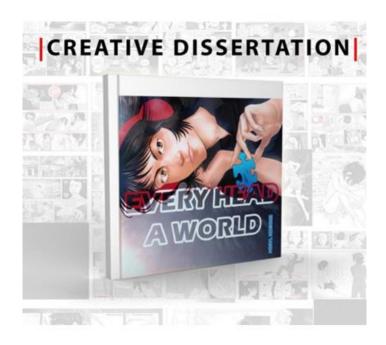


Figure 2: The comic that was created to address the research topic and question posited. Title: *Every Head A World*, 2023.



Figure 3: Pages 28 to 29 of the comic show a mundane situation in Stuart's life playing out. This was purposely done to communicate the lived experience of the character to the audience.

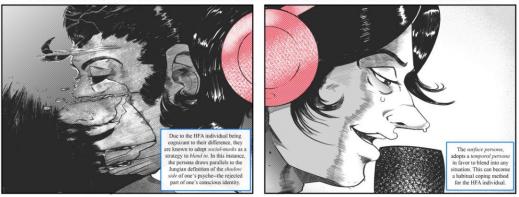
The narrative of the comic was inspired by the "slice of life" narrative technique (Lehan, 2005; Rusca, 2012; Suvilay 2018). The narrative technique was chosen due to the strength of the device, through its allowance of a flexibility in the structure of the plot. The main character in the comic, an amalgamated result of all data, Stuart Yoshihiro, acted as the central driver of the plot within the comic.

This was to ensure that his depiction was as authentic to one individual's ASD experience as much as possible – given the limitation that one depiction of ASD cannot speak for the entirety of the ASD populace. Stuart's depiction is restricted to the higher functioning aspect of ASD only for this reason (DSM-5, 2013; ICD-11, 2018).

Stuart's experience was written to be demonstrated in a two-fold manner: externally, with how he existed in his immediate physical surroundings; and internally, with his inner monologue and lamentations. All data generated the composite of the character's creation. These are the resulting traits:

- Sensory reactivity/dysregularity
- Insomnia
- Stimming
- Social masking
- Difficulties in communication and mind blindness/social obliviousness
- Substance abuse as a coping mechanism
- Hyperfocus and insistence on sameness/systematic thinking
- Comorbid conditions
- Hypervigilance and sensitivity
- Meltdowns and shutdowns
- Executive functioning issues

🕽 A PANORAMIC HAZE, SHOULD FALL UPON DESOLATE RHYMES OF HER FOOTSTEPS, TETHERED TO THE ABSENCE OF HER TENDER FACE... 🎜



\$...O' THE DAYLIGHT, AS IT CUTS THROUGH THE VISAGE OF A GOLDEN BOY... WHO LEANT ON HIS GLORY DAYS. ₽

Figure 4: Panels seen on page 24 of the comic. Here informational textboxes coloured in blue show clinical definitions of ASD, another device for communicating the condition to the reader.

Sensory reactivity/dysregularity

Participants (Phase II) remarked that they would get drained by crowds, due to sensory overload associated with a variety of sensory dysregularities – this same experience is illustrated for the character.



Figure 5: Pages 30 to 31 of the comic. Here Stuart is illustrated to be experiencing a variety of manifestations of sensory dysregularity.

The symbolism of crossing out the faces of individuals in the public crowds shows his aversion to looking at their faces and, by extension, eyes.

Insomnia

All participants in Phase II interviews mentioned that they had issues with sleeping, therefore this was depicted in the comic.

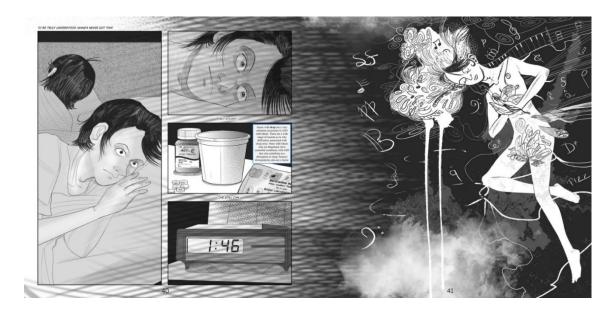


Figure 6: Insomnia.

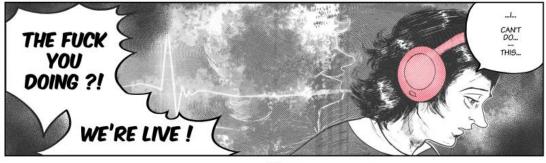
The scene is also accompanied with a caption that further provides context for sleep issues in ASD individuals.

Stimming

Stuart as a character is inferred to supress the need to stim, due to a fear of exhibiting any form of his condition to anyone. Stuart stims on two occasions in the comic (pages 32 and 33). One of those manifestations is mimicking piano playing (fig.9), which is a reference to one participant from Phase II, who is a musician. Stuart was designed to be an 'artistic' character to challenge stereotypes.

Social masking

The portrayal of Stuart's character is of a person who feels as if they are the 'other'. This coincides with the data from Phase II interviews, where participants shared their experience of social masking (DSM-5, 2013). Through his social masking, the character is also depicted as exhibiting a clear self-awareness.



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Figure 7: A panel from page 22 of the comic. The hint of Stuart's alter-ego, a representation of his "social-mask" is foreshadowed here. This takes place during a scene where Stuart can't perform at a gig, due to a variety of factors.



Figure 8: Page 58 of the comic. During his meltdown, Stuart meets the mental construct of his "social mask", the idealized self.

Difficulties in communication and mind blindness/social obliviousness

Stuart's difficulty in articulating with words whilst communicating is referenced from the ASD rubric of diagnosis, Criterion A "Social communication" (DSM-5, 2013) – this was triangulated with data from Phase II where the sample demonstrated that they were challenged in this domain (fig. 9).

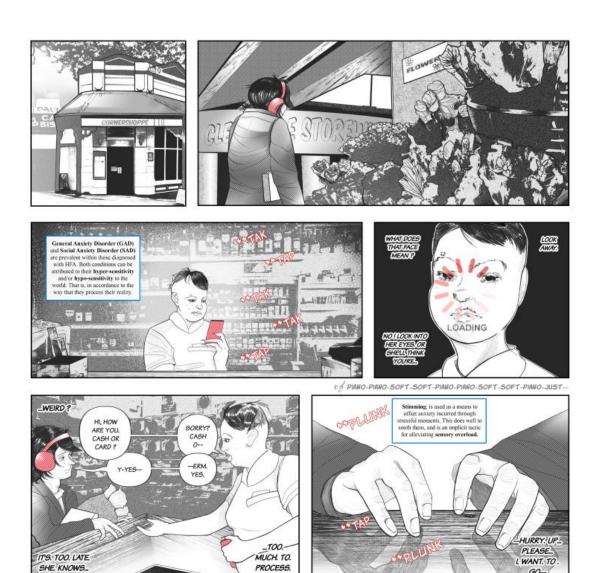


Figure 9: Stuart is interacting with a store clerk. Here his inner monologue reveals his issues with deciphering emotion, maintaining eye-contact, processing phenomena, anxiety, and communicating.

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Substance abuse as a coping mechanism

As observed in two participants in the Phase II interviews, alcohol as a coping mechanism is utilised for anxiety. This reality isn't depicted in ASD mass-media representations at all.



Figure 10: Here the supporting characters show concern over Stuart's reliance on alcohol. Stuart is also seen to have a cigarette in hand, giving a subtle hint of another coping mechanism of his.

Hyperfocus and insistence on sameness/systematic thinking

Stuart exhibits this trait on pages 18 and 19 of the comic. Additionally, the character is depicted to 'hyperfocus' as a means of offsetting stress; this is illustrated on page 34 with Stuart saying "I'm drained... I need to write".

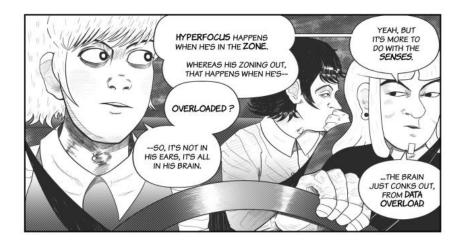


Figure 11: A panel from page 19 of the comic. Here supporting character Andy explains to the foil character, Colin, that Stuart is not ignoring them... rather, he is hyperfocusing.

Comorbid conditions of depression and anxiety

Findings from the literature review showed that the occurrence of comorbid conditions in ASD individuals is quite high (DSM-5, 2015; ICD-11, 2018; Silberman, 2015). Corroborating this, all participants in Phase II of interviewing mentioned that in their lived experience of ASD, they experienced comorbid conditions (fig.12).

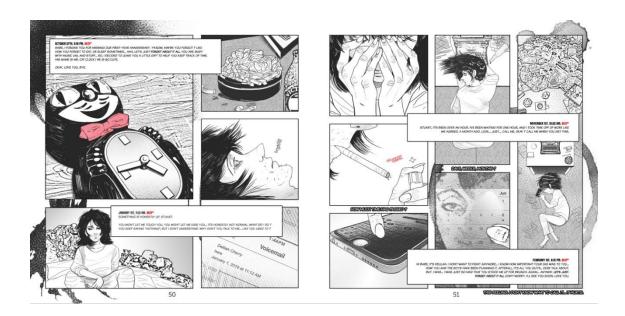


Figure 12: After his girlfriend leaves him, Stuart's symptoms of depression and anxiety are exacerbated. This isn't explicitly written, but rather inferred visually. This is further demonstrated through surroundings, reliance on substances, and a dishevelled appearance.

Hypervigilance and sensitivity

Stuart, as per the cognitive profile of the ASD individual, exhibits a hypersensitivity to the world. This hypervigilance was also found among the sample of individuals interviewed during Phase II.

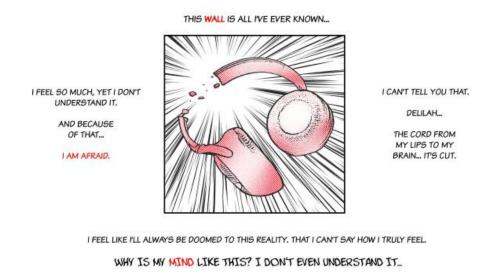


Figure 13: The entire sample from Phase II utilise headphones as a means of coping with sensory dysregularity in public spaces. Stuart does the same throughout the entire narrative. Here, he laments about the catch-22 of using them as a coping mechanism.

Meltdowns and shutdowns

The depiction of Stuart's meltdown is not overtly physical in its representation... and is rather, artistically represented through fantastical elements. The focus of its representation is in the 'despair' the ASD individual goes through in feeling as if they are losing control. This is drawn from the researcher's own experience in being diagnosed with ASD, as well as accounts from Phase II interviews (fig.14).

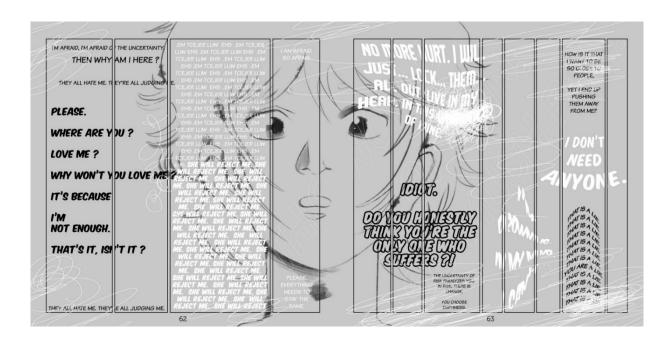


Figure 14: The "meltdown" sequence which occurs for the character. Here, he confronts his own insecurities in the space of his own mind.

Executive functioning issues

Page 39 exhibits a stylistic explanation of executive functioning by way of supportive character Andy's understanding of it. Within the sequence, he is attempting to educate problematic character, Colin, who assumes Stuart is faking the condition.

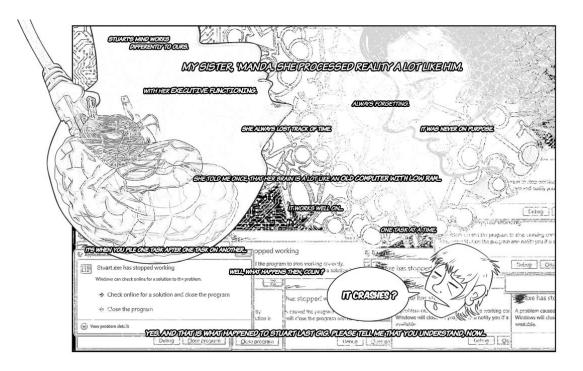


Figure 15: Parallels are drawn between a computer and Stuart's mind. Andy describes, by way of his sister's diagnosis, that Stuart would do well to focus on one thing at a time, lest he fall victim to crashing like a computer.

Data evaluation: Phase IV, testing the comic

After the creation of the comic, interviews were conducted. Twelve participants were interviewed – feedback was recorded and transcribed. This phase references phenomenological heuristic inquiry, through employing both stages of "creative synthesis" and "validation". This stage combines elements of research into a creative result to communicate the findings with others. The validation stage is a process within phenomenological heuristic inquiry which seeks to then both measure and record the progress of the result of synthesis, to seek validation of its efficacy from others (Patton 2015). These are the questions this phase sought to address:

- Did the comic address the aims and objectives of the research?
- Did the comic enhance understanding and awareness of ASD?
- Were any gaps within this research inquiry revealed through this process?
- Are comics effective in communicating and bringing more awareness and understanding to a serious topic matter, such as ASD?

A week before participants were given the comic to read, they were instructed to answer preliminary questions through email. The questions gauged each participant's knowledge of comics and ASD, respectively. This was to discern whether the work would impact their understanding of the condition. Of the participants, 66.6% answered that their knowledge of ASD was very limited, whilst 16.6% claimed that they possessed a high level of understanding of the condition. When it came to comics, 25% of the sample said that they had no familiarity with the medium at all, while 50% believed they had a strong familiarity with it.

After participants answered these questions, they were given the work to read for one week. After week had passed, each participant was then interviewed. The main findings were that comics as a medium can communicate serious topics, whilst enhancing the understanding of readers. This demonstrates that the objective of increasing awareness of ASD through this medium is indeed possible. This is evinced through the positive reception of the comic, provided by 100% of participants – who detailed that the work enhanced their understanding of the condition in a variety of ways. One participant stated "...I think it has managed quite well, and personally I found it very enlightening, if you will. It affects you quite emotionally, as well." They also said, "Because I basically knew nothing coming into it. Now, I know quite a lot more... That I didn't know that he had sensory overload." As well as, "...it's really good to inform people when they read it... you'll be able to understand what goes on with their minds, especially when they are in a situation where they have to be, when they are with themselves, yeah, like Stewart with himself..."

The positive reception for the comic was overwhelming. Certain themes presented themselves through the data, such as:

- Theme 1. All the participants said "yes", to recommending this work to others.
- Theme 2. The comic increased understanding of ASD for the participant.
- Theme 3. Some participants appreciated the art of the comic and its power to add and support communication of the work.
- Theme 4. The comic informed them of the inner world of an individual with ASD, as well as some of the behavioural manifestations of the condition.

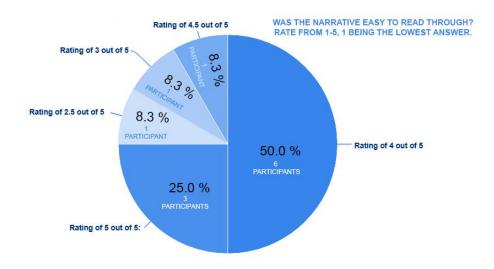


Figure 16: Question one of Phase III interviews for testing whether the comic works.

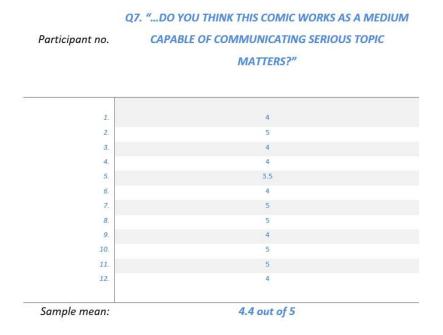


Figure 17: Question seven of Phase III interview, querying about the efficacy of comics.

Conclusion

In summary, this research demonstrates that comics are a medium capable of educating and informing audiences on a serious topic. Whilst ASD diagnoses are increasing in Australia, this is also a global phenomenon. Diagnoses are anticipated to increase more with developments and innovations in diagnostic measures, as well as an increasing awareness of the condition. Yet the challenge remains of more diversity in depicting ASD, which isn't inherently stereotypical. This can only be managed through more contributions toward this research inquiry by other individuals

who can offer a variety of perspectives as per their lived experience. We should aim to portray ASD through a basis of both lived experience and clinical rubrics, rather than relying on the former to constitute the totality of ASD experience. Additionally, the medium of comics presents a plethora of research opportunities. The utilisation of comics as a medium in the academic context can provide further support to validating the medium and challenge pre-existing stereotypes of its poor status. There are always many other uses of the medium that are indeed worthy of further inquiry.

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