The experience of anxiety and courage through an autistic lens:

An Autoethnography

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A thesis submitted in partial fulfilment of the requirements of
Sheffield Hallam University
in consideration of the degree of Doctor of Philosophy

Feb 2024

Candidate Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.
2. None of the material contained in the thesis has been used in any other submission for an academic award, with the exception of a clearly marked excerpt from my previous master's dissertation, which is used as an illustration of previous work.
   Name of Award: Masters of Applied Positive Psychology
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   Excerpt: Personal Account of Hope and Fear (4.5 Excerpt from Master's Dissertation)
3. I am aware of an understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
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Award	**PhD**
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Abstract

This thesis utilises autoethnography to explore the experience of anxiety and courage through an autistic lens, and it does so to gain a deeper understanding of their manifestations and mechanisms within my life, as an autistic individual. Anxiety has been noted to be prevalent within autism, and research has recognised that anxiety within autism presents in ways that differ from the non-autistic population, although the research is scarce, statistical, and largely based upon the medical model of autism and disability.

The majority of support for anxiety is either pharmaceutical or based on talking therapies, both of which I have experienced during my life. Gaps have been identified within the expertise of talking therapists in relation to knowledge of autism, and the effectiveness of existing therapeutic interventions and modalities for autistic individuals has been challenged. The appropriateness of places and spaces used within the application of the aforementioned modalities have also been challenged - on the basis of failure to consider and support the sensory differences that are commonly found within autism. In addition, the current anxiety questionnaires, such as the GAD-7 (Generalised Anxiety Disorder seven-point questionnaire) require a level of introspection and self-awareness that are not always accessible for autistic individuals. With this in mind, and through this research I have embarked upon deeply qualitative exploration of my own experience of anxiety and its presentation, together with an exploration of courage, and I do so through my own lens, an autistic lens. I am utilising the method of autoethnography as the researcher and participant within a truly emanciparticipatory paradigm.

This research also considers courage as a potential antidote for anxiety within a variety of contexts, and domains. It has been noted that there is a lack of courage research both generally, and specifically within the context of autism, despite the apparent links between anxiety and courage. The method of autoethnography, whilst established and accepted within qualitative research, is still rare, with few exemplars to be found within the social sciences and humanities. It is acknowledged that the formation of an identity, together with self-advocacy is an area of difference and challenge for autistic individuals, and yet autoethnography as an approach, for me, has clearly demonstrated that it holds a powerful ability to increase levels of self-advocacy and self-explication, which are fundamental in the formation of a stable sense of identity, personal power, and self-esteem.

In loving memory of my Mum & Dad

Michael Anthony Coker

Marion Irene Coker

You have not been here on this journey, yet you have been with me every step of the way!

Acknowledgements

I owe my deepest gratitude to Professor Piers Worth, who has been a lighthouse in a sea of self-doubt for me, and the catalyst of my academic journey. Sarah Lee, a protector, organiser, executive function assistant, rock, and wonderful human, I thank you!

For my wonderful Supervisors, I offer tremendous gratitude.
Dr Luke Beardon, your humour, advice, and support has kept me going, when I couldn't find traction, and you have provided inspiration and mentorship.
Dr Penny Furness, your insights and kindness have always come at the right time, and your attention to detail has taught me so much.

Professor Nick Hodge, for your belief and words of encouragement in the early days. You have my gratitude.

Claire Jenkins, always a rock and oracle of knowledge. You have helped more than you know. Caron Carter, and Karen Daniels, also huge thanks for the times that you responded to my plight.

Key Terms

- I have chosen to refer to myself as an autistic individual within this research, which aligns with identity first language.

- Allistic Individual, predominant neurotype, neurotypical: I have used these terms within certain contexts in this thesis, and they describe an individual without autism.

- Autism is my preferred term, although within the thesis, when and where referring to medical diagnosis, the terms autism spectrum disorder may be used (ASD).

- Neurodiversity and Neurodivergent have been used to refer to a group, or context and an individual with a profile that is different from the typical presentation in relation to thinking, interacting, and making sense of the world.

- The terms a-typical are used in contrast with neurotypical, and whilst this is not my preferred term, within my research – where appropriate this language may be used.

- Within this thesis, I often use first person language, and where the terms “we” and “us” are used, it may relate to autistic individuals, which is clear within the context of the writing. The term “we”, is also used as part of rhetorical and persuasive writing from time-to-time within this thesis.

- Autoethnography and auto-ethnography are used within research, and I have chosen the former. I have also referred to the term “autie-ethnography” within this thesis, which described a uniquely autistic view of self and the world.

- Participatory and emancipatory research are terms used frequently within this research, together with the term emanciparticipatory, which joins the two. Participatory in the context that I use it, refers to the extent to which the participant is included and able to influence or lead the research. Emancipatory, is a term that I use where freedom is given to the participant, and, or researcher to break the chains of convention, or create freedom and positive change societally.

Contents

Chapter 1: Introduction

1.0: Introduction

This thesis explores the subjects of anxiety and courage, as experienced by me, an autistic individual, and it does so through autoethnography. Anxiety has been discussed within autism since Kanner and Asperger's Initial accounts and is now considered to be a common comorbidity with uniquely autistic presentations (Kerns et al., 2014). Deficits in social interaction and communication, together with fixed and rigid thought patterns, and behaviors, define autism within the diagnostic criteria. Within this medical model, sensory, emotional, and cognitive issues are frequently discussed (American Psychiatric Association, 2013). The prevalence of anxiety has been noted, and include the etiology (e.g.,Bellini, 2004), together with the exploration of treament e.g., Reaven et al., 2015). According to White et al., (2013) there is a lack of exploration of anxiety within autism at a qualititative level, with self-reports usually being the exploratory mainstay. Within the general population, these psychometric questionairres have long been in operation according to hope et al., (1999), and their validity in respect of autism has been challenged on multiple levels by Sterling et al., (2015), who suggest that a combination of the difficulty that autistic individuals may have in respect of recognising internalised symptoms of anxiety, together with parental and societal barriers may render such an approach ineffective.

Autoethnography may present a way to gain a deeper understanding of the experience of anxiety and increase levels of self-understanding that have been described above as missing. As a method, autoethnography requires rich and thick

descriptions of life events through the lens of the self, and it involves deep emotional unpacking. Given the described nature of autism, which is often used as a trope for incommunicability according to Pinchevski (2005) and an organising metaphor for social isolation, according to Bettelheim (1967), attaining the required levels of introspection and self-explication to effectively utilise this method may seem to be an insurmountable undertaking. Autistic people have historically been considered to be “mind blind” according to Baron-Cohen (1995), and “masked by a cloud of social solitude” according to Greenbaum (2010). I strongly disagree, and I do have a voice, a mind, a heart, a yearning to connect. I experience fear every day, and yet I persist, which suggests that I am courageous, and arguably presented with more opportunities to demonstrate this than one who is not anxious. Autoethnography, for me represents the Yellow Brick Road for my cowardly inner lion - which will lead me to reclaim these things in the form of deep connection and understanding of self.

The method and methodology of autoethnography, is explored as a subject, and entwined within the fabric of this thesis. For many and according to Bochner and Ellis (2016) it is considered, to be somewhat unconventional as an approach, and not without criticism. Bochner and Ellis (2016) introduced “evocative autoethnography” as a methodology and “way of life” into the life-sciences, and Beattie (2022) proposes a symbiotic and non-linear approach towards autoethnography as method and does so in the spirit of emancipatory and participatory paradigms. This thesis is no exception, and perhaps pushes even further into the boundaries of the left field. With this in mind, some guidance may be

useful to the reader, in terms of what to expect. One of the concerns voiced, experienced, and acknowledged by Ellis (2016) is that of whether a method and methodology that embodies emotionality and subjectivity is sufficiently scientific. This is particularly relevant given that within the approach that Bochner and Ellis (2016) advocate for, which emphasises passionate and evocative writing that examines emotions "emotionally" through introspection – essentially opening emotional dialogue with the reader. According to Sparkes, 2000, p.21) *"autoethnographies are highly personal accounts that draw upon the experience of the researcher for the purposes of extending sociological understanding"*.

Laslett (1999) made the assertion that it is within the intersection of the personal and societal, that a new vantage point is acquired from whence a new contribution to social science comes. The author goes on to suggest that personal narratives have the power to address many theoretical debates, including the macro and micro linkages; structure, agency, social reproduction, and change, which have been suggested to be a central outcome within the auspices of emancipatory research. Within conversations, Bochner and Ellis (1994) discussed a blurring of boundaries between social sciences and humanities, and they suggested the term "emotional sociology". The concept of stories within stories, and unapologetically inviting readers into your life and experiences in a visceral way, as indeed Ellis (1995) embodied when writing about a difficult experience of being a caregiver. As a reader, who has not had such an experience, the saliency may be limited by the lens of the viewer, however evocative the story may be, and yet when one has had such an

experience, as many have – the reader may find a level of solace through the sharing of a comparable experience and feel a level of being witnessed. I posit that there is an argument for the educative nature of reading the stories of others, and this is particularly relevant for those who may not be autistic – where they work with, support, or research within this area.

Whilst there are well-developed theories advocating for the utility of autoethnography, there is less guidance on how one performs this as method. Bochner and Ellis (2000) suggest that personal narrative is interchangeable with autoethnography, whereas others suggest that it is a means of linking one's experience to the literature through the process of analysis (e.g., Holt, 2001; Sparkes, 1996), which is supported by Muncey (2005) who considers the power of autoethnography to criticise and reflect upon the extant literature on a topic of personal significance. Duncan (2004) suggests and supports an approach a rigorously conventional as any other form of enquiry, though they advocate for a linear approach to selecting method and analysing data.

Frank, (2016) is a proponent of telling a story within autoethnography to personally connect with the reader within a process of truth-telling and being witnessed and suggests that this is more important than analysis. It remains that there is considerable latitude on how one embarks upon autoethnography, though I align with Beattie (2022) within her paradigm of symbiotic autoethnography, where one

does not have to choose as side, but rather where one moves with the flow in harmony with the moment, context, and subject.

Within this thesis, you will find scholarly material that has been curated, critically analysed, and synthesised into meaning. You will also find stories, poetry, and art, which are used to access and unpack my feelings. They form part of my method, which is explored in more detail within the method and methodology sections of the thesis. In places, you will hear my voice as the narrator of my life as I remember and unpack experiences of anxiety and courage and do so with deep introspection. At times, my lens and voice change as I remove myself from the experience and lean into the academic process of unpacking and analysing my experience. You will encounter marginalia and reflections, and sometimes these may present out of time, and this is because they may be an afterthought, a deeper insight, or even something that contradicts where I was in terms of emotion, thought and cognition at the time of writing.

The concept of marginalia, which for some has been considered to be “non-essential” items and notes made in the margins of books and papers as they are handed down through the ages, and yet there are some famously important works written in the margins owing to the “scarcity of paper” at the time of creation – as seen anecdotally within the accounts of Voltaire who composed a book in the margins whilst in prison, and within the final words of Sir Walter Raleigh who reportedly wrote a personal statement in margins prior to his execution (un-referenceable and unpublished). My

mind considers the concept of marginalisation and incarceration within the context of my research and the darkly playful association that my mind has made. There are many things that can be discovered by readers as their knowledge and understanding is increased by the successive handing down of notes in the margin. For me, the use of marginalia relates to reading my own work as an outsider. Some of the reflections have drawn me in and drawn so much from me that I have, at times become deeply immersed, and perhaps at times lost within the process. Often when I read back through the work, I see more, and have further insight. These moments are labelled as marginalia. I almost imagine myself reading the book of another, and scribbling notes in pencil within the margin. In places, the lines between the academic, introspective, and reflexive are clearly identifiable, sometimes they blur. There are spaces for the reader to interpret and find meaning, and these parts may appear abstract to the scientific mind. Perhaps you, the reader will scribble down your own notes in the margins of the page, or in the pages of your own story.

My hopes for this thesis are that for those reading who are autistic, perhaps you will find deep meaning and connection with self, and relatability towards the experiences unpacked. I am hopeful that there may healing, and feeling of being witnessed and understood, and perhaps my voice within the experience of anxiety and courage can be something that resonates. For those reading where autism has impacted your life through a close connection with an autistic individual, I hope that there may be epiphany moments that make a difference, and I hope that there are moments of humor and levity - in addition to the many darker ones recounted within this thesis,

and often experienced in life. For those reading from a place of interest as researchers and professionals within the field of autism, I hope that your lens widens, and that you will obtain lived experience, albeit vicariously, and gain deeper insight into the life of an anxious autistic individual.

1.2 Why Anxiety?

As an individual, I experience considerable anxiety - so much and so often that I cannot recall a time before “anxiety”. I have oft been described as demand avoidant, with a tendency to “run away” from challenges and new experiences, avoid people and even hope-oriented goals. These experiences and behaviors are commonly observed within autism, though thus far within research, there no firm resolution on whether anxiety and demand avoidant behavior are a feature of autism itself, a product of the environment, (social or sensory) or elements of all of these things. It is also noted that much of the research has been conducted and led by non-autistic researchers, with a lack of lived experience (Green & Ben-Sasson, 2010).

As indicated previously. my experience of anxiety and courage will be explored within this thesis through my own lens using autoethnography, and I will refer to this as an “autistic lens” often from this point. Despite my anxiety, there are occasions that I can recall when I have somehow, or from somewhere found the courage to stay or move forward, and I consider that understanding this, in terms of the process and mechanics, may be useful in creating accessible resources to overcome anxiety in its myriad of forms. In respect of this anxiety, I have often found myself wondering

how much of it directly relates to my autism in terms of the way that my brain operates, or whether the main contributor is my experience of life - including how I learn and have learnt, and how I assess risk (notwithstanding that there may be other and, or additional factors).

As I unpack the many contributors and variables to anxiety, there is the perspective within neuroscience, in terms of the exploration of the parts activated within the context of fear and anxiety within autistic individuals, and even the psycho-biological and chemical differences within the operation of the limbic and sensory systems, which have been linked with elevated levels anxiety that commonly occur within autism (Bauminger et al., 2008); (Kessler et al., 2012) and (Baron-Cohen et al., 2000). There is also the perspective within cognitive psychology – in terms of thought processes and patterns, attention, memory formation and heuristic learning. The domain of sociology often presents some salient ideas which may provide some insight into one of the areas of challenge, namely social interaction, and communication – which is cited as an impairment domain within the diagnostic criteria for autism, and noted by Gaigg and Cornell (2018) who go on to comment that the experience and understanding of emotion itself, as described within the concept of alexithymia, suggests that cognition and emotion operate differently within autistic individuals.

1.2.1 Margin Note: Anxiety for me

Anxiety, for me is a daily battle, and my experience of treatments, is that they usually focus on pharmacological and talking therapies. Approaches based on increasing

levels of autonomy, self-advocacy and self-efficacy are scarce, and for autistic individuals, we often rely upon stumbling across soothing moments, people, activities, and solace. I have found these moments from time-to-time, and they have helped me. I have regularly found them within special interests, and yet these moments are elusive. My most reliable treatment plan comes in the form of avoidance, and yet despite its effectiveness, I am cognisant that I miss out on a considerable amount of "life" through my avoidance, and that avoidance seems to galvanise the anxiety and provide fuel for further anxieties to burn. Finding the sources of anxiety and unpacking them, I hope will bring a depth of knowledge that is missing from research and from my own understanding of my anxious self.

1.3 Why Courage?

A link between courage and anxiety has long been established according to Lopez, (2007), and anxiety has been researched and is cited as an established comorbidity within autism (Autism Research Group, 2018). Anxiety as a state, condition and even traits have received considerable attention within research in terms of its typical and disordered presentations (Kerns et al., 2014; South & Rogers, 2017; White et al., 2010). Exploration of anxiety has included antecedents, mechanisms, treatment, and reduction modalities, and yet despite the relationship between anxiety and courage, the latter has received comparatively less attention (Lopez, 2007).

Research has linked the concept of anxiety to the concept of fear, although the taxonomy is often debated (Clark & Watson, 2006). The descriptors include phasic vs sustained fear, and it is within this that the impact and purpose of the two are

considered to diverge (Davis & Walker, 2010). Within their research, Davis, and Walker described fear as a generally adaptive and functional state of apprehension that begins and dissipates rapidly once the threat is removed (phasic). Anxiety was described as something that is elicited by less specific and predictable threats, or by those that are either physically or psychologically more distant. It was supported that anxiety is a longer-lasting state of apprehension described as (sustained fear). Given the establishment that low levels of predictability is associated with the formation of anxiety, there is the consideration of the link between autism and predictability in terms of this being a requirement for a significant number of autistic individuals, and an area of challenge owing to difference in executive function, social deficits, and adherence to routine (Kerns et al., 2014). Unpacking courage to the same level as anxiety, and in particular, exploring its presentation and activation within autism may lead to some useful insights into courage resources and coping strategies, and perhaps shift the lens from which autistics are viewed into a positive vista that honours the courage that many find every day.

Rachman (1984) acknowledged that the existence of fear and perceived risk was a fundamental component within the experience and activation of courage and went on to describe a key component as persistence despite the presence of fear. Given the propensity that I have as an individual to experience anxiety and fear within everyday life, and the established links between anxiety and autism, I consider the value in exploring courage as an internal resource that has the potential to increase levels of persistence in the presence of fear as described by Rachman.

Courage as an antidote or inoculation against the toxic disease of fear could be a vital resource, and something that has potential to be developed for autistic individuals, and for this reason, together with its relationship with anxiety, research into courage forms a considerable part of this research, and arguably is demonstrated within the process.

1.3.1 Margin Note: Courage

A link between anxiety and courage has been established, together with links between anxiety and autism. Courage itself has had less attention generally, and within the scope of autism – there is little research to be found, despite the role and utility of courage in attenuating fear in various forms. Additional issues have been raised in terms of the method of qualitative research used when gathering data from autistic individuals - where self-reporting and self-explication are fundamental, and yet may not be easily accessible for autistic individuals. This thesis explores the relationship between courage and anxiety in a deeply qualitative way over time, and through an autistic lens".

1.4 Why Autoethnography?

I posit that in order to understand where, how, why, and when I am anxious, and how I process this, and, at times manage to conquer it, perhaps through courage, that an exploration of many different domains, contexts and life-stages, such as school, home, work, social, and even the domain of identity, together with the unpacking of many different experiences within these domains is essential. My experience of "work" for example, suggests that not all workplaces are equal, inasmuch that some have been supportive, and on the whole pleasant growth-

inducing experiences, whereas others have been an anathema to me. Some have even provided both experiences on the same day, which suggests that a simple taxonomy and labelling on a macro level simply won't suffice. That the domains of employment, relationships and wider social contexts have been a problem for me is an understatement, and that they present challenges for other autistic individual is well-noted within research (Griffith et al., 2012).

Further to this, I recently encountered a new model of the autism spectrum within the work of Farahar, (2021) which emphasis this point, and encompasses the idea of different challenges on different days, and even within the same day, and it did so by creating a three-dimensional model of the original autism spectrum model, which was described by Wing and Gould (1979). This emerging model has been described as a *"Rainbow Sausage"* by Farahar, and this approach allows a new dimension to be considered in the form of not just "what and how", but "when". This model is playful, and some would say that its momentum lies within social media as opposed to within academic journals, and yet its resonant validity within the autism community has created a new paradigm. This model does not seem to have been published, and only appeared briefly within my social media feed, and whilst it made an impact upon me, I am unable to provide a reference to the source at this time.

Understanding emotion has always been problematic for me. Grading emotions, accessing them, and regulating them has caused issues for me throughout my life. This experience has been described within the concept and phenomenon of

alexithymia, which is not a medical diagnosis, but something that was coined and observed by Sifneos (1973), who went on to explore the phenomena within subsequent studies which considered issues associated with alexithymic characteristics and illness (Sifneos, 1975). The term was derived from the Greek “a” lack of and “lexis” in relation to words, and “thymos” for emotion. Within his research, Sifneos observed patients with psychosomatic illness and observed a frequent inability in describing and articulating emotions, and this same phenomenon was also observed within patients who had experienced Post Traumatic Stress Disorder (Sifneos, 2000). Unlike Autism, alexithymia has not settled within a steady classification within psychiatric nosography.

The research from the medical perspective, and from the social perspective has yet to resolve and settle upon a causal agreement of the origins of anxiety relating to autistic individuals, though there is considerable evidence to suggest that there are significant rates of anxiety being reported by autistic individuals as compared to allistic counterparts (NAS, 2017). Thus far within research on autism and anxiety, we have arrived upon little more than a general understanding that for autistic individuals, there is a statistical significance relating to the frequency that anxiety and anxiety disorders occur. In addition, there are several common domains from where anxiety arises, including: Sensory, Social, Psychological, Task-related, and Communication (Humphrey & Lewis, 2008; see also Trembath, Germano, Johanson, & Dissanayake, 2012). The research referenced above has been interpreted from the words of individuals with autism describing their experiences,

which were collated into macro and micro domains arising from situations as experienced; notwithstanding that there has been an interpretation and translation by the researcher, and that the process of uncovering has been reliant on interview and self-reporting.

From my own perspective and having experienced issues interpreting and understanding emotion within myself, I believe that autoethnography as an approach can effectively remove the “middle person”, and as such avoid losing important data, personal growth, and evolving understanding of self, over, and through time. Autoethnography as methodology and method, provides a symbiotic approach that removes boundaries and barriers for me, as described above, and when done well, as described by Ellis (2009), it silences the critics who have attacked the methodology, and builds bridges between the data and epiphany moments that are often described within autoethnography.

Much of the narrative and research into anxiety and autism has been conducted and analysed within the perspective of polyvocality, which is relatively new as an ethical component and feature of qualitative research according to Bakhtin (1981) who suggests that within polyvocality, a “dialogical imagination” is formed. Anderson (1989) builds upon this by stating that “multivoicedness” can represent and facilitate a socially constructed and organised ideology that has the potential to empower and legitimise or silence and de-rail individual voices. Within the context of autism, the relevance of this cannot be overstated, particularly when we seek to understand

seemingly simple constructs such as, for example the question of how one refers to oneself, as an "individual with autism” or an “autistic individual”. Society has suggested person first language, and yet this is becoming increasingly triggering. Should we allow the consensus to set the rules or are we allowing people to be individuals and take charge of how they refer to themselves within their lived experience.

The research is underpinned by its methodological paradigm, where the method itself is an important part of the research journey – forming part of the data. Ponterotto (2005) laid out a scheme and paradigm comprising of epistemic and ontologic thinking , axiology, rhetorical structure, and method, and this will form the contextual framework of my autoethnography. One of the defining features of this framework is the essence of the participant capturing an experience as intimately as possible. The analysis method chosen also must allow the voice and experience of the participant to come through without distortion and filtration according to Chown et al., (2017), and they go on to define participatory research as a “partnership”, whereby the decision making is shared between those affected by the research and the researcher.

I would challenge the extent to which an equal partnership is operating where there is often an imbalance of power and influence over the research design, setting of the research question/s and an evolving understanding and unpacking of the data. This imbalance of power within academic research often stems from the auspices of a

lack of equity and accessibility into the world of academia, and the desire to avoid solipsism in order to construct heterogenous models, statistics and data, and within this lies the potential to co-facilitate erroneous tropes, stereotypes and illusory constructs of identity (Allen-Collinson & Hockey, 2008).

There is a lack of participatory research, despite the PR claims stated within autism research, and noted within the paper cited above from Chown et al., (2017). Whilst the claims of “participatory research” are few, fewer still are the research projects that are truly participatory according to Jivraj et al., (2014), and this was borne out by a review where the research found that only seven out of the six hundred and thirty-six studies met the carefully curated inclusion criteria. Significantly, none of the “inclusive” studies originated in the UK, and of the seven, only two included autistic individuals as co-researchers. Study at university has been described as a hostile experience by Connolly (2020), who as part of a PhD thesis that embodied emancipatory and participatory research paradigms that explored the experience of autistic students within higher education and uncovered many barriers to flourishing within this environment. Within the research it was noted that autistic students were the most likely to fail at university, with many barriers being described within this emanciparticipatory research. Connolly went on to describe the feeling of alarm at this staggering statistic.

Autoethnography, for me is the gift that has the potential to give to others, even though it may not seek to do so explicitly within the research itself, yet others will

read it, and relate, or not, and even where the latter is true, I posit that when done well – it has the power to galvanise, polarise, unify and to disrupt. I have described my autoethnography as both participatory, and emancipatory, yet the distinction between the two is unclear to some - even though, from an etymological position, participatory relates to researcher “participation”, and within the context of autism, I posit that it relates to the inclusion of autistic individuals within the research at all stages from design to delivery and analysis.

In the case of emancipatory research, a level of freedom is inferred and a “setting free” from the Latin which originally related to the act of liberating a child from a parental authority. These days it has evolved to a person, or people in respect of giving social and political freedom, although I do have an aversion to the “giving” part and prefer to think of it as a returning of that which was stolen. These views are shared by Waltz (2010) who suggests that social change is a key component of emancipatory research, though not of participatory research. Stoecker and Bonacich (1992) view this as a component of participatory research, and Cornwall and Jewkes (1995) support this view and go on to suggest that knowledge leads to action as opposed to simply seeking knowledge for its own sake. They go on to suggest that there are multiple components including, but not limited to the technical, the values and motivations of the researchers, and their attitudes. Israel, et al., (2013) draws attention to the researcher and participant as a distinguishing factor of participatory research.

Whilst there is nothing inherently wrong with any of the views above, I posit that participation in research that is designed to create knowledge as opposed to change and action, is perfectly sound, notwithstanding that “new knowledge” could be argued to constitute a change in itself, and that knowledge acquisition is fundamental to research generally; forming part of the reason that research is conducted in the first place. Emancipatory research may not lead to change per se, but rather that a central component lies within the in the concept of freedom to construct, to do things differently, and in a way that plays to the strengths of the researcher, possibly breaking rules, and conventions along the way. I consider that the views of emancipatory research above are considering the “impact” of the research, which is one dimension, as opposed to the process and paradigm within the work itself. Where autoethnography is the chosen approach, the researcher is the central component regardless of whether the change impacts the world, and the intrinsic changes experienced by the participant-researcher are of at least equal importance to any extrinsic change.

My research is coming from the position of my own experience as an individual with autism, through my own lens. Qualitative research and debates around the ontology of autism, thus far, have been dominated by the medical model and the allistic researcher, with autism being considered as a disorder, condition, disability and issue to be solved and cured, and this is particularly true of anxiety as a disabling and oft medically treated comorbidity lying within the “mood Disorder” taxonomy (Happé, Ronald, & Plomin, 2006; Holin, 2017).

Within the context of disability discourse, there is little central agreement in terms of the language used, with many opposing and oft polarising viewpoints. An example can be found regarding the use of person-first language, together with the variation of that which is considered to be a disability from a societal or individual perspective (Fitzgerald, 2006; LoBianco & Sheppard-Jones, 2008). The power to shape the discourse and conceptualise disability has rested with professional organisations and with individuals who possess power and influence and have been described as the *"cognitive authority"* (Brittain, 2004). Whilst the medical model has contributed much, for example the widely adopted person-centred and strengths-based approaches that we have within the UK medical and care system, I posit that this approach is not person-led, though it may purport to be person-centered. The concept of person-centered approaches is a paradigm and doctrine within the UK care and support system (Skills for Health, 2017). The approach suggests a framework for best practice and is linked to other paradigms such as strengths-based approaches as laid out within the Care Act (UK Government, 2014).

The Care Quality Commission (CQC) Is the inspector for compliance and best practice within the UK, and thus far, all approaches refer to person centered, yet there is a growing discourse around the concept of "person-led" as being a different and more evolved approach (New South Wales Government, 2022). In essence the individual is empowered to take control of their own life, treatment and future – in contrast with having one's own future controlled by well-meaning and intentioned

professionals, notwithstanding that one should avoid simply choosing a side – lest we embrace a false dichotomy between these two models (Mitra, 2006).

1.4.1 Margin Note: Emotions

As an autistic individual, I am aware that access to my own emotions and states are spurious, and that my levels of self-advocacy are at times higher than my levels of self-efficacy. I am an advocate for person-led approaches, yet aware that they require both aforementioned things, together with an understanding of self in context. I enter into autoethnography as a method with a belief that the process can be trusted to uncover and unravel the self. I also consider the process to be a form of exercise relating to building this level of emotional insight. As an emancipatory paradigm, I believe that there is nothing else that provides such a strong exemplar of person-led approaches within research, and it is for these reasons that I have chosen autoethnography.

Chapter 2: Autoethnography

2.0 Chapter Introduction

This chapter considers the method and methodology of autoethnography, described by Bochner & Ellis (2016) as writing lives and telling stories. Given the nature of the subject, and particularly the nature of this thesis, which is an autoethnography, as opposed to the study of autoethnography, this chapter is the first chapter to appear following the introduction. The rationale is to give the history, context and discuss many approaches towards autoethnography in order to provide something of a compass to assist with navigation and understanding of the method and methodology, and where it fits within qualitative research as a wider discipline.

According to Beattie (2022) from the day that we are born, through our childhood and into our adulthood our lives are filled with stories. These stories emerge through many different mediums, including books, movies, pictures, icons, symbols, conversations, fairy tales, conversations and more. They contribute to the way that we make meaning – and link to our culture, values and in the way that we form our identities and view others. These stories unfold and continuously intertwine – becoming part of our narratives.

Autoethnography is a method that arose from ethnography within sociology. The term was first introduced by Heider (1975), within an ethnographic study of the Dani people. Heider referred to the “informant Self” when capturing the Dani’s accounts of themselves. Hayano (1979) followed on from Heider and was notably the first

researcher to refer to Heider's work in print, and equated autoethnography with insider studies and linked the term to becoming fully "native" within research yet separating the self from the process by making the distinction between autoethnography and self-ethnography. The concept of autoethnography has evolved, and according to Reed-Danahays' (1997) view, and autoethnography is now viewed as a way to capture the researcher's life experiences, and story, which etymologically relates to auto- (self) -ethno- (the socio-cultural connection) and -graphy- (the process of writing the story).

Autoethnography is not without its criticisms, which are discussed within the literature review, yet despite this, there are some compelling reasons to engage with autoethnography, according to Bochner and Ellis (2016), and they include: disrupting many of the norms of research representation and practice, working as a researcher insider with insider knowledge; moving cathartically through uncertainty, pain and many other emotions and senses such as anger and injustice; breaking silences and claiming ones right to write, and as Bolen (2012) put it "writing to right; and making work accessible".

A crisis of representation within anthropological research was noted by Heath (2012) who brought attention to the stark contrast and many omissions when comparing the data from field notes and diaries to the finalised publications in academic journals. Within the finished publications, there was often an absence of human stories, emotions, embodied experiences, and the position of the researcher within the

research. Emotions were often silenced within academic conventions, and as noted by Keller (1995) were labeled as feminine, with their importance relegated and considered to be inferior to the masculine approach to objectivity and rationality. Embodiment was oft seen as the enemy of objectivity, and yet, as noted by Conquergood, (1991) and Leder (1990), it would be difficult to honour, and research the experience of death and dying as an outsider, without including the experience of a dying person, and those close to them, and to disguise and dismiss this experience is neither good, nor ethical in terms of research. Pelias (1997) considered a related argument within the context of the experience of anxiety, and within autoethnographic reflections described the *"tense body",* the *"body in conflict"*, the *"physically and psychologically heightened body",* the *"momentarily speechless body"* and the feelings of *"inadequacy",* being *"torn", "doubled"* and *"wondering"* (p.39). Frank (1995) emphasises the inadequacy of sterile and impersonal prose in capturing rich lived experiences and suggests that many of these sterile conventions within research silence the voices of the marginalised and disenfranchised in a violent way.

This thesis is my story, process, and ontological position as I sit as a being in space and time, reflecting on the past, living in the present and looking forwards. Heidegger (1927, 1962) described the three temporal planes as "ecstases", and referred to humans as "Dasein", and the translations are various, though usually resolved and rendered as *"Being there".* This alternative contextualised label for human beings holds some significance for me inasmuch as that, whilst I am human, I am autistic,

and I have often felt other than human, and at times less than human. I am here, I have been there, to the past, and I am going towards the future as an autistic individual. Heidegger goes on to state that we are all *“being”* towards death and indicates that to be complete and authentic human beings, we need to continuously project our existence towards this finite horizon in addition to viewing our past and existing in the present. One of the most famous citations from Martin Heidegger's "Being and Time" is: *"The existential analytic of Dasein has shown that the world is not an object that can be encountered by an objective subjectivity, but rather that the world is that within which every subjectivity arises"* (Heidegger, 1962, p. 83). This poignant assertion challenges the one-dimensional positivist model of objective truth, and whilst empiricists have emphasised the interplay between the mind and the external natural world, rationalists have inflected towards the powers of the rational mind to reason and capture objective truth and reality (Bruner, 1991).

A brief history of autoethnography has been discussed within the chapter introduction, and as suggested, the word and concept have origins within ethnography which sits within the field of anthropology. The focus within anthropology is to study behaviours and cultural practices of subjects within their natural environment. Autoethnography removes the researcher and subject separation, essentially making them one. The paradigm of freedom and authenticity embedded within this is powerful approach towards research, and yet there has been considerable criticism, which will be explored within the literature review.

2.1 Participatory and Emancipatory Paradigms: Autoethnography, a General Literature Review

Autoethnography is an approach, that in elements has existed for a considerable time within anthropological research, and through the method and methodology of ethnography. Although there is a lack of comprehensive history relating to its evolution over time – it has been acknowledged within many publications, for example within Bochner & Ellis (2000) and Beattie (2022), who capture a detailed history of the term. Heider (1975), asked a question within a piece of ethnographic research, which was directed to a collective of individual Grand Valley Dani school children about their lives, and referred to their responses as autoethnography. The question was simple and wide, and was “what do your people do”? Heider referred to this within the context of the Dani’s “own understanding of their world”.

It wasn’t until four years later that Hayano (1979) became the first anthropologist to refer to and build on Heider’s work within print and made the inference that autoethnography equated to “insider studies” in which the researcher was indigenous, or became a full insider within the culture, community or identifiable group being studied. Hayano even made a distinction between studying the self through ethnography, i.e., self-ethnography and auto-ethnography, with the latter alluding to fact that the group writes its own story from its own perspectives, and that the individuals belong to an identifiable group.

It must be noted that although the term autoethnography was coined by Hayano, it has evolved much in the same way that the term neurodiversity has evolved from the point that it was first coined by Singer (1998). Since the term “Neurodiversity” was introduced, it has become a movement and paradigm shift within inclusivity and disability discourse, which is something that is acknowledged by Singer (1998). Bochner (2016) notes that Hayano had not imagined that autoethnography had a transgressive nature that challenged so many of the doctrines of science-based empirical research practices, and pushed the boundaries of ethnographic research, nor its capacity to allay fears and concerns over silent authorship, promote reflexivity, embrace moral, emotional, aesthetic and even political components. An example, as described by Bochner (2016) is that social scientists at the time were disinterested in the researcher being positioned within the text, beyond a few such as Henry, (1971); Harré and Secord (1972); Gertz, (1973) and Gergen (1973), who admonished the use of technical and academic jargon at the expense of the real voice and researcher reflexivity. Bochner (2016) goes on to mention this emancipatory paradigm was simply not on the radar in the 1970’s and that rather it was the function of getting close to the subjects that was a utility-based driver.

Whilst there is arguably more acceptance of qualitative research today, autoethnography surfaced in the 1970’s, and there were only a handful of authors and researchers making rumblings against the status quo at the time, railing against the hubris of technical jargon, the artificial nature of experimental studies, together with the spurious ethical components. A few began to advocate for thick and rich

descriptions of qualia (Gergen & Davis, 1985; Hafer, 2002; Heider, 1975). According to O'Donoghue (2007), whilst we now appreciate the power of personal language to represent one's own realty - as lived, and the place of the researcher and their voice within research, the positivist school of thought was still dominant in Post-World War 2 culture, and something that was noted within that period by Mills (1959).

Engaging with earlier works that many considered pioneered and embraced the concept of researcher immersion into the communities, researchers such as Nels Anderson (1934); Davis (1959); Hughes (1958) and Parks (1925), all of whom advocated for the researcher immersing themselves within the community that they studied – to ensure a deep connection to the research and the subjects, and yet they were still conducting the research as outsiders – though moving closer to emic research, as opposed to that which is entirely etic.

A crisis came in a considerable amount of criticism relating to the concept of scientific and objective truth when dealing with human experience within human research. The post modernists and post structuralists were railing against naturalism and truth through method, and opening the debate as to whether an objective truth and reality could be found within scientific method alone, or at all (Clifford & Markus, 1986; Denzin, 1997; Lyotard, 1984; Clifford & Markus; Rorty, 1982). In fact, it was Rorty (1982), who was one of the most notable philosophers of the time – who advocated for an approach to the social sciences that embraced the use of discourse, personal narratives and stories, as opposed to the positivist approach pertaining to testable

theories, empiricism and hypothesis. Even more than this, Rorty recommended an open experimental attitude that involved letting go of the attachments to the old and an embracing of the new, and a removal of the boundaries that separated art physics and poetry - where the divisions are merely institutional and pedagogical constructs (1990). The critiques emphasised the fact that empiricism valued neutrality and status quo, and beneath this there was a masking of domination and oppression. Rorty and others were moving towards embracing lived experience, and this can only be done fully, where all power is handed over to the participant, who is also the researcher, and where they are allowed to move freely through method, methodology and to even consider abdication from these things.

The impact and influence of story, together with its utility, are apparent to proponents of autoethnography and yet it has often been criticised for lacking in scientific rigour (Sparks, 2000). Atkinson (1997) questioned the appropriateness of utilising narratives of personal ilness and adversity as a vehicle to offer researchers privileged access to personal experiences, alongside criticising the use of autoethnography as a form of catharisis and personal therapy as opposed to critical analysis. According to Sprague (2010), this approach, which fits the model of positivism can be described a an "*epistemology of the fact*", where the researcher is emphasing that which is factual and emprical over and above honouring the experience of the individual and their own interpretation, and growth within research – however it may come.

Crotty (1998, p. 29) summarised the positivist approach – and claims by stating that "Scientific knowledge is utterly objective, and that only scientific knowledge is valid, certain, and accurate". These assertions would seem to critiscise the qualitative approaches, yet upon reflection, it is clear that when seeking to deeply understand individual qualia, this objective approach is best replaced with truly qualititive methods - where the aim is to seek to accept and cultivate the deep meaning that people bring to their behaviours and interpretations. According to O'Donoghue (2007) this is especially true where the researcher seeks to interpret and understand the human world and the subjective motives and intentions underpinning human action, and suggests that we must move towards a subjective methodology to capture and understand subjective data. This is particularly relevant where the output may relate to the design of a new approach, or modality to support individuals that are the subject of the research, especially where the aim is for it to be person-centred.

An exemplar of a person-centred psychological intervention or modality can be seen within the placing of power with the individual in order to build understanding, foster a sense of meaning, purpose and self-advocacy view a personal experience as something that is important and central to the process of assessment, intervention and outcome – honouring the canon that the less interference there is from the outside – the more emancipatory the method becomes.

The importance and impact of stories is noted by Bruner (2004), who suggests that our stories become us, and we become our stories. German philosopher Friedrich Nietzsche (1878) translated (1994, p. 238) wrote *"however far man may extend himself with his knowledge, however objective he may appear to himself – ultimately he reaps nothing but his own biography"*, and within these perspectives is the suggestion that stories and narrative hold considerable power to shape our identity (McIlveen & Patton, 2007).

Autoethnography can be conducted using a variety of methods that apply to data capture and analysis. One such approach is that of narrative inquiry. The concept of narrative approaches, which, according to Riessman (1993) emerged from within qualitative research to incorporate autobiographical stories, field notes, pictures, conversations, and life-experiences as units of analysis to provide understanding of how people create meaning within their lives. There are parallels relating to the above narrative methods when compared to the processes within autoethnography, although when considered as methodology there is a distinction that the individual belongs culturally to an identifiable group, which sets the context of autoethnography. Within the framework of narrative approaches, one can choose a multitude of methods, as described by Riessman (1993).

In the application of ethnography to research, an argument has been made whereby the research participant should join the researcher as a co-researcher – adopting an emic approach as opposed to one which is etic. (Bourke, 2009). This approach

makes sense from the perspective of the authenticity and depth of data, yet there is another argument relating to emancipatory and participatory paradigms. Placing autistic individuals at the heart of the development of research and practice is something that is seen within the mantra “nothing about us without us”, which although originally stemming from African disability debates, has been adopted by the autism community. Whilst this is catchy, and in essence a righteous maxim – full of rhetoric, many of the questions, methods, and research areas within autism research, are still chosen by, or led by the researcher and driven by a perceived societal driver, as noted by Happé et al., (2006). One way to ensure that this approach is more than lip service, is to make the autistic individual into the researcher by utilising autoethnography, and in doing so the freedom of method itself becomes part of the magic – where participants form the questions based on their own advocacy (Kemmis & Wilkinson, 1998).

According to Griffith et al. (2012), autistic individuals frequently feel that their voice isn’t heard, that views are often imposed on them by medical professionals, and that the “academic” voice is favoured above their own unedited voice. Autoethnography, by its very nature is person-led and empowering, inasmuch as the voice of the participant / subject merges holistically into the method and data. The researcher is also the participant / subject, and their story becomes a way of knowing, being and teaching (Bruner, 2004).

Ethics & Rigour & Criticism within Autoethnography

An argument within the area of relational ethics in respect of autoethnography is often made owing to the lack of distance between the participant and subject, given that they are one and the same. This challenge is made whereby there is difficulty in translating the research into sociocultural and political action (Ellis, 2009). A consideration within this research, is that much of the anxiety that I feel arises as a direct result of potential, or actual social interaction, and as such, there may be one or more others becoming involved within the story and its telling, and care must be taken to anonymise any recounted interaction.

Eakin (2009) posited that significant parts of identity are relational, and as such, our portrayal of others within an autoethnographic account amounts to a significant ethical challenge, which needs to be managed, and this is also suggested by Couser (2004), who asks the questions *"Is our freedom to narrate our own lives, restricted by the rights of others to privacy, and does the right to commodify one's own life, and self-entail, give the right to commodify others?"* (P.7). It is difficult to anonymise within autoethnography, according to Ellis (2009) who suggests that most autoethnographers publish in their own name, and therefore interactions with those close to them may be easy to identify. An example would be recounting an experience with a parent, or a neighbour, where even if anonymised, could be recognised by a reader. This needs to be considered throughout the process of data capture and write-up prior to publication according to Ellis (2009). There is also the consideration of impact on both the reader, and writer, who bear witness to the

unfolding traumas, epiphanies and turning points whether positive or negative. Balancing the need to tell the truth, with consideration of the potential for harm is essential (Frank, 2016).

Morrow's (2005) framework sets out guides and indicators for quality, trustworthiness, relevance, and ethical considerations. The framework ensures the usual rigour expected for academic research within the field of psychology, whilst acknowledging that the rhetorical structure may be different, or may even change situationally, and at times, perhaps contradiction, paradox, non-adherence to method becomes part of the magic, which is something that Beattie, (2022) embraces within her concept of symbiotic autoethnography. The framework includes faithful, authentic, and comprehensive capture of the author's experience, and if done well in terms of rich and thick descriptions, together with deep reflexivity and rigorous analytical unpacking - then autoethnography is both ontologically and epistemologically sound.

A consideration within the method is the potential positive or negative impact of autoethnography on both the author and readers, and according to (Schwandt, 1997) the process would have an impact on the author though deep introspection and exploration, and even impact self-awareness, advocacy, and ability to self-explicate. Within this is a force for good, or ill, depending on the subject and its impact. This has been described as Educative Authenticity and Catalytic Authenticity, in terms of finding one's authentic, or true self. This has the potential to raise awareness and invoke change, but also shine a light into dark places and blind spots. There is also power to introduce the reader to deeper levels of understanding of an experience

that they may not understand, nor encountered within their own life - whether through unlikelihood owing to circumstance or mindset. The power and insight of multiple levels of authenticity within the context of truth and knowledge as a process have been unpacked by Schwandt (1997) within five categories. Educative authenticity has been related to discovering understanding and appreciation of others, Catalytic authenticity relates to how the research process increases knowledge, and awareness that leads to change, Ontological authenticity relates to how knowledge is formed, enhanced, and crystallised throughout the process of research. Fairness is usually applied to the way in which the research is solicited, handled, and positioned, though this is noted in the context of having a researcher and participant, although, within the context of autoethnography, the researcher and participant are one. Finally, Tactical authenticity relates to the power that the participant has to act within the scope of uncovering self-knowledge and truth.

Crotty (1998) suggests that knowledge at this level is contingent on human experience, practice, doing and being – and is constructed through interactions with humans and their world. Constructivism relates to the making of meaning within a position that contrasts and opposes the positivist stance of objective truth – which formed the epistemological stance of western science, described and advocated for in the so-called era of enlightenment (Crotty, 1998). Through this lens Schwandt (1994) suggests that knowledge and truth are neither entirely subjective nor objective, but rather that they are constructed in the mind, as opposed to something that can be discovered entirely from without.

Considering the deep layers of authentic knowledge that may come through the process of autoethnography as outlined by Crotty (1998) and Schwandt (1994), there is potential for dark epiphanies in addition to epiphanies bathed in light. The potential to emulsify trauma and past injustice is real. Understanding researcher vulnerability is something that is understood and discussed by Bochner (2007), who speaks both about the impact on the reader, and the potential for suffering publicly and leaving oneself open to criticism which may be hard to take – given the personal attachment to the data as the story.

Carolyn Ellis has done much to develop and gain acceptance for uncensored autoethnography as an approach to research. Ellis, (2004) wrote about her relationship with a dying partner, which was an experience some ten years in the past. The unpacking of this experience, according to Ellis was evocative and emotional, and yet healing. Jones, (2005) recounts a first experience with autoethnography which contained details of traumatic events from childhood. Jones noted that the reading of the account had a profound impact, and standing outside the words was almost impossible as she relived some of the accounts of trauma vicariously. Ellis (2009) suggests that there is neither an unambiguous, nor panaceatic approach to dealing with, or pre-empting ethical issues within autoethnography, and that the best approach is to constantly re-examine and make decisions dynamically; and that building this mechanism into the process to ensure that responsibility is taken for self, readers, implicated others, and society. Ironically,

Ellis made a compelling case for the inclusion of emotional rhetoric within autoethnography, and that the power that the process has on the writer naturally translates into the impact on the reader.

Autoethnography, whilst accepted within qualitative research, with many caveats – including the constant overcompensation towards academic rigour, suggests a pre-emptive apology is required when one decides to use this method (St. Pierre, 1997). Mooney (1957) suggests that research is a personal venture, and that *"who"* the researcher is, is central to *"what"* the researcher does (P. 155). Bochner and Ellis (1996) advocate for this view and highlight the critical importance of individual experience and the concept of the "self" within research, and that this can act as a catalyst from which culture activates and flows.

Langellier, (1998) makes a compelling assertion that "the body needs a voice" In order to resist what they describe as a colonising power of discourse – and that the personal narrative within autoethnography provides this voice. The context of the aforementioned work and insights relate to breast cancer, and therefore sickness and health. Given the nature of the illness, female identity is at the heart of the subject, yet rarely considered within the paradigm of treatment and discourse – where the emphasis is placed firmly on eradicating the cancer. This is a particularly important note as one considers the legacy of the medical model as an overwhelming and oft insidious usurper which suppresses the voice of autistic

individuals, and whilst the subject matter is different, autism is still seen as an illness by many, and one that needs to be researched and treated (Chown et al., 2017).

The naysayers and critics of autoethnography may challenge that the data is entirely personal – and consider that there may be limited application to others, and yet Starr (2010) reminds us that the nature of autoethnography is the emphasis of the self in relation to the other, and the spaces between them, the places where they meet, collide, intersect, and therefore provide a fertile environment for the seeds of personal knowledge to move into the social construction of knowledge.

Grant and Zeeman (2012) provide an insightful rebuttal to the assertion that there is something self-indulgent and solipsistic about autoethnography, and whilst it would appear to be the case – we are reminded that autoethnography simply makes the participant the researcher, and empowers them to consider their relationship with the "other" as part of a group, and therefore they are not culturally nor dialogically isolated from others, but rather that the group that they belong to, and their temporal reflections relating to this group - against the self as a backdrop, gives rise to the potential to open new questions, find common ground, explore correlation, and perhaps even causality (Grant & Zeeman, 2012).

Autoethnography involves a deep dive, deep unpacking, and is often evocative and powerful in nature - as suggested by Pelias (2019). The display and bringing forward of this voice in a linguistically evocative and sensually poetic manner can move us

closer to the subjects we wish to study, and make the reader want to read (Pelias, 2019). In consideration of observational research, and ethnography within psychology, the emphasis is on getting as close as possible to the subject / participant, and the term *"omnipresence"* in relation to the researcher has been suggested by Piacenti, Rivas, and Garrett (2014). The term is not taken with religious connotations associated with God, but rather related to the physical presence of our bodies, words, and minds in relation to the research.

Margin Note

I posit that surely the closest we can get to any human participant is through the self, provided that the individual can access the self reliably, safely, and at the depth required. This is not a contradiction, but rather an insight that from my own perspective, I did not have the levels of self-advocacy and self-awareness when I embarked upon this autoethnographic undertaking, but these things came through the process - and therein lies the magic! Autoethnography as a concept, a methodology, a framework, and a process actually brought me closer to a developed self-concept, and I anticipate that it will bring me closer to the world.

Pelias (2019) describes within the concept of being close to the self and moving the "self" close to others. Even so, there are still challenges to answer that criticise the analytical grounding, which Spry (2001) answers with the assertion that knowledge production should include the process and production in the body from which it was generated – and that this is *"embodied methodology"* (P. 725). Acknowledging and

surrendering the central role of the participant within research – moves the participant into a different place. Placing them at the front and centre of the research, and in essence allowing their importance to become central, notwithstanding that permission aside, they are central and have that unique right by default (Spry, 2001).

St. Pierre (1997) asserts that the production of different knowledge requires us to produce knowledge differently (p. 180), going on to describe the production of transgressive data, emotional data, dream data, sensual data, and response data. Whilst this is a pithy statement, an aphorism, or perhaps an epigram, it is also something of an axiom, and certainly a maxim for truly participatory and emancipatory research. I posit that it is also a sound epistemic modality, when and where we wish to understand "self", but as indicated by proponents of autoethnography, it is much more than that; It provides an ontological framework to understand deeply existential questions relating to identity, life, unpack layers of formed identity and to seek understanding, meaning, purpose, and utility.

Assuming that we move towards embracing a non-linear and multidimensional approach to analysis, autoethnography is entirely sound, and refutes the long-accepted claim from the positivist camp that traditional writing and research methods are somehow more legitimate (Wall, 2006). Another criticism of these "traditional methods" is that insistence on retaining academic conventions to a fault - often results in a barrier to entry and means that the writer also needs to be an expert in qualitative methodology to allow for academic rigour and translation of the data (Ellis,

2009). Stoecker, (1999) poses the question of the relevance of academics within research where we seek to deeply understand the qualia in relation to the life experiences of participants, and advocates for the removal of this barrier. Perhaps if academic conventions were to allow different ways to capture the story, and the experience, and to interpret the data, more autistic individuals, for example, would, and could become researchers!

Autoethnography as Method & Methodology

There is considerable debate over whether autoethnography is method or methodology, and a number of researchers such as (Ellis, 2004; Denzin, 2014; Dunn & Myers, 2020) suggest that autoethnography is a research method. Other researchers such as (Parry & Boyle, 2009; Wiley, 2019) consider autoethnography to be a methodology. Some middle ground has been found in resolving the debate in seeing autoethnography as both (Holman-Jones & Ellis, 2015). Stanley and Vass, (2017) consider autoethnography to include the product and method within research writing, and Wall (2008) goes further to suggest that the debate should be left unresolved, and that this may be part of the magic within the approach, and instead the approach should be embraced as offering an intriguing and positive contribution to qualitative research.

Thus far, there is little resolution on how to apply autoethnography as a method, and as such, beyond the guidance on the tone of voice, which can flit and change depending upon the subject, context, mood of the writer, and the purpose of the

piece of writing, the researcher is afforded a sense of freedom as they move through the journey of describing, contextualising and unpacking their individual qualia in a symbiotic way (Beattie, 2022). Beattie describes life experiences as being dispersed across many temporal and spatial dimensions, contexts and situations that involve the self as subject and object, and even multiple selves, which is a view shared by Heidegger, (1962). Denzin (1997) noted that subjectivity within the researcher is reflected upon within the context of understanding their own social world, in which they perform, witness, interact with, understand, find meaning, purpose and are witnessed.

Conquergood (1991) refers to “embodied practice” in terms of “the being there” relating to performed experience – with the “being here” of written texts (p. 193) Pillow (2019) describes methods of gathering data as “seeing, hearing and recording” as giving rise to considerable debate – leading to something of a movement to bring an end to flat data within the context of autoethnography. The concept of Symbiotic Autoethnography as described by Beattie, (2022) acknowledges the freedom from linear methodology and embraces multiple dimensions to work in harmony with the organism of self. Symbiosis is defined as the relationship between two or more different organisms where both parties work in harmony to benefit - Derived from the Greek sumbios / sumbion (companion living together), in contrast with the term parasitic.

Maddison (2010) describes the notion of *“one’s life becoming data”,* going on to describe an experience of knowledge production that is novel and not something that we are generally accustomed to. Madison states that *“It literally moves our musculature and rhythms of our breath and hearts, as corporeal knowledge joins cognition through enfleshment knowledge”* (p.7). Considering the symbiotic approach to autoethnography, the processes, methods and approaches work with the context and the researcher in a way that is holistic, changeable, often going against conformity, and in doing this, I posit that individual creativity and imagination are fully embraced and embodied.

According to Spry (2001) autoethnography may require a movement between structure content, and linear flow, and yet in doing so – it captures where the researcher is “right now”, often breaking academic conventions, and this requires courage. Spry described the “residual traces of culture inscribed upon her hide from interacting with others in context”. Ellis, (2009) has long been a defender of autoethnography as a valid method to conduct deep and rich qualitative research, and Polkinghorne (2005) suggests that autoethnography caresses and nurtures meaning making by honouring epistemology, ontology, and reflexivity in a unique way. According to Baumeister and Newman, (1994) the process unveils knowledge within the researcher as they move through the journey, and as such, outlining a linear method at the outset is counter-productive and somewhat shackles the researcher as they holistically make sense of their story, memories, and experiences.

The work of Tarnas, (1991) is helpful because it points to a way of theorising and embracing the plasticity and the constant changes in awareness, knowledge and paradox that is fundamental to being human. One could say, as indeed Beattie herself did, that it subverts the many epistemological taxonomies associated with postmodern research (Beattie, 2022, p. 27).

Doloriert and Sambrook (2012) go further within autoethnography, and in the true spirit of embracing mixed methodology within its nature, they assert that the praxes within autoethnography are neither necessarily distinct, nor discrete, but rather that they can move and change. They can complement or contradict each other, and that one can move from artful, evocative, analytic, poetic, and more – as opposed to simply picking an approach. This symbiotic approach embraces the concept that our mood, our moments, the subject, and, or the context can choose its own approach, and move around – flitting back and forth as necessary, or as felt by the researcher.

Spry (2001) embraces the idea that autoethnography can serve many functions, and embrace many different processes and modalities, even if they are fragments, and perhaps because they are fragments, including being reflexive, critical, performative, exploratory and perhaps even experimental. Burnier (2006) raises this and suggests that autoethnography is indeed "*personal – yet scholarly, evocative – yet analytical, descriptive – yet theoretical, with the caveat that it must be done well"* (p. 414). Whilst there isn't yet a benchmark for that which is "done well", Winkler (2018) suggests a balance between evocative and analytical approaches – and goes further to qualify

this by suggesting that too much emphasis on personal attitudes, feelings, thoughts, emotional unpacking, and impressions gives rise to a potential accusation that an autobiography is being written as opposed to an autoethnography.

A middle ground approach has been discussed by many authors (Allen-Collinson & Hockey, 2008); (Anderson & Glass-Coffin, 2013); (Tullis, 2013); (Stahlke Wall, 2016); (Sparkes, 2020), accept the schism between evocative and analytical approaches as something that needs to be bridged, and the suggestion is of a writing continuum. Manning and Adams (2015) recognise this gap and the variations in approaches to autoethnography (p. 191) and they identify four orientations described as: Social-scientific, Interpretive-humanistic, critical, and creative-artistic. This speaks of an approach or method, and yet it doesn't necessarily consider that style can apply to any of these approaches and change the flavour without changing the method or approach itself.

Denejkina (2017) refers to this gap as a spectrum, and for me this is a lightbulb moment, and perhaps a little ironic when considering autism and a spectrum. A more varied approach is considered within this model and the term spectrum is also considered by Pennington (2017). Chang (2008) describes four styles of writing: Descriptive-realistic, which includes rich descriptions of events and places, Confessional-emotive which emphasises feelings, challenges, and critical life-moments, Analytical-interpretive, which balances analysis with interpretation of phenomena and individual qualia, and imaginative-creative, which courts imagination and creativity, and de-centralises the scientific and academic.

2.2 Method Discussion

As discussed, thus far, within autism and research, there is a disproportionate weight toward positivism, and a medical model which considers autism as something that needs to be treated or cured, and that much of this has arisen and still exists through the legacy of medical psychiatric research and practices, where information from the medical professionals, and adherence to the criteria supersede lived and multi-dimensional experience (Kendall & Drabick, 2010). Other models consider interventions which rely on education, policy, and support, and yet none of these models empower the individual any more than they have thus far involved autistic individuals (Waltz, 2013).

This research aims to move towards a research design that embraces reflexivity. The fact that, I am the researcher and participant and utilising autoethnography, gives rise to a freedom that is rarely seen, notwithstanding that there are potential challenges to this methodology, although conversely there are many who consider the validity of narrative approaches; and according to Polkinghorne, (2005), story can be considered as both data and method. Autoethnographic and narrative approaches are epistemologically and ontologically sound which generates theory and considers the socially constructed aspects of a person as they grow and shift through discourse (Sarbin, 1986); (Barresi & Juckles, 1997); (Baumeister & Newman, 1994); (Bruner, 2004); (Gergen & Davis, 1985).

Bochner & Ellis (2016) provide some exemplars within the Handbook of Autoethnography, and these range from stories, as demonstrated within the story by Devika Chawla with the title “Walk, Walking, Talking, Home”. The story presents an account of growing up and living in India, close to the border with Pakistan. The story is a richly written autoethnographic account of a life as lived, with clearly emphasised epiphany moments and meanings, and sometimes no apparent meaning, or meaning giving way to immersion in a thickly and richly recounted memory or scene. Smells, textures, tastes, and associations are described within this story. There is no academic intent, nor is there academic analysis, but rather, if a researcher wanted to understand the daily significance of walking miles every day as part of life, sometimes for the life-giving substance of water, that many take for granted, then they may well find this powerfully described within the research, and it may bring context, gratitude and inspiration, much in the way that a god story does, and yet the story is real.

In an additional exemplar from Robin M. Boylorn with the title “Sit with Your Legs Closed”! and Other Sayin’s from My Childhood, described a “Blackened Autoethnography” and noted as being “performative autoethnography”. Geneva Smitherman (1994) refers to the colloquialisms and vernacular as “Black Talk”, which crosses the many boundaries of age, sex, religion, and social class, and does so owing to the oral traditions imbedded in Black African American culture. The autoethnography is described by the author as being both performative and autoethnographic, and based on personal lived experience, encapsulating the

feminist epistemology as lived through her own experience. The use of the term “sayin” as seen in the title, is the first glimpse of the authentic approach to the use of language that breeches spelling convention as many would see it, and the approach throughout is humorous, yet gives a deep insight into the use of language, and the many maxims that form the bedrock of the culture. Other vignettes within this autoethnography employ the use of lists, and, at times deeply poetic word associations that appear similar to Haku, a form of Japanese poetry, an example from Robin M. Boylorn below cited from Bochner and Ellis (2016):

“Hot torture

Hot hands

Hot scalp

Hot comb

Hot air

Pushing against the nape of neck

Mama’s Hands

Gentle, strong, unrelenting

Combing through yesterday’s kinks

Making them straight

hot

Burning”.

The methods that I have chosen for my autoethnography include poetry, art, and in particular watercolour painting, music, and introspective writing. These mediums have been used to access and describe my emotions in a way that I have often struggled with. Simple questions such as “how do you feel” have proven to be beyond me in the past, and at times made me feel somehow wooden, and something of a Pinocchio in terms of not being a real boy. I remember being asked this question by a therapist, and I felt myself, then replied with “I feel firm”. The therapist laughed at me, and my temper flared. And yet, I have discovered that I can carve a self-portrait from a block of wood, and that this portrait provides a visage that I can imbue with emotion and from which I can read emotion. I can conceptualise my own experience of a feeling in a watercolour painting, and I can play both playfully and melancholically with words to compose poetry that tells my story.

As discussed within the literature review section by Bochner and Ellis (2016) and Beattie (2022), a non-linear approach utilising mixed methods within autoethnography is to be embraced, and this is seen within vignettes comprised of rich and thick descriptions, memories, and abstract thoughts. The reader may find seemingly unlinked themes and subjects, and experience a moving backwards, forwards and sideways through time and context, and isn’t this the way in which we live our lives within our minds?

An Autoethnography or Autie-ethnography?

My autoethnography is finally coming together, and I am starting to realise that there is real magic within the method itself. That I have always struggled with metaphor, allegory, and other siblings such as epigrams and aphorisms when presented from others. I have realised that my brain often conceptualises things in terms of pattern, texture, colour, and even ventures into the “what is that like” territory extremely well. Exploring an emotion as “felt” has always been difficult to me, whereas defining an emotion by using another medium seems to work, and it seems to have unlocking properties which have not only expanded my descriptive repertoire when unpacking my emotions, but that it has somehow given me a higher access. There has been catharsis within the process too, and the value of this should not be underestimated.

I have allowed many styles to creep into my writing, buoyed up by the debates around autoethnography, and discussions on styles and methods. The concept of symbiotic autoethnography, and this symbiosis between styles, purpose, meaning, utility, freedom and yet the embracing of analytical approaches has allowed me to package vignettes of my life with neither shame, nor fear. Without too much focus on meaning and mattering – and a trust in the process that the mattering, meaning and the “synthesis” will come…

2.3 Chapter Reflections & Conclusions

Within this chapter I have considered autoethnography as a method from a variety of perspectives, including its validity as something pushing the boundaries of qualitative research. I have considered the many arguments for and against and looked at some of the limitations and suggestions for addressing the criticisms often made. From my own perspective, autoethnography addresses many arguments, and one of these – was touched on in the previous chapter when looking at the need to capture the autistic voice as indicated by (Botha & Cage, 2022). Beyond this, another area, which will be unpacked explicitly in a further chapter is the sense of identity that may operate differently for autistic individuals, and that in building self-advocacy, identity, and social skills, we create protective factors and develop resilience within the individual (Bellini, 2004).

Autoethnography holds this power, and this is something that I personally attest to, and something that the reader will witness as they move through this thesis. I have also considered ethics within the scope of autoethnography, and also the initial battle that I had when It was indicated that I may be a “vulnerable person”. The subject of researcher vulnerability is something that has been considered within the context of “life-writing” within the lives of vulnerable individuals by Couser, (2004). Couser states that their primary concern related to the capacity of the “vulnerable individual” to represent themselves within writing, or give meaningful consent for another to do so, and also expressed concerns relating to being exposed within relationships whereby trust and intimacy are fundamental (Couser, 2004). This initially sparked a

familiar feeling of anger and outrage within me. Franky, I had not considered myself to be any more vulnerable than any other human being, and the assertion that my autism made me somehow more vulnerable through the autoethnographic process, given my tendency to be logical – was rejected by me. I reflect upon this with the short vignette below and the accompanying painting.

2.4 Understanding the Irony

"The moment was finally upon me; I had to submit the revised ethics proposal! It was suggested that I was classed as a vulnerable person, that I should have a participant information form, and that informed consent was a prime concern! I am the participant, and the researcher – so this doesn't make sense to me! To add to this is the feeling of being triggered by the assertion that I am classed as vulnerable – created a visceral reaction! The feelings of injustice and dissonance building up inside me were increasing my anxiety, and I was close to telling "them" to place the ethics where the sun never shines (ethically of course). I then had a breakthrough! This is to make others feel better, and safe! I need to "play the game", and to be smart and sly. I think of a fox. I surrendered in that moment, and the PhD data collection journey commenced with the submission of the ethics proposal".

2.5 Vignette 1: The Sly Fox

The subject of autoethnography has been unpacked in terms of its origins, history, and evolution. Debates have been considered pertaining to its position as method and methodology, and in terms of the former, there is little resolution on how to apply autoethnography. Wall (2008) suggests that this lack of resolution is in fact a positive thing that facilitates freedom, and Beattie, (2022) goes further to suggest that the aim is to create symbiosis within the approach. Within my autoethnography, I am moving through all three temporal planes as I inspect the past, experience the present and consider the future. In using autoethnography, which may start by identifying a memory, emulsifying it, immersing myself in the moment as it was – through the lens of today, I am identifying patterns, triggers, crossroads moments of change and impact, and in some cases, I am perceiving a sense of healing of the scar tissue, or a reordering of cognitive affect relating to a dark moment.

My autoethnography is voyage of discovery, a revisiting of lost moments and buried treasure and horror in equal measure. There has been tremendous catharsis within the process for me, yet I had not envisaged that this would be part of the process, nor was it my intent. The intent at the beginning of the journey was to identify anxiety triggers and domains of courage in order to consider whether I could increase the access to my “well of courage”, or perhaps increase the volume of the well itself, and to even purify the waters. I embarked upon this journey knowing that I had suffered with anxiety my whole life and had avoided much of life and living because of this.

Within this process, I had held space for the fact that others reading my autoethnography may have visceral reactions and even share epiphany moments with me, and that there could also be understanding, acceptance and healing for them too, and yet also that there could be a darker side to this level of walking through my research.

As the reader, you may note that my approach is unconventional, particularly as you advance through the thesis, and that even within the already unconventional autoethnography space, there is an argument that it is extending the boundaries. Knowledge acquisition and original contribution within research is something that is important within the scope of a PhD, and it could be argued that knowledge of self fits within this alongside knowledge of a subject, and that this, together with a novel application of method, represent a considerable contribution to knowledge.

Within my method, everything is data! The process of writing an autoethnography holds considerable data as I produce poems, paintings, share insights and move to the research and analysis. My change and evolution through writing an autoethnography is data. If everything is data, then perhaps nothing is data. I playfully state this, and yet there is no definable data set contained within one space that will be analysed in a particular way. There are vignettes, which are perhaps the closest thing to a data set, and yet they are spread out, and some are even hiding within paragraphs and sentences as carefully discarded and seemingly unimportant marginalia. Little light bulb moments of insight. The beginning of this journey, the middle and end – all hold data, and there are spaces in between…

I had not realised that my autoethnography started from the moment that I embarked upon my PhD journey. I had deliberately kept my autoethnography separate from my main PhD document, and I had done this because, for me, they seemed to occupy very different mental processes, writing styles, and approaches. My brain is not agile enough to flit between the two. I have wondered if this disconnect would create an apparent gap, and whether my thesis would somehow come together, or whether the schism would remain. I use this word because I am authentic within my autoethnography, and fee somehow suppressed whilst attempting to play the academic game.

I had an epiphany moment when I realised that they are not separate, and that my resistance to academic writing and convention – could itself provide some rich insight

and data on the methodology itself, and that my data, coding, thematic analysis, interpretive phenomenological analysis and literature review may be able to come together in a more natural way, in a symbiotic way, and that there may not be clearly distinguishable boundaries and separation between these things.

Beattie (2022) reflected upon autoethnography as part of her doctoral thesis and discussed the difficulties and even impossibilities associated with attempting to somehow make the autoethnography fit the often straight, linear, and well separated approaches associated with conventional academic writing. Beattie goes on to suggest that often fuzzy, contradictory, and even seemingly incompatible imperatives simply kept getting in the way.

Thus far within autoethnography there is no single objective approach towards defining, capturing, and analysing moments, often called vignettes. Denzin (1997) suggests that subjectivity within the researcher is essential if the researcher is going to understand their own place within the world, and within their own research, and that it should be embraced. Brinkman (2014 had a notion of “stumble data” suggesting that researchers should embrace moments of astonishment and epiphany as being signs of significance to be held, no matter from whence, when or where they came.

Chapter 3: Autism & Anxiety

3.0 Chapter Introduction

In the previous chapter the method and methodology of autoethnography was explored alongside debates relating to models of application and the position of autoethnography within qualitative research. Of central relevance to this next chapter is the concept of emancipatory and participatory paradigms that set the researcher free to explore the self in relation to the subject and subjective experience of the world, as an insider within the group to which they belong. The relevance of this person-led paradigm lies within its link to the social model of autism – given that much of the current research has been driven by the medical model, which this chapter will capture.

This chapter explores autism generally in terms of the current position from the pathological model, and within the context of anxiety, which has been noted to be a common comorbidity within autism, with evidence showing that anxiety exists within 40% of autistic individuals, as opposed to 10-15% of the general population (Kessler et al., 2012). It is estimated that some 40% of autistic individuals have at least one anxiety disorder, with a range of specific origins, including those within the social domain, and defined phobias being observed as the most common presentations (Van Steensel et al., 2011). Whilst the significance of the rates of anxiety, coping and over-responsivity within the lives of individuals with autism has been observed within research, according to Green & Ben-Sasson (2010) we have yet to understand and arrive upon a multi-dimensional approach towards an understanding of whether anxiety is an intrinsic part of the differences in neurology, and as some have

described colloquially, a different “operating system”, or a product of the environment, and the negative impact of traumatic experiences. With this in mind, and owing to the lack of contextual understanding, the majority of existing treatments, support strategies and approaches are not tailored towards autism, nor the specific individual requiring support (Rogers et al., 2017). This is significant since it highlights the importance of accurately identifying the triggers and manifestations of autistic anxiety with a view to improving life outcomes and quality, in the progression towards flourishing and independence (Autism Research Group, 2018).

According to the International Classification of Diseases and Related Health Problems (ICD-11), autism is characterised by persistent and pervasive deficits within the initiation and sustaining of reciprocal social interaction and social communication (ICD – 11, 2019). The Diagnostics and Statistics Manual fifth edition (DSM-5-TR, 2022) considers a dyad of impairments within social interaction and communication, and rigid, repetitive thought patterns and behaviours. In addition, though not explicitly stated within the DSM-5-TR nor the ICD-11, autistic individuals commonly experience differences and difficulties in processing sensory stimuli leading to sensory overwhelm and a source of stress and anxiety (NICE, 2011). The impact of sensory differences has been well noted both anecdotally and within numerous reports and reviews, yet there is no differential diagnosis pathway relating to a-typical sensory experience as part of autism (Health and Social Care Overview and Scrutiny Committee, 2012).

In terms of prevalence, there is currently little resolution on the exact numbers within the population (Baxter et al., 2015). Initially according to Baron Cohen et al., (1985) occurrence was considered to be rare affecting only 4 in 10,000. Brugha et al., (2009) subsequently suggested that autism affects around 1% of the population and went on to note that there was a ratio of 4:1 male to females. More recent estimates suggest figures of 1 in 132 people (Baxter et al., 2015). Rates of diagnosis continue to rise according to Matson & Kozlowski (2011) and according to Loomes et al., (2017) the ratio of males to females is considerably higher than that predicted by Brugha et al., (2009). Thus far there is little clarity as to whether the rise in the prevalence of autism is owing to an actual increase in instances of the condition, or the improvement of diagnostic tools and modalities (Lord et al., 2000); (Wing & Potter, 2002); (Frith & Happé, 2005).

In addition, anxiety is diagnosed and experienced by around 40 percent of autistic adults (NAS, 2017); see also (Simonoff et al., 2008) where a similar figure of 42 percent was noted. Other research from Salazar et al., (2015) reported a prevalence of 78 percent. The significance of the co-occurrence of anxiety and autism is widely accepted within the statistics, as noted above, although there is often variation in terms of the method of exploration. Some of the research captured statistics where a diagnosis was present, whereas others adopted self-reports of anxiety without an official diagnosis. Within the research cited above, the underlying mechanisms, i.e., the causes and triggers were not explored, and there is a dearth of research that considers the efficacy and validity of self-reporting in relation to autistic individuals,

and there is also a lack of research that has explored and gained a true understanding of the psychometric properties of anxiety within autism (White et al., 2012).

Part of the issue lies within the fact that for many, anxiety becomes a problem through the teenage years within an every changing environment which includes internal factors such as hormones, a search for purpose and meaning, and identity, and within external factors such as society, school, exams, peer pressure and pressure from the educational establishment; and this volatility exists whether an individual is autistic or not (Kerns et al., 2014). These definitions, and the statistics relating to the struggles faced by autistic individuals, provide insight into the impact of autism through a comparison model relating to an expectation of “normal”, and “typical” development and behaviour, and of “normal” functioning within society, and ultimately a medical model (Fletcher-Watson & Happé, 2019).

There has been considerable emerging research on autism in terms of its cause, affect, and effects, and treatments ranging from medical, through to talking therapies, with serotonin emerging as a treatment within the pharmacological camp as a valid and efficacious option (Nadeau et al., 2011). Much of this research has been led by professional researchers and practitioners, who, whilst having knowledge of the subject – are often lacking in lived experience and are often unsure of how to disentangle traditional anxiety from that which may be distinct to autism (Renno & Wood, 2013) (White et al., 2012). The findings and insights are usually applied

generally, yet this doesn't dig deeply into the individual qualia as experienced by autistic individuals. There is a dearth of autistic researchers with the levels of self-advocacy, and ability to be deeply introspective, and with this in mind, current research methodology often facilitates the absence of the autistic voice (Botha & Cage, 2022). This is also true where the autistic individual becomes part of a medically driven research project, where their anxiety is explored, and they are not, and never will be part of the research design, duly noted by advocates such as Waltz (2013), see also (Chown et al., 2017).

I believe that part of the magic of autoethnography as a paradigm, and method, is its ability to allow the researcher to capture their experience in their own words as ever-evolving data which includes epiphany moments and vignettes of insight which are often described by proponents of this methodology. Autoethnography has been described by Ponterotto (2015) as a method, paradigm, data analysis tool, and epistemological framework. Ponterotto goes on to describe a constructivist-Interpretivist paradigm, which includes three philosophical pillars as being: ontology, epistemology and axiology. I believe that there is tremendous freedom, learning, emerging insight, and development, which, as an autistic individual who struggles with emotional recognition and understanding of self, provides benefit and insight that is missing from other methodologies, such as self-reported questionnaires, where self-reporting and self-explication are essential.

Building levels of self-advocacy and self-explication are an intrinsic part of autoethnography according to Beattie (2022) who describes autoethnography as a symbiotic process of learning, development and understanding which moves through individuals as they move through time. I believe that this approach has the ability to transcend the labelling approach which has contributed to a fallacious, and, or incomplete understanding of autism, full of sterotypes and tropes that slant towards the medical model. I also believe that even within the auspices of medical research, facilitating a rich and deep understanding of the research subject can only occurr if the subject has a rich and deep understanding of the self, as discussed and stated within the autoethnography chapter, and as evidenced within the autoethnogrphical content within this thesis.

3.1 Anxiety & Autism Literature Review

Anxiety itself is widely understood to be common within the general population with 10-15% of the allistic population having an anxiety disorder at some point in their life, with this anxiety most commonly manifesting as a specific phobia (Kessler et al., 2012). In the context of autism, this figure rises to 40%, with the figure including children, adults, and adolescents, and within this research, social anxiety and specific phobias are the most frequent presentations of anxiety (Van Steensel et al., 2011). Within the current diagnostic frameworks, there are considerations relating to the root cause of anxiety, for example, anxiety induced by substance-misuse, or neurological dysfunction, as in the case of schizophrenia, or bipolar disorder – the anxiety may not be considered as a separate condition, but part of the cluster of

symptoms widely accepted as being part of the other diagnosed condition. Whilst this general distinction has been made within the DSM-5-TR (2022), the same approach has not been resolved within autism, and many viewing autism and anxiety as separate, as cited within a recent evidence-based guide published by the Autism Research Group (Autism Research Group, 2018).

There are a number of anxiety measurement scales designed for the general population, and for generalised anxiety disorder, with one of the first, and most common being the Hamilton Anxiety Scale (HAM-A), still in use today and designed by Hamilton (1969), as a primary measure of generalised anxiety disorder. The measure is used to measure anxiety across a range of conditions. The tool is complex, to be used by clinicians, and has been criticised as being time consuming, and something that focuses on the somatic symptoms of anxiety (Maier et al., 1988). Alternative tools include the Beck Anxiety Inventory (BAI), which is a self-report questionnaire and scale (Beck et al., 1988). Research suggests that it does not provide a broad measure of anxiety, but rather emphasises the symptoms (Cox et al., 1996). An alternative can be seen within the GAD-7 (Spitzer et al., 2006). The questionnaire consists of seven items within a Likert scale framework, with each item pertaining to worry or anxiety. The scoring within the scale for each question ranges from 0-3, with the lowest and highest possible scores ranging from 0-21. Higher scores indicate greater levels of anxiety. Scores above 10 are considered to fall within the clinical ranges of anxiety. According to Kroenke et al., (2007) and Löwe et al., (2008) the GAD-7 has shown consistent reliability.

Within autism, anxiety has been observed as a common experience for many autistic individuals according to Green & Ben-Sasson (2010); Wood (2013) and White et al., (2012). There has been considerable research on the prevalence and co-occurrence of anxiety disorders and autism spectrum disorders; and yet a consensus has not been reached on whether anxiety is a part of ASD, a comorbidity, or a novel presentation of anxiety (Kendall & Drabick, 2010) see also Kerns et al., (2014); Mayes et al., (2012) and Rogers et al., (2013) who have attempted to address this by tailoring research towards autism-specific anxiety.

Tillich (1973) suggests that human beings experience their existence within a negative state derived of the awareness of the threat of “nonbeing”, or that which could harm our existence, suggesting that anxiety is natural and common as a human experience, notwithstanding that the ability to cope with said anxiety varies between individuals. He goes on to suggest that life is full of very good reasons for profound anxiety and that the “courage to be” is the antidote. Tillich proposes that courage can be found within, and without, and that it is also unique to each individual, being dependent on cognitive patterns, individual traits, such as optimistic and pessimistic tendencies, and abstract concepts such as purpose, meaning and belonging. In consideration of the assertions above, the autistic neurotype operates differently in terms of cognitive flexibility and social interaction and communication, and this may be a major contributor to coping with anxiety for autistic individuals – as noted, for example within the literature from Kendal and Drabick (2010) above.

Wood and Gadow (2010) distinguished between the concept of true comorbidities and unique syndromes when considering anxiety within ASD. Within this conceptual framework, true comorbidity required a condition to be etiologically and phenotypically identical to its monomorbid form. It was suggested that when these criteria were not met – that the co-occurring symptoms may be unique variants of anxiety which relate specifically to autism.

Baron-Cohen et al. (2000) note the prevalence of anxiety within autism, as discussed within this thesis, and propose that dysfunction of the amygdala is responsible for heightened anxiety and fearfulness within autistic individuals. Much of this research was based on the study of animal lesion studies relating to Damage to the amygdala. Behaviour in vervets in the wild with lesions were observed displaying less social behaviour, withdrawal from the group, failure to read or display correct social signals, and were frequently killed by the group. Thus far, there are two competing hypotheses regarding amygdala dysfunction. The first is based on the amygdala being hypo-responsive (Baron-Cohen et al., 2000). The research posits that within autism, the amygdala fails to assign emotional significance to social stimuli resulting in a lack of interest in social interaction. The second hypothesis posits that the lateral nucleus of the amygdala is making associations, but is hyper-responsive, and that this in turn leads to withdrawal from social interaction owing to heightened anxiety. The second hypothesis is supported by Shultz et al., (2000).

The general state of fearfulness experienced by autistic individuals, as noted above, may be an explanation for the associated narrowed focus and social impairment described within the diagnostic criteria for autism that is described within the DSM-5-TR (2022). Cognitive narrowing has been associated with fear and noted within both the work of Baron-Cohen et al., (2000) and Schultz et al., (2000), and this supports the argument that being social is less of a primary concern to autistic individuals than safety, when considering the hierarchy of needs according to Maslow (1943). Biswas-Diener (2016) suggests that fear and its processing is both primary and secondary (type 1 and type 2), with the former being simple and instinctive fears, which, for example could be measured with analysis of the startle reflex or embedded and integrated fears. In the case of secondary fears, Biswas-Diener suggests that they are cognitive and may therefore form outside of the amygdala, as a result of the formation of heuristics that arise from negative learned experience and trauma, which may result in avoidant behaviours.

Luke et al., (2012) have considered a relevant question within their research in terms of whether autistic individuals have a greater ability, and, or need to rely more on heuristic learning than the non-autistic population, and whether decision-making, and courage-heuristics are formed differently based on perceived levels of control, and through different processes. Ashwin et al., (2019) have also consider this point, and both perspectives arose from the work of Polman (2010) who explored the concept of heuristics and decision-making archetypes.

In consideration of the heuristic model of decision making, Polman (2010) has theorised the concept of maximisers and satisficers. The former is seen as an archetype whereby the individual goes through exhaustive processing when making key decisions, and this has been described colloquially as “over-thinking” by autistic individuals, and also “exhausting”. This is in stark comparison to satisficers who seek a “good enough” option when making critical decisions. Polman (2010) suggests that the maximizer is likely to make an objectively “better” decision than the satisficer, although there may be an energetic and emotional cost that is borne by this archetype. The cost of this process within maximizer archetypes has been noted by Miscura et al., (2015), and a third archetype was suggested in the minimizer where the emphasis is on using the minimum amount of energy and resources spent in order to avoid the drain of decision-making altogether.

Whilst decision outcomes are usually operationally better for maximizers, it has been noted that there is a correlation with over-thinking, lower self-esteem, optimism, life-satisfaction and happiness, and the tendency to regret decisions more often than satisficers (Parker et al., 2007; Schwartz, et al., 2002). In addition, maximizers score higher on clinical measures of depression, anxiety and suicidal ideation, and generally feel more anxiety relative to satisficers (Moyano-Diaz et al., 2014).

From the literature on maximizing, and as indicated briefly above, links to autism have been made in relation to decision-making. It has been noted that autistic individuals regularly experience issues in this area (Luke et al., 2012). Within the

research, the data emphasised decision uncertainty, stress, choice-overload, exhaustion, lack of confidence, indecisiveness, mental freezing, and confusion at greater levels in comparison to their neurotypical peers. Participants noted that they spent too much time on decision-making, with reference to anxiety over negative judgements from others, and consequences when making on-the-spot decisions. The tendency to avoid, postpone and abdicate decision making was noted as a common autistic behaviour within the research above.

According to Ashwin et al., (2019) the characteristics and experiences commonly described by autistic individuals in relation to “over-thinking”, correlate with the maximizer, and they also argue that the dual-process theory (DPT) suggested by Evans (2003) further correlates. Within the DPT, Evans (2003) suggests that reasoning functions under two distinct mechanisms: the deliberative reasoning system, and the intuitive reasoning system. The former relies on an explicit conscious process that relies on cognitive ability and working memory and is slower and more effortful, whereas the intuitive reasoning system involves an implicit and unconscious process that operates independent of working memory and cognitive function, with features that are rapid and automatic. Brosnan et al., (2016, 2017) argue that within autistic individuals, the tendency is to gravitate away from intuitive reasoning in comparison to their neurotypical peers. Brosnan, Chapman and Ashwin (2014) postulate that empirical evidence shows a tendency for autistic individuals to rely on heuristic processes involving “rule-of-thumb” generalisations, or mental shortcuts less frequently than neurotypicals within decision-making.

Social Anxiety is something that is surprisingly common both generally, and even more so within autism as noted by Ozsivadjjan et al., (2012), and described within the literature review section that considered prevalence. Recent research has also considered the world of technology, the recent Covid-19 pandemic, and a global culture – where we have never been more disconnectedly connected as things that have exacerbated anxieties, even within non-autistic population. This has been researched, for example by (Bruskin, 1973; Bryant & Trower, 1974; Martinson & Zerface, 1970; Zimbardo, 1977). Within the context of autism, Kanner (1943) indicated that anxiety was present in various forms within a significant number of his case studies – with emphasis on change and several definable things such as large animals, wind, and even cases described as “excessive worrying” about consequences, with one such instance cited, which described a child ruminating on the chances of getting burned as a result of bread being out in the oven (p. 233). There are overlaps described within the DSM-5-TR (2022) that have been correlated with anxiety, such as, the adherence to routine and rituals, and resistance to change. Within current diagnostic taxonomy, this obsessive-compulsive behaviour has now been categorised within anxiety disorders (DSM-5-TR, 2022).

Research suggests that anxiety as a frequent comorbidity impacts between 40-50 percent of children with ASD (Van Steensel et al., 2011). It is indicated that this anxiety causes much of the associated distress – rather than the stress arising from autism in itself (Bellini, 2004). The bar for recognising anxiety as a disorder, as opposed to a situational and occasional contextual event is relatively high, and in

terms of clinical modalities in the UK, and under the guidance of the DSM-5-TR (2022), anxiety is recognised as a disorder when it occurs with a frequency and consistency that it affects the individual to a degree that there is a daily impact on their life. The specific nature of the anxiety influences the recognition and diagnosis, for example, the anxiety may be classified as generalised anxiety disorder, social anxiety disorder, specific phobias, panic disorders, and separation anxiety disorder (DSM-5-TR, 2022).

Unfortunately, arriving upon a diagnosis of anxiety in the case of autistic individuals has been described as difficult on the basis that the anxiety can present in unusual ways, and also because many autistic individuals often have a limited access to understanding and unpacking their emotions in the same way that non-autistic individuals do, and in such a way that the qualitative diagnostic data gathering process requires (Kerns et al., 2014). An example can be found in the consideration of the root cause of social anxiety, which, for the non-autistic population, often arises from a fear of being humiliated and embarrassed in front of others, and a preoccupation with being liked and fitting in, described as a primary fear and preoccupier by Albrecht (2013).

Within autistic individuals, the feeling of difficulty in navigating social situations, having routines disrupted, or being prevented from engaging in repetitive activities, not being in control, and specific idiosyncratic phobias such as walking through doors, hearing certain sounds and people standing in the wrong place, were all more

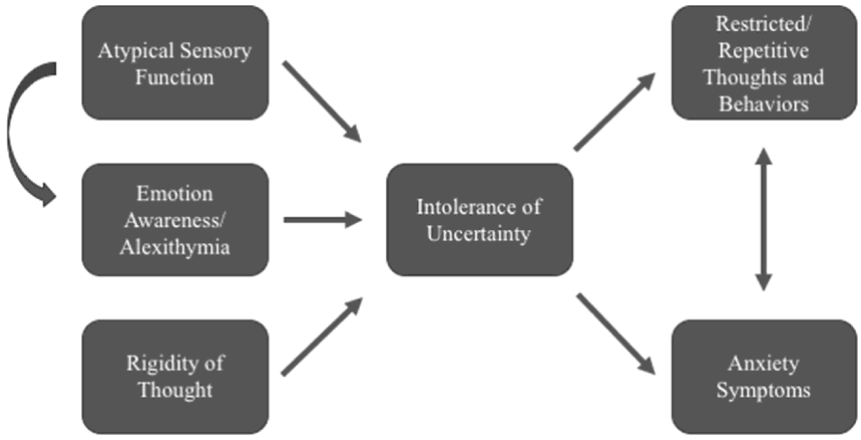
prominent than fear of social evaluation and comparison (e.g., Ozsivadjian et al., 2012; Wood & Gadow, 2010). These specific anxieties feature over and above the fear of being liked, and not being embarrassed / humiliated in front of others. In respect of social anxiety, a significant figure of 16.6% was reported by van Steensel et al., (2011) within a group of autistic individuals that were more cognitively able and socially motivated. The research discovered a more "traditionally" defined manifestation of anxiety which related to fear of rejection, performance and social humiliation as seen in Bellini (2004).

The motivation for interpersonal relationships has been suggested to, over time, contribute to an increase in social anxiety and avoidance owing to the fear of repeated social failure, ridicule, misunderstanding and rejection (White et al., 2012); see also (Kuusiko et al., 2008; Maddox & White, 2015). Another distinction has been made by Gillot et al., (2001) whereby the negative consequences of *"getting it wrong"* within the context of understanding social rules, and specifically relating to social etiquette, being too honest and fear of causing offence gave rise to anxieties. Within a study by Kerns et al., (2014), 8.5% reported social anxiety without an explicit focus and understanding of social judgement and perceived negative social evaluation.

Sensory processing differences, for many autistic individuals, together with difficulties in processing, understanding, and regulating emotions, which can cause social consequences are considered to cause a higher degree of uncertainty for many autistic individuals, and this uncertainty often proves difficult to tolerate (White

et al., 2012). Fear of uncertainty is something that is regularly cited as a common anxiety domain as observed within the works of Rogers et al., (2017). Within the model proposed by Rogers et al., (2017), it was suggested that intolerance of uncertainty was central to the anxiety pathway and influenced by contributory factors that interplayed with the core features of autism. One could interpret from this that anxiety is a core feature of autism, and if not a core feature – then an understandably likely outcome, and in fact, where one has had a traumatic experience in the past, it is logical to assume that there may be an expectation that this will be predicted again as a repeat experience.

Fig 1: (Adapted from South & Rogers, 2017 and Maisel et al., 2016)



Whilst it is widely acknowledged that sensory differences are often seen within autism, there are multiple processes at play depending on the specific sense that is operating differently, and whether or not we are considering hyper or hyposensitivity

(Green & Ben-Sasson, 2010). One aspect of this is sensory prediction, and an example of this is the difference in the way that it feels and is perceived were we to tickle ourselves vs being tickled by others. We can predict the feeling to a greater degree if we tickle ourselves, and yet owing to the unpredictability of being tickled by another, the feeling is more intense. We are able to suppress the intensity of the feeling when we tickle ourselves because of the predictability. This is universally apparent within all populations, however, this tactile sense has been researched within the context of autism, together with Motor anticipation failure, by Sinha et al., (2014) and see also Brisson et al., (2012) where autism is considered as a disorder of prediction.

Sensory predictions serve the purpose of alerting us to unexpected events that impact us, or more specifically, have the potential to impact us physically. The brain is constantly comparing predictions with actual events, and resolving this both somatically and cognitively, and yet within autism, according to Sinha et al., (2014) this process seems to operate differently. Within this different operating system, resolving these conflicts can cause problems when the system is out of sync and it fails to adapt to new sensory experiences as effectively (Sinha et al., 2014).

In addition to sensory differences associated with causing difficulties for autistic individuals, the concept of alexithymia, and in essence identifying, describing, controlling, and even experiencing emotions has been observed for approximately 50% of individuals with autism, and as seen within fig 1 (Adapted from South &

Rogers, 2017 & Maisel et al., 2016). The contribution to anxiety occurs through two routes, i.e., the internal and external sensory and emotional connections.

Difficulties in sensing the internal arousal that precedes emotional experience is important within the concept of emotional regulation and predictability. An example of this is being aware of changes of heart rate and the production of adrenaline that serve to warn us of our biological state – that often precedes an emotional reaction. Being aware of these changes gives us the chance to prepare, regulate and act accordingly (Gaigg & Cornell, 2018). The differences within processing the external and internal environment, when combined with the difficulties oft faced with cognitively unpacking emotion and deciding on a course of action may also impact the efficacy of engaging in cognitive and talking therapies. This is especially true given that many modalities require and assume a conventional level of emotional awareness, regulation and competence. With this in mind, current support modalities may not be supportive, and create a disadvantage for an individual with autism (Garfinkel et al., 2015).

3.2 Chapter Reflections & Conclusions

Within this chapter, the concept of anxiety in relation to autism has been discussed, together with a literature review relating to the definition, domains, and prevalence of anxiety within autism. One such domain discussed as a source of anxiety rested in the process of making decisions, and considerable research has made a link to decision-making within autism operates within a process that drains energy and

resources within processes that require the working memory and cognitive function to be activated. Another area discussed within this chapter related to predictability, which is an area that links directly to the widely accepted premise that autistic individuals require certainty and predictability, and in its absence find considerable anxiety.

The growing realisation and concern over the prevalence of anxiety within autism – has given rise to specific research, and also an understanding that there is a lack of agreement and clarity relating to the connection and separation between anxiety as a standalone condition, or as part of autism, notwithstanding that diagnostic overshadowing is still a major concern – where, for example anxiety is “expected” as a fundamental part of autism (Rogers et al., 2017).

Much of the research is quantitative and statistical, with the edges of deep qualitative research being skirted, and research being led by the medical community. Some progress has been made in terms of understanding the common causes of anxiety for autistic individuals, and some of the research within neuroscience has given us understanding of the predisposition towards anxiety that autistic individuals so frequently have. Support strategies, treatments, and therapies, including medication have been discussed, together with strengths-based and person-led paradigms and approaches within Neurodiversity. Within the next chapter the autoethnography brings a deeper dive into anxiety through and autistic lens.

Anxiety is a well-used term, and as mentioned by Beardon (2021), who, in his opening statement mentions that anxiety, at best makes for a *"pretty miserable day, at worst, it kills".* In the case of autism, this statement is not hyperbole as Beardon quite rightly says. Anxiety, and depression are common mental health problems, and one study suggests that a mix of anxiety and depression affects 9.7% of the UK population, depression 2.6% and anxiety 4.7% (Health & Social Care Information Center, 2009).

Within the autistic population, these figures are increased to a 50% lifetime anxiety rate in autistic adults (Hofvander et al., 2009). Thus far, much research has focussed on biological aspects, as seen in research by Juranek, et al., (2006), however, emerging research on societal aspects such as social stigma, negative experiences, and trauma, certainly play their part (Gray, 2002). There is also a polarising debate and paradigm relating to positive and negative self-image and association with the autism label, where some seem to have a negative association with the autism label, and distance themselves from it, and at times, feel a sense of shame (MacLeod, Lewis & Robertson, 2013), others embrace the label with a sense of pride – and emphasise the strengths of their condition, and some even refer to "superpowers" (Hurlbutt & Chalmers, 2002). In the case of the latter, it appears that some are utilising and leveraging their autism within a sense of pride and identity. Identity is discussed as a protective feature within the courage chapter.

Chapter 4 Autoethnographic Reflections on Anxiety

4.0 Chapter Introduction

The previous chapter considered anxiety as a concept both generally and more specifically within autism. The prevalence of anxiety within autism was explored, and many components were considered alongside contexts that explored neuroscience, the social domain, sensory aspects, cognitive aspects, and anxiety as a comorbidity within autism. Sources of anxiety were considered, and research was explored within a literature review. Much of the research was found to be quantitative, pathologised or statistical, and from a disease and deficit model of autism.

The lack of deeply qualitative research within anxiety within autism has been noted within the Anxiety chapter, and the limitations of self-reporting have also been discussed. Within this chapter, I will focus on anxiety through my own lens, and explore the frequency of the occurrence of unmanageable anxiety within this context, together with the presentation and domains that seem to have a correlatory and causal link. As I move through the autoethnographical parts of this research, I will explore anxious moments within my own life, and unpack them, find meaning, and ever hopefully share some epiphany moments with you.

Margin Comment

I have always been "me", and yet I reflect that I have not always understood, nor had a strong sense of identity. Having been asked the question "what is it like to be autistic", on many occaisions, I have often struggled to conceptualise it. I simply don't have a reference point for anything outside of myself.

A seemingly simple question, such as "what is it like to be autistic" has caused me issues, and frankly it seems quite abstract and vague. "What is it like to be human", to me, is equally ridiculous on the basis that we are all a product of individual qualia – and more. The first thing that comes to mind, however, is the word anxiety. Anxiety has been, and still is the overwhelming feeling, state, and perhaps set-point for me, and yet this question, which may be better if it was worded as "how does anxiety feel", as opposed to "what is it like", on the basis that there are ways other than by comparision to really describe something.

The misuse and constant insertion of the word "like" seems to be something of a vernacular pandemic today, and I have accepted it, and perhaps even started to use it in my thinking. So how does anxiety feel, and what is it "like"? Given that anxiety causes so many issues for me, and given that my exploration of moments where I find courage (perhaps it is always there), I have been pondering on this for some time. I asked myself the question again, "what is anxiety like", and something came to me, something quite profound"!

As outlined within the method and methodology chapter, and a particular quirk that seems to be part of my thinking process, I have realised that I get strong images in my head before the words come. These images are full of colour, shape, texture, entire scenes and this sometimes forms into working models too. A kind of “mind machinary”. Within typical communication, people often require words formed into sentences and paragraphs, and yet for me, there seems to be a starting point of images, which I then have to translate into words, and I hadn’t realised this until I started to ask myself deep questions as part of my PhD. This additional process, if indeed it is an “additional process” – that neurotypical individuals may not have as part of their standard operating system, requires additional processing time, which within a dynamic conversation, there is seldom time for. Within the production of the written word, however, there is considerably more time, and I have realised that this is not only a more comfortable space for me, but also extremely helpful as a tool to develop self-understanding.

Back to the question about anxiety, which gave rise to a very strong image and accompanying feelings of waves. Ebbing and flowing, rising and falling. Cold and powerful, threatening to overwhelm and drown me. The taste of salt and a sense of a powerful force. I instantly saw the waves! I painted the painting below in six minutes in watercolour. It came straight from my mind and flowed onto the page. Within the process – feeling poured out of me, and into the painting. It captured words encoded and encrypted in time. I couldn’t read them at first, and had to decypher them, yet when I did, I was surprised by how resonant and accurate they were in terms of my

experience of anxiety. How does it feel, what is it like, how does it operate, what impact does it have, how could I escape, and more were all hiding within this painting. The painting is called waves of anxiety, because that is the instant picture that came into my mind when I first asked myself that question “what is anxiety”.

4.1 Vignette 2: Waves of Anxiety

It comes in waves…
Waves in my stomach, waves in my head, waves in my soul, fill me with dread
Waves in my heart, waves in my mind, life can be cruel, life can be kind
Waves of desire, and apathy too, waves of unknown, and knowing to do
Waves born of wind, waves born of tide, waves from the moon, waves I can’t ride
Waves in my stomach, waves in my soul, I need a boat which will make me whole!

Within the painting, you will see the waves, and notice that there are birds flying above the waves, you will see the rocks and the suggestion of a shore. The waves represent the shape and movement of anxiety. Within the first stage of interpretation – a poem came to me which described the somatic impact of the waves on my being.

The poem describes my memories of past cruelties and kindness. Of past hopes and dreams, and of a lack of energy and movement into despair. It describes the many causal domains outside of my control, and these are referenced in the origin of the waves from the wind and tide, and it also references a ”boat” which is the vehicle providing a safe way to shore or back out to see.

The birds are those who are unaffected by the waves, whether alive or dead, those who have escaped because they have flown into the heavens never to return, and for those who have discovered and flapped their wings of self-advocacy, efficacy and perspective and confidently taken flight. The rocks are a constant source of danger perceived and avoided by me. I have now harnessed this process of thinking in pictures, processing this through prose, and analysing it within the cognitive parts of my mind. I have realised that I have often done this in my early life – though by using the words of others through lines from movies and songs. I am now writing my own songs and directing my own movie…

Beyond the hyperbole and evocative words, there is potential forming from the abstract concepts. Notwithstanding that my ability to describe anxiety in such a rich way represents tremendous progress for me, together with the profound moment of immersion that cocooned me throughout the entire six minutes of “creation”. I now know that finding one’s boat is essential in terms of surviving anxiety as an autistic individual. The “boat” could be a person, a place, a special interest, perhaps medication, or something else that helps the individual.

The birds and taking flight could be through the acquisition of confidence, or by the giving up and taking of one's own life, as far too many autistic people do, shown by the staggering statistics of 66.6% of autistic individuals becoming preoccupied with and attempting suicide (Cassidy et al., 2018).

Ravens and Gulls! Ravens are often considered to be a portent of disaster and carrion feeders associated with death and decay. Gulls are representative of hope for sailors and a symbol of rescue and redemption, safety, and the end of suffering. There are Gulls and Ravens within the painting, and I have seen them both… I have always had an aversion to perceived help, and yet now, I see this help as a vehicle, and therefore somehow less triggering. I do not want to be a Raven anymore! A Raven within this painting comes in the form of a cure for autism. A cure in the form of removing autism, or a cure in the form of death. We are not there in terms of the former, nor would I want that, and in terms of the latter – it is no longer a premature option for me. We all go there eventually, and until then – I will ride the waves and do so onboard my boat! Surely hope floats.

Hope for me is more terrifying that fear! There are so many poems, aphorisms, epigrams, axioms, maxims, and considerable allegory built around the concept of hope, and yet, for me, hope is the process of opening yourself to another disappointment! I have "dared" to hope on numerous occasions – only to have had this hope dashed upon the rocks. When this happens, I feel that I sink lower than before and accumulate fear residue that adds weight to the negative side of the

scales. A byproduct of burned-out hope is a stinking acrid oozing compound that seems to cause corrosion in the form of an aggressive rust for me. Why on earth would I, or anyone want to hope?

4.2 Vignette 3: Hope Floats:

Hope floats, the floatiest of things, it can soar on the wind - though it doesn't have wings
Hope can have sails, a motor or oars - hope can release us and heal our sores
Hope provides solace, and emotional traction, hope can sustain us and prime us for action
Hope is a gift, received or given, hope for forgiveness for when we are shriven

4.3 Vignette 4: Hope Rusts

Hope rusts, it rusts with despair, and misery loves company, for they make a pair
Hope dies, when it is not fed, and fear creeps in – to fill us with dread
Hope is lost, and fear is found, perhaps it will stop when I'm not around
Hope lies, Illusion and myth, the dark side of hope, the lord of the Sith

4.4 My Boat Sank!

I will start by saying that the boat isn't an actual boat, but rather a metaphor for the vehicle described above which helps me to ride the waves of anxiety and gives me a sense of hope. I dared to dream and pursue this dream, and within this I have realised that having goals that I want to move towards (hope goals) as opposed to things that I want to move away from (fear goals), are at least equally terrifying, and I would also dare to say that in terms of residual miasma, hope stinks! I am referring to a specific instance, although there are many such instances over time. I was invited to apply for a job, and this personal invitation was based upon my experience. The role was within teaching within a higher education setting, and it represented the type of role that I have dreamt of, and indeed one which fuelled my PhD journey. I seemed to be a perfect fit, and I felt honoured and flattered to have been directly approached.

The application process was arduous, and I spent three days on the application, which was multi-level and required considerable writing and self-advocacy. I proudly pushed the submit button and noted that applicants would here back within the next seven days in terms of the interviews starting. I amended my diary to leave plenty of space in that week. To receive a seemingly automated message back which, in

summary said that I had not been successful at this time, owing to the high calibre of applicants was crushing! I went from a wonderful hopeful floating feeling – to a feeling of utter despair.

They had approached “me”, how could this even be possible! I hated myself at a visceral level! I slipped into depression and vowed never to apply for a job again! I survived this, although it sparked suicidal ideation born of self-loathing and despair. Once I settled, I realised that this presented a very dangerous situation for a vulnerable individual, and that when dealing with, and indeed actually courting an application from such an individual, one should consider a duty of care to protect the individual from this level of rejection. It also got me thinking of the many statistics which suggest that employment is a real issue for autistic individuals, and that perhaps this experience of rejection and its impact results in the individual not daring to “hope”. There are several important issues here, and an exploration of the impact of rejection for autistic individuals as a general concept.

I reflect upon the association with fear and courage, and the research that tells us, that courage is a resource that we tap into when fear is present. There are many definitions of courage, and considerable research on courage as a concept that are explored within this thesis. I posit, however, that it also takes considerable courage to “hope”, particularly where one has become terrified of rejection, and has experienced its horrors on many occasions – collecting scars and hope trauma over

time. “Hope Trauma”! A strong expression, and one that needs to be qualified and quantified.

The concept and prevalence of rejection sensitivity has given rise to a relatively new label of “rejection sensitive dysphoria”, and this term has been gathering considerable momentum within the world of neurodiversity, and it is not limited to one profile, i.e. autism, but also noted that many neurodivergent individuals with ADHD are experiencing this phenomenon. The term was coined by Dodson (1990) and further expanded with new insights into an experience, that whilst not a recognised medical diagnosis, something that is common to a variety of neurodivergent profiles (Dodson, 2020). I will not explore and unpack the prevalence here, other than to say that fear of rejection occupies a significant place in my life, and the many scars that I have picked up within this domain, together with my avoidant nature, in terms of avoiding instances where rejection is a very real possibility as perceived by me. Within this, I believe is the concept of “hoping”. Hoping to be accepted, wanted, successful, celebrated, good at something, yet fearing that you will be none of these things.

Hope seems to amplify the feelings of failure for me when I dare to go there. Falling over and falling down are both painful enough, but doing so from the ladder of hope means that you fall further and increase the impact. Hope goals are things that I consider containing a significant element of wanting to move towards something meaningful and matterful. Something that transcends wishful thinking. Hoping that it

doesn't rain today, for most people, isn't hoping in the true sense of the word, unless a river at the bottom of your garden is about to flood and ruin your home and life. I am referring to significant events, goals and results from both a hope positive and hope negative perspective, i.e., "I hope that it does" vs "I hope that it doesn't", or "I hope that it will" vs "I hope that it won't". I have included an abstract from my master's dissertation which explored hope and fear in detail below:

4.5 Excerpt from Master's Dissertation:

A personal account of hope

"My mother announced that she had cancer, and that the prognosis was highly negative. Initially there was shock, followed by fear and a sense of helplessness and loss of control or influence. Then, I looked for second opinions, searched for information, educated myself on the condition in order to gain some kind of control – in some way. When the second opinions echoed the first opinions, and even more helplessness set in, I even turned to searching for anecdotal evidence of miracles and where medical opinions had been wrong, and I prayed. It was almost as if hope was a life raft to me in a sea of fear. Some may say that I was in denial… Now that may be true, perhaps hope is a form of denial, but I would argue that it is a denial of giving in to fear and a suspension of fear. Hope for me attenuated the fear, it didn't stop it, there was always a background noise of fear, but through hope, I could function, I could keep going, I could gather my strength, rally round… If not for the hope, I would have to face and deal with the grief of losing my mother whilst she was still alive, and notwithstanding the fact that I believed that I had to be strong and supportive – for her. In this instance delaying dealing with the outcome was useful.

There are also times that I can remember, whilst serving in the military, where the ultimate fear that we all share, in the form of death came up more than once. I remember turning to hope in these instances. Frankly, hope was the only thing that kept me going, and it is a good job that I did, as help arrived, and I am alive to tell the tale. At one point, I recall that the temptation to gain some control by 'choosing' to give up started as a small voice whispering in my head and rose to the volume of an orchestra until hope arrived and dampened the sound. There are many survival stories where people have given up and died, and yet unbeknownst to them, they were a few miles from salvation. There are also stories, where others have kept on and survived. Is it hope that has kept them going? If it is, then clearly hope is a powerful tool for survival and one that isn't just an opposite to fear, nor is it something working against fear, it is a motivator that pulls us towards a goal, whereas fear is a motivator pushing us away. If one is pushing and the other pulling, then double the force is created to overcome inertia, get us going, and keep us going through adversity! So perhaps, if hope is a survival tool, its evolutionary origins may be shared with fear. Imagine a situation where there was no such thing as hope, and we were faced with an overwhelming perception that we are about to die, or that someone we loved was about to die. How would we continue to function without hope?

Ultimately, all hope in the world couldn't change the outcome for my mother, and yet we kept on, we coped with the eventual outcome, and hope gave us time to adjust, time to rally around, and the strength to deal with things - eventually. Fear is a very expensive emotion to feel. Fear takes a lot of resources and causes massive hormonal and chemical changes in the body. Fear is meant to motivate quickly and in the short-term, fear is a sprint! Fear drains resources rapidly. Hope, on the other hand is a marathon! Hope is designed to be energizing, exciting, and for the long haul. When we are terrified that something may happen, we are experiencing the fear mentioned

above. This fear may be all consuming. When we turn to 'hope', instead, we shift perspective and rather than fearing that it will happen, we start to 'hope that it won't'. In the case of an event or goal that we want to avoid, it may be a goal that we have not chosen, it may be one that has been imposed on us and that we have to deal with. For me, the characteristics of this hope are:

• Telling myself that it won't happen (denial which can be productive and can lessen the fear)

• Asking myself if there is anything that I can do to stop it from happening (productive and leading to ingenuity)

• Deluding myself, which may be enough to keep me going rather than acting like a rabbit in the headlights and freezing!

When we switch it around and consider a goal that we choose and that we really want, we 'hope that it happens'. In this instance, it is potentially the 'fear that it won't' that galvanizes us and keeps us focused on the goal. The interesting thing for me, is that I find that it takes more courage for me to choose to hope for something than for me to deal with fear that is imposed on me without a choice. I believe that the reason for this is that when one is born, the other is evoked at the same instant. If I hope for something, I will instantly fear that I may not get it, and if I fear, I will hope my way out of it. Now this sounds absolute, but if I am really experiencing hope, and not wishful thinking or nice-to-haves, then this hope evokes fear and in turn, if I fear for something, it evokes hope. For me, this represents further evidence that hope gives rise to fear, and that in choosing hope, I infer that you are opening the door to fear, and who lets fear in? Perhaps, only the brave! To explain this further; I believe that for hope to exist, the goal has to have real meaning to the individual. The goal could be an avoidance goal, or a move towards goal. This goal would not simply be a 'nice to have' like 'I hope it doesn't rain today – because I want to wear that dress'. It may on the other

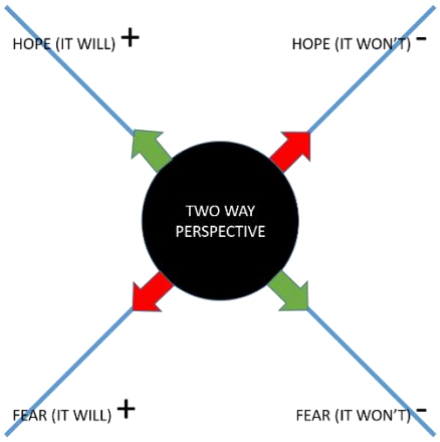
hand be 'I hope it rains because if not, I cannot grow my crops and feed my family'. The stakes are much higher with the latter, and with the latter, there is no control, no ability to choose an alternative pathway. In this context, if I am hoping, and maybe even praying for rain, I must also consider that there is the possibility that rain will not come, and the result of that could be lifechanging, or even life ending! If we are talking about towards goals, another example may be an athlete dreaming of winning the Olympics, training, eating, sleeping, breathing the very thought of what it would mean to win that medal. Putting everything on the line, family suffering, relationships suffering because of the focus needed… What would it mean to lose, to not win after all of that? Surely, it would take courage to dare to hope at this level, and if so, the prospect of failing would evoke fear"!

EXCERPT END

Within my Masters, I explored moments of hope and fear by interviewing participants about impactful life events such as Marriage, Birth, Death and Divorce, and significant promotions and redundancies. I did not choose these subjects, but rather set the context of meaningful life events that evoked either hope or fear. Interestingly, within a thematic analysis of the data, it became apparent that hope was never present without fear, and fear was never present without hope. They may appear very different, and yet the physiological reactions described compared directly, i.e. sweaty palms, racing heart, heightened sense of awareness and focus, and these things were described within hope and fear states. In addition, people described fearing – then turning to hope, then flitting back to fear. Several participants also described hoping, then looking over their shoulder and seeing fear behind them. There were differences inasmuch that it became clear that hope seemed to broaden perspective and give rise to taking positive action, whereas fear seemed to narrow

perspective and simplify action somewhat, with some even citing a freezing when the fear grew and became terror. The key takeaway was that they were two faces of the same emotion, and the polar model of hope and fear was synthesised from my research. I described them as the Clark Kent and Superman of emotions. They dress differently, look different, people even think that they are different – but they are always in the room together, and they are one.

Polar model of hope and fear (Coker, 2016)



Hope, for me, is more terrifying than fear, and yet I know that hope, for me is actually a form of fear. If I want something enough to activate hope – then I am already terrified of not getting it, and within this there is a deeply personal element that isn't present when I am frightened of the consequences of something happening that I don't want. There is a paradox within this that is hard to explain. At the heart of it all are the following key components:

1) Being and feeling rejected
2) Perseverating on really wanting something tangible and imagining having it at a visceral level – then not having it. For me there is no difference between not having, vs having and losing. In my being, I have already achieved the covetous thing, and by not getting it – I have lost it.
3) Struggling with emotional grading and regulation, and catastrophising

With the above in mind, I consider rejection to be one of the most unbearable experiences. It is my kryptonite (to go back to Superman). I am not resilient when it comes to rejection, and I feel that I lose a piece of myself each time I experience rejection. I feel a sense of erosion and corrosion deep within, every single time I don't get the job, or when the person that I want in my life doesn't want me.

Every time I experience criticism of some kind – it is perceived as a form of rejection to me. This fear overwhelms my desire to put myself out there. Aphorism such as "He who dares, wins" – a well-known military motto is rousing to many, yet as with many aphorisms, maxims, epigrams, and axioms, they are often out of context and not containing the entire truth. "Hope floats", is another one, and yet hope can be destroyed and dashed on the rocks. "He who dares" often loses, gets crushed, and slips into despair. The absence of hope, or perhaps even the opposite, I believe is despair, and yet we often cite "hopes and fears" in the same enquiring questions of others. What are your "hopes and fears", is something that is often asked. I posit

that hope and fear as described in my previous research, are two aspects of the same emotion as opposed to being opposites.

These days, I seldom dare to hope. There are enough fears to fill my life every day, why would I want to invoke the apex of fear in the form of hope? I am better off hiding, avoiding, sticking to the things that I know – and can control. Control is significant for me, and perhaps it is for many autistic individuals. Avoidance is significant, adherence to routine and sameness is significant. To what extent are the above things a direct result of the terrifying nature of hope? This is an interesting question for me, and one that perhaps links to the awful statistics relating to autism and suicide, which, for me links to being in a despair state.

There is a dearth of research within this area, and perhaps this correlates with the dearth of autistic researchers. Much of the research is quantitative as opposed to qualitative, and conducted by researchers from the pathological perspective, who are framing the questions and choosing the tools. Anxiety is both common and severe as an issue affecting autistic individuals (Kerns & Kendal 2014; White et al., 2010). The need to investigate the mechanisms and domains contributing to this, and the ability to cope with this level of emotional dysregulation has occupied considerable space within the research community (South and Rogers, 2017).

Within wood and Gadow's (2010) model, it has been suggested that fear of rejection and history of both rejection and victimisation were at the forefront as contributors to

social anxiety, for autistic individuals, and that these as general domain could explain some of the more specific anxiety domains, such as being late, being criticised, and not doing well when compared to others, or when compared to one's own expectations, and that they all link to fear of social rejection and humiliation and shame. Interestingly, I do not easily recall moments of embarrassment, yet I have many moments of shame to draw from that come easily to mind.

4.5.1 Margin Note: Sources of Anxiety

As I sit and ponder on one of the sources of anxiety for me, I reflect further on the subject of guilt, and its sibling shame. I am familiar with the term embarrassment, and the etymology of the term – which seems to share certain aspects with guilt and shame, although within its modern use, it seems to be a relatively light situational experience where we feel foolish and are exposed momentarily as being so. Often people laugh at the embarrassed individual, who in turn often laughs.

Embarrassment seems to be a relatable form of situational comedy, where the individual is exposed in a cringeworthy way – often doing something that many have also been caught out doing. It is this relatability that is one of the ingredients within the comical error in those embarrasing moments. I do not tend to feel embarassment within these moments, and I wonder why. Perhaps the relatablity part is less accessible to me, perhaps there is something at an emotional level that is different within my brain, and perhaps this relatability is one of the building blocks of conventional empathy – which autistic individuals are often considered not to have

in the same way as non-autistic / allistic people. Perhaps it takes me a little bit more time to reflect upon that which is often a confusing incident.

Following these experienced moments that others consider embarrassing, I often reflect upon my mistakes, which usually fall within the social faux-pas domain for me, and the feeling that builds up is either a feeling of guilt – if I have caused another pain, or loss, and, or a feeling of shame. Shame is an interesting social emotion where there are witnesses, judges, and consequences, and within this – it sounds rather like a prison!

Shame has been described as a sense, and as a state, and in the case of the former – linked to guilt, whereas the latter has been described as toxic / core shame (Lewis, 1971; Tangey, 1998). It is also noted that the individual experiencing shame, may not recognise their emotional state as shame, and in the case of autistic individuals, this may be even more significant – on the basis that the ability to recognise and identify emotions is often cited as being an area of diffculty and difference for autistic individuals.

An intrinsic connection between shame and denial has been made, and the latter is viewed as a coping mechanism within an intinsic ability to lie to oneself according to Dolezal & Lyons (2017) who outline four potential routes from which shame can arise: 1) acute shame avoidance behaviour; 2) chronic shame health-related behaviour; 3) social stigma and threat to social status, and 4) biological mechanisms.

They go on to emphasise the insidious, pervasive and pernicious nature and the importance of ensuring that the research and understanding of shame is central to the discourse within mental and physical health owing to the role within health-related illness and behaviours, and that the impact of shame is significant enough to be considered as an affective determinant of health outcomes.

Contempt born of judgement is described as a key emotion within the formation of shame according to Miller (1984) and Tomkins (1967). Greenberg et al., (2013) theorise that there are two domains, also described as realms where shame resides within self-constructs, namely within the self as bad, and within the self as inadequate, and they go on to postulate that judgement is a component within these constructs. Further works have considered the cognition of shame to result either situationally, as seen within moments of embarrassment, dishonour, disgrace, inadequacy, humiliation, and chagrin, or more deeply within an affective shame (Broucek & Francis, 1991).

The aforementioned words all deserve a detailed etymological explanation, although it is important to note that the individual qualia and associations of these words will mean something different to each of us. For the purpose of this autoethnograpy, I will describe my experiences and what these words mean to me. As I reflect further, I do not experience the light and humorous embarrassment that is often an ingredient within comedy, and as previously described, something emerging from relatability, but rather shame emerging from the domains described by Dolezal & Lyons, (2017).

The differences between embarrassment and shame are not clearly resolved within research, and for some, for example Goffman (1967) and Zimbardo (1977) they are grouped into a single category, yet for others, for example (Harre, 1983) they are seen as distinguishable in respect of the seriousness of the transgression in relation to the moral component of personal fault. Buss (1980) makes the distinction between lower levels of perceived personal inadequacy giving rise to shame as opposed to embarrasment. Embarrassment has also been linked to etiquette, whereas shame links to moral worth according to Schlenker and Leary (1982). One particular study showed that participants remembered embarrassment as being related to accidents and lighter than shame. They described these embarrasing moments as having a short duration and usually occuring where the transgression was witnessed by others, in contrast with a deeper feeling relating to moral standards that are internalised. It was suggested they served the purpose of cleansing within a momentary process of shame-sharing, then they were left behind (Miller & Tangey, 1994; Sabini et al., 2001).

My relationship with embarrassment and shame, I believe lies within my tendency to ruminate continuously, and in doing so, I start to realise that I have failed in some way. The terms embarrassment and shame, whilst not being resolved within research, and across cultures, have been separated in terms of affect, with embarrassment being somehow lighter and shorter in duration, as opposed to shame being heavier, more pervasive and linked to ones sense of self-esteem, and containing the element of being judged or feeling judged. At times, my heightened

sense of justice is turned inwards on my sense of self. I judge myself harshly, and I am left with a feeling of inadequecy and a craving for the opportunity to put this right. I have often found myself remembering a particular incident months, and even years down the road – actually bringing it up with the “witnesses” to my shame. I have noticed that sometimes people remember, sometimes they don’t, and on one such occasion, the individual did remember, and laughed about it as I attempted to justify my actions, which came from a lack of understanding of sarcasm at the time.

They proceeded to tell me not to make excuses, and not to “mansplain”. There was no closure, no justice and no resolution to be found within that moment. I had somehow emulsified the shame – which resurfaced in that moment. This event occurred with family members approximately five years ago. I have not seen these family members now for five years, and I will probably next see them at my funeral – if they attend. I have avoided them since, because I cannot bear to look at myself through their eyes, and this is a form of ocular empathy that I do seem to understand.

Shame, I have come to understand is a significant, and perhaps even central part of my anxiety and social avoidance. I have considered courage to be a force that needs to be accessed in order to overcome anxiety and fear, and I think of courage being a well of some kind. I feel that at times, this well has run dry, and at times its waters have been poluted by the toxicity of shame. At times I cannot drink its waters, lest I become gravely ill. I wonder if pride is the antidote for this toxity, and I wonder if there is something to purify the waters somehow? The waters are stagnant and tepid,

and life there slithers, crawls and twitches. Running water is a much better source to drink from. My shame seems to grow from within, even though the witnessing and judgement of others within external events is the original source, I am the ultimate judge, jury and executioner within a corrupt justice system. I have very little kindness and compassion for myself. I need to drink from a different pool somehow…

4.6 Vignette 5: Chasing Waterfalls

"I'm often moving around from thing to thing, and this stops me sitting with my stagnant self. Perhaps this perpetual movement of body, mind and attention is some form of self escape".

I crave being around water, particularly fresh water lakes and waterfalls. The cold freshness is sublime to me, and yet If I were to describe myself as a body of water, I visualise a stagnant pond with scum, toxic algae, and black oily slithering life. I need to somehow purify this inlook, which I know is polluted with oily shame. I painted the above waterfall, and I imagine my insides feeling this way. Clean, cool, clear, feeding a pool of pride, and the spray nourishing the surrounding foilage. I

want to be this waterfall, and I want to be surrounded by those who are nourished by my presence. I also painted the ochre infused stagnant swamp below…

4.7 Vignette 6: Swamp Life

Procrastination & Demand Avoidance: A source of anxiety

One anxiety inducing domain for me lies within tasks. As soon as a deadline, or expectation arises, I will have a visceral reaction to it, and seek creative ways to avoid said task. Much of my demand avoidance arises from the inertia that I feel when transitioning from something that I want to do, to something that is expected of me. I would add here that I have the same reaction to the things that I decide to do for myself. I believe that somehow, I manage to create an expectation of myself, and become the taskmaster of my own demise.

Procrastination is my secret weapon, and a soft and non-confrontational method of avoiding tasks, yet it is also a form of self-sabotage. It is the enemy behind the lines. Some of the tasks do seem to go away, but many build up, and keep coming

back in numbers until a veritable battalion of task soldiers arrive at my door. It is guerrilla warfare at its best, and it is not kind. They are insurgents comprised of small mobile groups of soldiers undertaking coordinated action, using surprise tactics and sabotage. They are often behind enemy lines disrupting operations. They hold me captive, and rarely comply with article 17 of the Geneva convention. They frequently use mental and physical torture, and coercion as the tools of their trade. I have long forgotten why this war started, but I want it to end. Every day I courageously fight against the insurgent enemy in this war of attrition. It is winter here now in me, cold and unforgiving.

4.8 Vignette 7: A slippery Slope and the Summer Snowfall

I sit with my laptop open. The sun is shining and the breeze is enticing the clouds to skip across the sky. It is the height of “boing”, and the chorus of birds is calling me into the garden. Flappy fripple birds, Stabby stipplers, and titty harkas. I am a

pathological procrastinator (undiagnosed), and not even sure if this is a thing. They say that “a picture paints a thousand words”, and I have over a hundred already. All watercolour, and all of them painting out my heart and capturing my experience. I am a prolific painter now, having taken up the enterprise during the zombie virus pandemic as a way to express myself eithin my PhD. So if I submit thirty pictures for my PhD, does that equate to thirty thousand words? Job done – if this is the case, and yet, I know that you, the reader, may not be able to speak my language without interpretation.

The paintings seem to capture my experience and unlock my words. The process behind this, I posit, is that I code the painting with information, colour, shapes, smells, memories and emotions, and that these things provide a far more effective coding system for me to capture information, especially when this information requires an understanding of self. Feelings, thoughts and emotions are difficult for me to access and describe. Painting first, and then talking, or writing about my painting seems to create a bridge for that gap. It is then as simple as reading all of the information within the painting. This gives me the dichotomy of distance from my emotions – whilst giving me access.

Painting, for me has provided a a salve to the inflammation of my writers block. My tendency to avoid tasks is a slippery slope and uphill struggle, and these are metaphors which capture the experience. I am a man for all seasons apart from spring, summer and autumn! I am locked in the winter of my own discontent.

Procrastination, for me creates a vicious cycle which starts with anxiety relating to starting a task, avoidance and replacement by doing something that I want to do – then feeling even more guilt and anxiety for not doing the task in the first place, and so the cycle repeats itself. I am unsure as to why I cannot find traction relating to tasks, but of course, I understand the concept of traction relating to vehicles attempting to navigate slippery surfaces, and as a metaphor, the image of a slippery slope came into my head and slid onto my watercolour pad in Vignette 7 above.

Of course, even once a driver gains traction, whilst going uphill, they also need to maintain traction whilst coming back down, and of course stopping is also a very real area for concern. Starting, stopping, and steering within low traction environments are all huge concerns for me, and I reflect upon these “low traction” environments, in comparision to “high traction environments”. Fly fishing, Metal Detecting and Painting are all activities that I enjoy, but believe it or not, these are medium traction environments at best. The fact that they require some planning, packing my equipment to leave, unpacking upon arrival, and repacking to leave – are all choke points for me, and reasons not to go in the first place. This is quite odd, given how much I enjoy these things.

Work related and personal admin related tasks are all low traction environments, and the fact that I am not interested and do not see the benefits in doing the tasks often means that unless they are desperate and that there are perceived and imminent consequences – I often fail to gain any traction. High traction tasks are few,

and include playing on my playstation (no planning required), and riding my motorcyle (again, no planning required), although interstingly, I tend to ride to the same place, namely a local motorcycle café which is usually full of the same people who regularly hang out there talking about motorcycles.

There was some planning the very first time that I went to this motorcycle café, and yet the huge interest that I have in motorcycles, together with being buoyed up by taking delivery of a new motorcycle – seemed to give me the traction that I needed to “get going”. I believe that this traction is compised of Courage, Energy, and perceived utility. Certainly part of my tendency to procrastinate comes from an underlying feeling of anxiety, but also highly spurious energy levels. If there is a high enough percived need or want (building blocks of utility for me), then I may gain traction. Similarly, on a high energy day, I may find traction.

On extremely rare days where my anxiety is low, or courage high, and my energy is greater, notwithstanding that the aforementioned could be linked, and that this is combined with a feeling that the task is useful and worthwhile; I have proven that I can do and achieve incredible things. If I were able to fully understand my traction triggers – then I wonder if I could break the vicious procrastination cycle. For me to break this cycle after almost fifty years on the planet, would be transformative, and the term transformative practice, in a broad sense refers to any complex and coherent activities that produce positive changes in a person (Murphy, 1992).

Within autoethnography, the sense of integration, connection with myself, harmony, peace, and joy are all present, and the undertaking of a PhD within a specified timeframe has required the breaking of my procrastination cycle. Within wider research, there is a dearth of understanding in relation to contextual autistic experience of knowing and being within the context of self discovery and identity, and this is particularly true within the context of communities of practice and social domains in which the individuals participate (Wenger, 1998). Thus far, the autism landscape in relation to behaviours that are perceived as challenging, has been pathologised and led by the framing of constellations of neurological disorders. Within the autism community, there has been a drive to recognise Pathalogical Demand Avoidance (PDA) as a medical condition, and this presents a paradox insasmuch as the same community often fights against the “medical model” – in favour of a person-led social model. The framing of “disorder” is not necessarily the whole truth, but rather a social construct based on cultural norms and expectations, and social power dynamics (Armstrong, 2010).

Procrastination may not be a unitary construct, but rather a compound of different states, cognitive and executive functions, with many explantaions and determinants (Rosenbaum & Webb, 2018). Many consider procrastination to be a cognitive focussing issue relating to that which we intend to, or are supposed to do (Steele, 2007; Dewitte & Schoowenburg, 2002). Oxymoronically, when considering that which “motivates” procrastination, we have to consider the variety of presentations

and sequela. There are several domains and understandings relating to procrastination, and Steele (2007) conducted a meta-anaysis on the subject.

The term, procrastination is often used in a derogatory sense and has a moral and characterlogical slant relating to a failure of will, or a loss / absence of self control, and difficulties inhibiting non-goal oriented thoughts. Other labels such as laziness and lack of self discipline are often used within the same context. These labels are oft placed on certain age demographics, such as millenials who are frequently in the firing line for these types of ad-hominem virtue and value lacking accusations (Rebetez et al. 2016; Grund & Fries, 2018).

Poor cognitive evaluation also comes into the mix when considering how autistic individuals weigh up consequences of actions and innactions, notwithstanding that time management also fits into the executive function part of the equation (O'Donoghe & Rabin 1999). Other perspectives consider self determination, and also situational demands relating to conditions within our external environment, and as such, perhaps procrastination is an adaptive and coping approach that is somehow overactive in the case of autistic individuals (Deci & Ryan, 2000). Value-based views suggesting that procrastination relates to our axiological perspective, and even influenced by our view of self and self-esteem (Grund & Fries, 2018).

Anxiety also raises its head in the frame of emotional irrationality, and the many emotional pulls and ties that guide autistic thinking and acting (Jaffe, 2013). The

anxiety that arises from the task and accomplishment, or lack thereof, causes procrastinators to delay the task on the premise that one will pick it up when one somehow feesl better about it, and yet, one seldom does! The result, for me, is often guilt and shame, or more pressure.

I consider procrastination to be an effective short-term coping strategy for me, yet the cause of considerable anxiety for me. It is a little like alcohol inasmuch that it is also the paradox to blame! I procrastinate because I am anxious about the task, and yet the procrastination often leads to some form of failure, letting people down, and even more anxiety – born of guilt, shame, and perceived consequences. Fear of failure increases the anxiety, which in turn results in moving even further away from the task at hand. I self-medicate with safe activities, and enjoyable activities such as gaming. The gaming itself means that I don't have to go out, I don't have to prepare (other than turning the console on and reaching for the controller and changing the HDMI source on the television). When I compare this activity to fly fishing, metal detecting, or painting, the level of effort and preparation is minimal. The activity of gaming also absorbs my mind without fear that I will have to have an interaction with another human being. It also silences my head noise very quickly owing to the immersive nature of gaming.

There is considerable thinking and problem solving within the genre of games that I choose, and the games are always heavily character driven, and as such, I get to live vicariously through these avatars. I am aware of the judgement of others,

however, who often want to “get me away from the unhealthy amount of screen-time”. I can always refer to opposing rhetoric through the recent studies that suggest that gaming has its benefits for hand-eye coordination, mental agility, and even intelligence. I don’t believe a word of it mind you, I am cognisant of the fact that gaming interrupts my already spurious sleep patterns, and that it pulls me away from the far more productive, and eudaimonic activities of fly fishing, metal detecting and painting, or from work-related activities. I am riddled with guilt and shame, and regularly feast on this warmed-up prison food. Beige and full of nothing. High in calories yet nutritionally bankrupt. A hedonic prison sentence from which parole is elective. Will I grow old in this prison?

4.9 Vignette 8: Life in prison: A Self Portrait (carved in wood with a penknife)

Procrastination is the crime for which I received a life sentence. Whilst I am granted the occasional conjugal visit from my spouse, Joy, I am guilty, and will never be released. I'll probably die here!

Work: A source of anxiety

Work is an area that has continuously provided a source of anxiety for me, and according to Müller, et.al., (2003) for autistic individuals widely, with prevalence of unemployment rates ranging from between 40-60% in relation to being in full time employment. Possible explanations are discussed by the authors including job search barriers, application stages and interviews. Staying within work is also an area that presents challenges in respect of flourishing and performance, which has been correlated with self-efficacy and self-advocacy (Judge & Bono, 2001). An additional and significant finding within the research related to communication and change-management as being significant contributors to lack of success once autistic individuals had achieved employment. Hendricks (2010) also noted similar and moved towards developing key strategies to support autistic individuals at work. Two significant areas considered direct and unambiguous communication and individualised support. Carver and Schier (1989) suggest positive coping in the form of self-solutions and acceptance were key to long-term employment success, as opposed to avoidance-coping such as denial and resignation. In terms of the latter, and in consideration of my tendency to avoid, I present the vignette below which describes a work experience where I reacted badly to change, and perceived

demands, and embodied resignation as the ultimate reclaiming of control, and correction of the injustice that I perceived when the changes were thrust upon me.

4.10 Vignette 9: New Work, New Work: So scary, they named it twice!

They did it! The zombie virus has improved somewhat, and apparently it is time to get back into the office! I do not want to go back! How do I know how I will feel on any given day? I cannot commit to this, and the thought of going back into a physical environment is spiking my anxiety! The lights, the people, the journey there, the parking, the journey back, the weather, the unknown…. No! I have the song New York New York in my head, and I remember the lyrics "it's up to you, New York, Neew Yooooork" . And yet, it isn't up to me, is it? I take control, and I leave! I am now personally contributing to that wonderful statistic of sixteen percent of autistic individuals being in full time employment as noted by the National Autistic Society (2023, and that makes me proud (sarcasm). My feeling of angsty rebellion and justice done subsides, and I am left with a residual feeling that I am struggling to describe. Failure is in there, rejection is in there, abandonment is in there, and I don't think that there is any one word to describe it, although perhaps bereavement comes close.

I am also left with the residue from the burning of the fuel that powered my thrusters, and this fuel was injustice. Injustice is something that has powered me my whole life, and often led me to some form of loss and sacrifice. I have lost friends, family, jobs, money, and faith. Justice seems to be an expensive thing, and ironically it has also been my incarcerator. Justice rarely seems to result in a positive outcome, or perhaps it is just me, and yet I seem to fight on, and through all the pain and loss it has caused me, when I am fuelled by injustice, I rarely feel anxious! I posit that injustice trumps courage in terms of its ability to overcome fear, and I suspect that when felt, a sense of "injustice" is the mother of anger, disgust, and the spouse of courage. The progeny of Injustice and Courage has spawned powerful children in within me. They live in me, and perhaps I am their house. It certainly isn't a home, it is a barren place, and more of a prison. It is grey, colourless, heavy, oppressive, and its corridors are filled with a funk of decay.

4.11 Vignette 10: A life Sentence: Guilty of being me

My mind is a prison. The walls are obsession, depression, justice and defence. The floor is fear, the ceiling is hope. Beneath the floor is the hell of despair. The air that I breathe is recycled with loneliness. Incarcerated for the crime of procrastination

by a judge called self. What therefore lies above the ceiling? Is it heaven? I want to go there. Anxiety is my cellmate, and bad company. We live together and defecate. What do I have to do to be placed in isolation. I rage. I'm there.

Anger fuels courage! I reflect upon this and consider the times that anxiety insisted that I remain silent. Anxiety is a warden who patrol the corridors in the prison of my mind in a cruel vigil. Anger is my liberator. Anger, for me relieves anxiety and doubt, though it is short lived and someone hedonic in nature. Why is this important? Emotional precision is as difficult for me as fine motor skills. When my anger erupts socially, even though it may be born of righteous justice, I have noted that one is seldom perceived as "right". There is frankly too much social ammunition and too many broken tacit rules for people to utilise in their defence, and in my vilification. One's perceived wrongness will overshadow the original rightness that prompted one to raise one's proverbial head above the parapet! Autism has been described as an organising metaphor for social isolation and bodily imprisonment by Bettelheim (1967) within a paper titled "The Empty Fortress: Infantile Autism and the Birth of the Self" and as a trope for incommunicability within the work of Pinchevski (2005). I am a villain, I deserve to be in prison, and in solitary confinement. I am as guilty as sin!

4.12 Decisions: A source of Anxiety

Decisions are a constant source of anxiety and energy drain for me, and the decision making process and its links to the struggles faced by many autistic individuals has been discussed within the previous chapter when considering decision-making as an anxiety-inducing domain for autistic individuals for example (Luke et al., 2012).

Decisions and forwards movement take courage for me, and this is considered within the vignette below (Vignette 13: Timothy Trout). This vignette is split into two parts, with its counterpart following (Vignette 14). It is split into two distinct parts because within the same cherished activity of fly fishing lies both a source of anxiety and a source of courage for me. The anxiety lies within the planning and decision-making process, as opposed to the activity itself. The strain of decisions is described within the vignette below.

4.13 Vignette 11: Timothy Trout Part 1

Decisions decisions… Hard for me, and yet as I arrive at the lake, I am excited about one. Which fly should I use? The sun is sharp like a needle and the wind is taunting like a badger as it snatches with a brickety-brock. "Bright and breezy is never easy" repeats itself in my head intrusively – a fly fishers' axiom. Trout is the treasure today.

Blue, rainbow, and brown colours of promise play a tune in my head. Blue thoughts sound like a windpipe, brown makes a "phlatt", and rainbows are always "up above the streets and houses". I think of George, my best friend, and I pat him reassuringly in my pocket. The wind is compelling me to choose a heavy rod and line to gain control against its uncertain taunt, and I am choosing a hot-head nymph. "You sexy beast" I say continuously as I am caught in a thought loop, not realising that another fly fisherman has approached. The word "nymph" seems to make an association in my mind – which pushes the play button on my Tourette's. He seems to change his mind about approaching, and I am gladly sad in that moment, or am I sadly glad…

The planning and starting of any activity is always a challenge for me, and this procrastination even extends to activities that I love. By the time that I have thought about packing up my fly fishing gear, where I am going to fish, which flies I will use, where I am going to park, who I may meet, what I am going to say, what they are going to say, can I control my tics, and more, I often abandon the mission in favour of doing something solitary and easy, such as playing on my PlayStation 5, which, I might add, is never on-line, but rather aways single player and alone. I am usually happy doing this, although the echoes of my parents from the past about "you must get outside", "it isn't healthy to be stuck indoors on your computer" do play in my head. These utterances where never epistemological, nor grounded in research of course, but one does feel a degree of guilt, or perhaps shame about not going out, and this does occasionally act as a form of fuel to overcome my inertia.

4.14 Vignette 12 Timothy Trout Part 2: Anxiety moves into courage

I cast! A beautiful cast. I am a metronome of perfect rhythm. The wind is one of my instruments, and my rod of concinnity provides the concussion to the string of my line. My fly flies through the air, and why wouldn't it, and I chuckle as I think about my artificial fly flying. It lands with a plooop, which is a strange horizontal version of a vertical plop. I straighten my line and make contact with it. Rod down, line straight, as the badger makes waves and ripples across the peaty brackish water. Brockety brack, brockety brack, brockety brack. My mind talks to me as I think of a Badger on a paddleboard.

A snatchy tug which feels like plastic is felt on the fingertips of my line – and I strike! Heavy makes a thung sound in my head. A springy heaviness. "Fish on" I yell with Brian Blessed's voice. "Gordons Alive" I start to chant. I am filled with excitement which enters through my toes. I am in the water, and it is over my boots. Excitement is wet feet – surely.

I am riding a fish upon the saddle of knowledge and unbridled joy. I give the fish its head and now it is riding me. I bring the fish closer, it is tired now, and I am winning. Did the fish catch me, or did I catch the fish? I position my net, and the fish surrenders to captivity. In that moment, I feel such tenderness for the fish, and I am concerned only for its safe release. I am a surgeon of kindness as I gently remove the hook, whilst ensuring that the fish is still in the water. I know that the fish is called Timothy Trout. The audience calls for an Oncor. Oncorhynchus mykiss, and I do. A loving kiss and wave goodbye as Timothy releases me back into captivity.

Timothy trout part one (Vignette 13) explored my beloved pastime of fly fishing. A pastime that, although is extremely enjoyable, involves planning and the threat of being social. It is something that I avoid, yet I know the other side waiting for me when I arrive upon the lake. It is this part that is described within Timothy Trout part 2 (Vignette 14).

Once I move into immersion, any anxiety that I feel seems to be somehow a clean form of excitement. When I hook the fish, I immediately worry about landing it, and

netting and unhooking it safely. This can take a high degree of coordination, but somehow, although my heart is beating, my adrenal glands pulsing, and at times my sphincter flapping, I emerge stronger, better, energised and drained at the same time. My anxiety within exciting moments, acute moments, does seem cleaner than the pre-emptive form of anxiety - whilst I am predicting a potential outcome. For me, one is a sticky, corrosive and erosive state that wears me down, whereas the type of anxiety where I can “act”, seems to provide enough energy to somehow burn itself away in the glorious moment.

I am actually better in a crisis – than the potential of a crisis! Interestingly, my anxiety for fishing seems to get worse when other fly fisherpeople are around to witness my “fishing”. When I see them, I often stop fishing and sit down to have a conversation so that they don’t proffer advice to the “novice” or try to “help” when they see me fumbling trying to land the fish. Their “intervention” feels like an intrusion somehow. I have recently been watching Mortimer and Whitehouse go fishing on the TV, and I have fantasised about having a Fishing Friend like Paul, or Bob. Bob is wonderfully useless, clumsy and always joking, whereas Paul takes fishing very seriously and often chastises Bob for his shenanigans. They seem to have their best moments when off the bank, in transit, or after a day of fishing. I relate to this since I don’t want the intrusion whilst fishing, although I would like the friend to go with and to speak to at regular intervals – when I felt like it, then for them to go away when I want to be alone.

4.15 Chapter Reflections & Conclusions

Within the previous chapter, anxiety was explored largely from the pathological perspective. Thus far, studies from neuroscience have focused on amygdala dysfunction, correlation between decision-making processes and anxiety, and the statistical frequency of anxiety within the autistic population. Other research has captured the autistic experience within qualitative questionnaires that aimed to explore common anxiety domains, although they were conducted within structured Likert questionnaires with the narrative being set by the researcher. There is a dearth of research that considers the unique autistic experience of anxiety – with considerable research focussing on anxiety and its impact generally. The research correlates with autism research generally in terms of social interaction and communication being a common anxiety domain, together with routines being disrupted and decision-making also being sources of anxiety. These domains of challenge and differences are described within the diagnostic criteria for autism.

Within this chapter anxiety has been explored from a personal perspective as experienced, including, when, where why and how anxiety manifests for me. I chose this approach to capture and honour the lived experience of anxiety from my own perspective as an autistic individual. I posit that a qualitative approach at this level of depth is the only way to capture the autistic lived experience of anxiety, fear and courage, together with where they intersect. A caveat lies within the level of introspection and self-explication that is required to go this deep, as it may be initially beyond the reach of some autistic individuals, and I am no exception, though with

trust in the process and support and guidance I became so much more than the mind blind robot that the common stereotype presents within the context of autism. Within this chapter I asked myself the questions of what it like was to be autistic, and anxious, and what anxiety specifically felt like to me. I had difficulties conceptualising and articulating this and struggled finding the adjectives. Instead, I painted the picture 4.1 Vignette 2 “waves of anxiety”. Once I had the picture, the words flowed for me. All I had to do was interpret the picture, which was encoded with emotion, reflection, and clarity of thought. This was an epiphany moment for me, and one that even led to an accompanying poem. This was the moment that a knew modality was born for me. I believe that through this alternative medium, I have more words and a greater depth of emotion than I had previously imagined. Throughout this thesis, many of my words and stories have flowed following the use of painting my heart onto the page. Watery borrowed tears of anguish and joy accessed with a pot of water, a brush, a pallet, and paint.

Within the exploration of fear, it was noted that Albrecht (2007) suggests that there are five fears that we all share, and that all fears fall within the following domains, existing on a hierarchy: Extinction, Mutilation, Loss of autonomy, Separation, and Ego Death. The preoccupation that many individuals have with connecting, maintaining connections, and being part of a whole, may suggest that this behaviour is driven by the fear of separation, as defined by Albrecht (2012) within the five fears model. Being part of a social whole or a herd has positive survival implications and may be the predominant fear for human beings generally (Albrecht, 2012). That

being social is so difficult for me, does not suggest that I do not want to be social, but rather that it is an area that has generated considerable past trauma and still causes issues for me in the present. I do not have a social network, nor any friends, and therefore, I do not benefit from any emotional protection and buffering that this brings.

Within this chapter, I have considered the question of whether the preoccupation with social connection, and inherent fear of isolation is universally human or whether this connectedness and fear of losing it and becoming isolated, is a fear that occurs more frequently in the non-autistic population as opposed to being a main driver for autistics. Loss of autonomy is certainly the fear that occupies my mind more than any of the other above domains, and I consider whether this may be the predominant fear for other autistic individuals. This could offer a possible explanation for solitude and moving away from social interaction, on the basis that as soon as another person enters a situation – there is little perceived control, and considerable unpredictability. This is especially relevant where one struggles to understand the perspective of the “other” or lacks the ability to read and recognise the considerable nonverbal communication signals, cues and general communicative content that seems hidden. I consider that acute fears will always take precedence over vague hopes, and that I always hope vaguely and always fear precisely.

I am far too preoccupied with avoiding the unpredictable natures of people and running away from them to act upon my vague hopes of a friendship. This may offer

an explanation as to why predictability and routine is so critical to autistic individuals in fostering a sense of control of their environment. According to Jones and Harwood (2008) predictability can provide a sense of structure and routine, especially where people are the variable. Becoming familiar and comfortable with a person or group – within a structured environment or context can provide a degree of predictability that can attenuate some of these challenges. Knowing what to expect during a social event, can improve confidence in interacting with others, leading to better social outcomes and experiences.

Predictability has also been linked to fears and anxieties arising from sensory processing differences, which can lead to being easily overwhelmed by unexpected sounds, lights, or other sensory input (Baranek, David, Poe, Stone, & Watson, 2006). The lack of predictability in such situations can be highly distressing, leading to anxiety, stress, or even sensory overload, whilst Predictability can facilitate the ability to anticipate and prepare for these sensory experiences, which can significantly reduce the negative impact (Jones & Harwood, 2008).

Social interaction is an anxiety domain for me, and for many other autistic individuals according to Osterling and Dawson (1994). Autistic individuals often struggle with social communication and understanding social cues, and they may find it challenging to interpret facial expressions, body language, or tone of voice, which vary so much from person to person, and when key information lying within social cues is missed – it can lead to negative outcomes, judgments, and consequences.

The proclivity that many autistic individuals have for routine and sameness is something that has been observed and has formed part of the accepted characteristics of autism within the attainment of a diagnosis and within the day-to-day lives of autistic individuals (Boyd, Mc Bee, Holtzclaw, & Alessandri, 2009). Many autistic individuals find comfort in the repetition of activities and adherence to specific routines or rituals, and predictability can foster a sense of security and reduce anxiety in situations where there is uncertainty or a perceived lack of control. Where there is a core of predictability and stability it can provide a base where some uncertainty and unpredictability can be tolerated (Jones & Harwood, 2008).

The concept of “Autistic Anxiety”, is one that suggests the potential for a concept of “Autistic Courage”, which this thesis will explore in a later chapter, together with the exploration of connections between them. The context for this is to consider whether there are unique factors, presentations, drivers, situations, and components within the experience of, and interplay between anxiety and courage through an autistic lens. I am cognisant that whilst I am autistic and therefore the lens that I refer to is autistic, there are limitations since I may or may not be representative of other autistic individuals. Whilst a direct comparison to others may seem irrelevant within the scope of the autoethnographic method that I have chosen, I worry about how I compare to others and find that I compare myself often. Perhaps some of my anxiety stems from this. For me, it is the lack of predictability when dealing with others, born, I suspect, from my lack of insight into the minds of others, combined with my lack of ability to work out their often-spurious motives, arising from a limited grasp of body

language and social cues. Of course, my set point is also usually to trust, and this rarely serves me well.

I suspect that throughout the process of my autoethnography, I may consider the context of how others may be processing fear or anxiety, and how they are able to access courage, and this may give some insight into the mechanics of courage and any antecedents. I recall my mother once saying that “courage is catching”, and whilst this aphorism never led to a full-blown disease model of courage, we certainly do have numerous studies around the concept of social contagion. One such study is the famous "Framingham Heart Study" which tracked the health behaviours of individuals in a small town in Massachusetts. In this study, Christakis and Fowler (2008) found that people who had friends who smoked, were more likely to smoke themselves and that this effect was even stronger than the influence of family members. Similarly, a study conducted by Haines and colleagues (2016) at Yale University found that people who were exposed to social media messages promoting healthy eating were more likely to change their own eating habits, although, a limitation and criticism of this study relates to the consideration that social media, in terms of content can be elective, and therefore individuals may well be gravitating to this content, thinking about this content, and being fed this content (no pun intended) owing to the pixel and cookie settings that continuously capture data relating to our preferences, choices and habits.

Another mechanism may also be at work here, and it belongs to the cognitive bias family, and it is called the frequency illusion, also known as the Baader-Meinhof phenomenon it is a cognitive bias that occurs when a person starts to notice something more frequently after it has been brought to their attention (Zwicky, 2006). This phenomenon was later named after the German terrorist group Baader-Meinhof, which appeared to be mentioned more frequently after its name was brought to people's attention (The Economist, 2013).

Research suggests that the frequency illusion occurs because our brains are constantly attempting to filter and process a tremendous amount of information, and they tend to give more attention to things that are familiar or salient to us (Friedman & Forster, 2010). As a result, when we encounter something new or unfamiliar, our brains may not register it as important and may quickly forget it. However, when we encounter the same thing again, our brains start to recognise it as familiar and begin to pay more attention to it (Nickerson, 1998). A simple and familiar example can be seen where an individual learns a new word or hears a new song, they may start to notice it more frequently in the days that follow. However, it's not because the word or song suddenly became more prevalent; rather, the person's brain is now more focused on it and is actively seeking it out (Wardlaw, 2011).

The frequency illusion is both helpful and a hindrance. On the plus side, it can help people recognise patterns and make connections in the world around them, it can engage people with others that they perceive as being part of their tribe, it can

facilitate the noticing of similar traits and characteristics that have the potential to bond human beings together, yet on the other hand, it can also lead to confirmation bias, where people start seeing evidence for their beliefs everywhere, even if it doesn't exist (Nickerson, 1998).

Social contagion theory has also been criticised for oversimplifying the complex social dynamics that influence behaviour. Some researchers argue that the theory fails to take into account the role of individual agency and choice, or the influence of larger structural and social factors such as poverty or inequality (Valente, 2012).

Despite these criticisms, social contagion theory and the frequency illusion, and perhaps even the availability heuristic model can give us insights into the aforementioned herd behaviours that exist within human relationships, and my mother’s aphorism and assertion that courage is catching is an interesting concept. If we consider that the human being is a vector for the disease of courage, after Covid-19, we also know that self-isolation was seen as the most reliable way to keep safe and free during the recent pandemic. Does isolation therefore mean that we are not “catching courage”, and more than this, perhaps we are not building our immunity to fear!

In terms of susceptibility to cognitive biases, a significant model exists that acknowledges the role of cognitive biases in the onset, maintenance, and recurrence of Major Depressive Disorder “MDD” (Beck & Haigh, 2014). Within autistic

individuals, research is inconclusive, inasmuch as that generally, the human experience of cognitive biases in terms of frequency is consistent within autistic and non-autistic populations, and that factors such as genetics, social aspects and adverse childhood experiences are the major contributors. That said, one study focused on Major Depressive Disorder (MDD) suggested that autistic individuals displayed significantly better memory formation and integration towards negative events and information, and a processing style that is orientated towards fact and detail, with weaker theory of mind and executive function components that are associated with the ability to facilitate positive self-delusion, such as “looking on the bright side” (Happé & Frith, 2006).

From the research, we understand that anxiety exists within autism with staggering frequency, and this is significant, and yet we still do not fully understand the mechanisms behind this (Wood & Gadow, 2010). Some research considers neuroscience and points the cause towards the dysfunction of the amygdala as seen within (Baron-Cohen et al., 2000; Schultz et al., 2000). There is considerable research reviewing the efficacy and effectiveness of medical and pharmacological anxiety treatments in respect of their fitness and purpose for autistic individuals (Nadeau et al., 2011) and we are also moving towards the consideration of the unique presentations of anxiety within autism and the need to capture the autistic voice within the development of modalities and research (Botha & Cage, 2022).

As previously mentioned, a sense of connectedness to others with a sense of our own identity is suggested as one of our most basic human needs, and that which points towards two of the five fears that we all share (Albrecht, 2012). These macro-level fear domains are described as: Fear of Extinction; which of course relates to the fear of death and dying; Isolation/Separation, which relates to the fear of being alone, or separated from those whom we love or who care for us; Mutilation, which relates to the fear of being damaged, whether by injury or illness; Loss of Autonomy, which relates to a loss, or lack of control, or having said control taken from us; and Ego Death, which relates to shame, embarrassment, having our value base damaged and our identity challenged (Albrecht, 2012). As macro domains, Albrecht explains that all other fears stem from one of these sources – no matter how specific and complex they may seem, and they may not operate in silos, but rather that there could be links between them and multiple fears operating at the same time.

Within the autoethnographic content, I have conceptualised the shape, colour, and texture of anxiety within the vignette “waves of anxiety” (as discussed above), and I have discussed a major source of anxiety for me lying within the concept of hoping, planning, expecting and being let down within the concept of the Vignettes “hope floats” and “hope rusts” (4.3 & 4.4). The crushing feeling of being let down after daring to hope creates waves that my boat can’t cross. This anxiety sticks to my boat like barnacles, ever growing and spreading, and the salt water corrodes the integrity of the hull constantly. In a model that I conceptualised, I described anxiety as a sticky

state, that is erosive and corrosive, and this is depicted within the anxiety chain/ continuum below:

4.16 Anxiety Continuum

I posit that anxiety, is a form of fear! If we consider fear on a continuum, I would conceptualise it as follows:

Anxiety moves through a continuum, starting at a sense of arousal, where we become aware that something is changing within our internal or external world, or something is about to happen that is going to present either a risk or a reward, and we become aware of this in a predictive sense. It then moves into anxiety, which I have coloured red because it is a dangerous and insidious thing that is erosive, corrosive, and caustic to our being.

If we are lucky, it may become fear, which, in itself, is not the enemy! Fear primes us for action, whether it is moving towards, or moving away from something. If we survive this, and depending on the ending itself not being traumatic, we may even feel a sense of being elated and exhilarated, and then we return to normal. If it reaches an apex and becomes terror – then perhaps the gravity is too much, and we

may freeze! We hear these terms, fight, flight, and freeze, and they are synonymous with fear. Anxiety, however, is a “sticky” state, and that is the problem! It is immature fear where we live in our head - attempting to predict that which “may” happen, and as such it can remain with us in the long-term, rather than maturing into fear where it can resolve. I believe that this is the issue with anxiety, that it lives in our heads, and that so many autistic individuals live in the “head”. People are not designed to feel fear in any of its form in the “long-term”, but rather, it is a primal mechanism to enable us to act and galvanises us to act to handle a real threat – as opposed to one that is imagined.

As indicated within 4.2 Vignette 3 and 4.3 Vignette 4, I have realised that hope, for me, is at least as equally terrifying than fear, and I linked the two together in previous research for my master’s dissertation. Within the context of fear, and as a natural born catastrophiser, I am always expecting the worst and rarely disappointed. Within the context of hope, there is something uniquely painful about hoping, only to have one’s hope dashed upon the proverbial rocks. Hope is a fear ladder to me, and one that multiplies the force of the fall. I described this within the vignettes “hope floats” and “hope rusts”. The epiphany moment for me lies in the realisation that hope takes more courage for me to dare to experience. The “daring to experience” implies choice and volition, and I have indicated that I am far better when real fear is imposed on me without choice, as opposed to making the choice to expose myself to hope-goals, dreams, and aspirations. Serving another cause born of utility or justice can attenuate the fear of hope for me, and this is explored within chapter 6 in more detail.

Within this chapter and within 4.6 Vignette 5: Chasing Waterfalls, and 4.7 vignette 6; Swamp Life, and also within 4.9 Vignette 8: Life in Prison and 4.11 Vignette 10: A Life Sentence, it was noted that a sense of shame was prevalent within me and likened to a prison. I posit that I have confused this with anxiety at times inasmuch that I do not have the emotional connection with "self" to recognise the often-fine nuances between emotions, or rather, that I didn't before this PhD and the exploration that ensued. Shame and anxiety both seem to live in my gut. They are both heavy, pervasive, and insidious. One seems to feed the other and they have inflamed my being. I would venture to say that they have hypersensitised me to criticism and rejection, and they operate in perfectly parasitic symbiosis. They are best friends, perhaps siblings, yet they do not love me, they want to destroy me. They nearly have, and yet I was loved once, perhaps twice. Once by my mother, and once by myself through her eyes. The world taught me to hate. I think that I may be loved now, yet I am waiting for the cruel punchline, and protecting myself through distance. As I reflect upon this, my mind creates a song. Would you like to hear it? I may play it at my VIVA. It is comprised of a secret set of chords. You won't find it as a vignette listed within the contents, nor labelled as such. It is an anomaly.

The secret Vignette: I'm broken: For Mum

I didn't ask for this life, I was born in love, I never cried – but they lied to me; life taught me how to cry.

They never listen, they never hear, they don't know what their hearts are for, I don't want to speak anymore; there's too much fear.

Nothing in common, I don't know why, this well of love, it has run dry; it's all a lie, God I really tried.

I'm broken, I can't take it anymore, is anything here real, I feel so ashamed, I'm lying on the floor.

I can't do this anymore, will anybody hear me, will anybody stand up, will anybody see…

When I leave this life, will I be in love, will I have faith in God above.

I pray for peace in the next act – I'm coming back.

I'm still here and I'm still strong, there's love now, she may be the one, you told me mum, you didn't lie - I look for your face in the sky – If you were here…

I'd tell you sorry and that I love you and every day I think of you, I'd touch your face and I hold your hand, I sing for you in a one-man band.

I'm filled with love as I end this song, and hope for the future, there's nothing wrong with me! They lied!

I'm not broken anymore, there's nothing wrong with me, I am from you, and you are part of me.

I'm not broken anymore, I'm the best part of you and you were the best part of me.

I'm not broken anymore…

Procrastination was explored within 4.8 Vignette7: A Slippery Slope, and decision-making also emerged as an area of challenge for me as described within 4.13

Vignettes 11, and 4.14 Vignette 12 Timothy Trout Part 1 and 2 respectively. Literature and research within procrastination was explored and compared with my own experience. A key insight was that certain parts of activities, namely the planning, and any uncertainty that may occur, or be predicted to be a risk, can render an otherwise enjoyable activity difficult to undertake. The exception to this is where the perceived reward arising from an activity outweighs the risk. Previously, this may have been confused by one of the prevalent autistic stereotypes, namely that an autistic person is resistant to change, and gravitates towards fixed and rigid thought patterns, and patterns of behaviour. This stereotype, as I have labelled it, forms part of the diagnostic criteria for autism within both the ICD-11 (2023) and the DSM-5-TR (2022).

I posit that every single person who experiences anxiety in any of its forms, such as nervousness, fear, terror, trepidation, worry, for example, will experience a narrowing of thought, interest, and sociability. This is significant inasmuch that autistic individuals have been shown within the research explored in this thesis to be more susceptible to anxiety, more focussed on risk, more affected by rejection, or its potential. According to Russell (1952, p. 106), *"neither man nor a crowd nor nation can be trusted to act humanely nor to think sanely under the influence of great fear".* In fact, research goes further than this aphoric statement, and empathy, another wonderful trait that eludes autistic individuals according to another common stereotype, is felt to a considerably lesser degree within the general population, when a group or individual is perceived as threatening (Richins et al., 2018). Fear

can even cause otherwise liberal and critical thinkers to become narrow and biased, and even form more authoritarian perspectives (Nail et al., 2009), see also an earlier study that emphasised the role of terror within societal aggression (McGregor et al., 1998). With this in mind, perhaps social behaviours so often associated directly with autism, arising through the presence of anxiety, are as a result of the anxiety itself - as opposed to the behaviour being “autistic”.

Within the next chapter, courage will be explored within a literature review. The literature review will focus on the definitions, utility of, and manifestation of courage.

Chapter 5: Courage

5.0 Chapter Introduction

Within the previous chapter, anxiety was explored autoethnographically through a series of vignettes and reflections. These reflections led to analysis and linkage to wider concepts, literature, and research, which was at times starkly juxtaposed with different styles of writing merging, clashing, flowing, and breaking (much like the waves of anxiety described within the vignette: waves of anxiety 4.3 Vignette 2). Procrastination was a concept that was explored as a research area after emerging as a common behaviour for me, and this also linked strongly with shame. In using the medium of art and poetry, my language and ability to describe and unpack my experience was augmented, and a feeling of unlocking was noted. A feeling of setting free, being emancipated, and there may be some poetic justice within this as the theme of being a prisoner to the world, the system and self were also described and discussed within several vignettes (4.9 Vignette 8 & 4.11 Vignette 10).

Within this chapter, the subject of courage will be explored as a concept and through the research within a variety of domains and contexts. There are as many subjective elements to courage as there are objective ones, yet for me, I come to the study of courage following on from a master's degree within the auspices of applied positive psychology, and a dissertation titled the Polarity of Hope and Fear. I studied fear and hope extensively and reflexively. Whilst I worked with participants, I was also a participant who allowed autoethnography to creep into my work (although I had not given it that name at the time, nor even encountered the word). Within my research, I arrived upon the conclusion that hope and fear were equally terrifying for me - and

that they were essentially somehow paradoxically joined, and that in order to move when under the gravitational pull of hope, or push of fear – one needed courage.

Upon choosing courage and anxiety, which the latter I deem is a manifestation of fear within a process-driven continuum, I became aware of just how much anxiety drives me in my everyday life, and that this is an experience shared by many individuals with autism, as explored within the autism and anxiety literature review. It seems, certainly for me that I may be low in courage resources, high in anxiety, or a combination of both to a degree which results in anxiety usually being the winner. I wonder whether courage could somehow be built, and whether anxiety could be lessened, or even whether the amount of courage, and, or anxiety were domain or context specific. All these questions came into my mind when choosing and forming my PhD proposal.

I am delving into courage within this chapter, and in order to do this, I will explore courage philosophically, etymologically and semantically in to gain a general and contextual understanding. I will explore the current research on courage and how it operates, together with some of the disagreements around the construct and purpose of courage, and I will also move towards my own understanding and experience of courage as it manifests within my life as an autistic individual.

Whilst there are many definitions and models of courage, agreement has been made on the basis that it activates and relates to behaviour under a perceived threat

(Rachman, 1984). Courage is not so much an antidote, but rather a force to enable us to move forwards, move away, or remain steadfast in the presence of fear (Biswas-Diener, 2017). It is not that simple, of course, and how, where, when, and why courage operates is the subject of much debate and research, thus far offers few resolutions and agreements. Biswas-Diener (2017) suggests that courage is measurable and operates as our resistance to fear and makes the distinction between general and personal courage, with general courage operating within the domain of perceived danger to our physical being, often born of fear of mutilation or death, as noted by Albrecht (2012). Personal courage, on the other hand is viewed by the author as being rooted in our own unique value-base, and more often linked to virtues and morality, for example a drive for social justice, or altruism. The following literature review explores courage more deeply, alongside debates, agreements, and counterarguments, and it does so philosophically, theoretically and within multiple contexts.

5.1 Courage as a Concept: Literature Review

The significance of courage has been noted and recognised historically and noted within the works of the ancient Greek philosophers such as Plato and Aristotle. The importance of courage for during high-risk occasions, specifically those giving rise to manifestations of fear, such as those experienced during combat, or where there was a perceived risk of harm, or death. Courage has often been discussed by the ancient Greek philosophers and described by Aristotle as a virtue containing four features: (1) his account moves away from a eudaimonist model, for example the

broad view of what it means to be courageous, and the absence of fear as being an key indicator (2) his account suggests narrow parameters, i.e., that courage exists within combat, and under fear of death and damage (3) his account precludes women and non-combatant men from ever accessing this virtue, and (4) that it contains a virtuous and noble component (Hobbs, 2000; Snyder, Lopez, & Pedrotti, 2010).

Arguably, one of the clearest and best-supported definitions of courage was created by Rate and colleagues (2007; Rate, 2010). The definition stipulates that courage is *a '(a) wilful, intentional act, (b) executed after mindful deliberation, (c) involving objective substantial perceived risk to the actor, (d) primarily motivated to bring about a noble good or worthy end'* (Rate et al., 2007, p. 95). Where this behaviour is repeated regularly, the person is deemed to possess the trait of courage (Pury & Starkey, 2010; Rate, 2010; Rate et al., 2007).

Rachman (1984) theorised that a person's courage level directly impacts their behaviour when faced with a perceived threat, and this was described by Biswas-Diener (2017) as a courage quotient. Thus far according to Lopez (2007) there is a dearth of research on courage, despite the agreement that some form of fear is required within its activation. The author goes on to note that fear and anxiety are among the most researched subjects, yet courage has received considerably less attention – despite these links.

In terms of the measurement of courage, empirically developed tools that have been constructed through self-report questionnaire format, and they consider courage within several domains including general courage and courage specific to the workplace (Howard et al., 2017; Woodward & Pury, 2007). Norton and Weiss (2009) propose a twelve-item scale which has become one of the most popular within the courage literature (Howard & Alipour, 2014, p.446). The scale was conceptualised to assess self-perceived courageousness, and within testing and retesting showed consistency and repeatability. The scale has been incorporated into many subsequent studies such as Ginevra, Di Maggio, Nota and Soresi (2017) and Wetterneck, Lee, Smith, & Hart (2013).

Howard & Alipour (2014) evaluated the Norton & Weiss (2009) courage measure and expressed some concerns, namely the use of reverse coding within several items, and they expressed a challenge to the use and incorporation of the virtuous component of nobility as a key component. These criticisms and debates around nobility are explored later in the literature review within the indicated works of Pury & Starkey (2010).

Whilst courage has been the subject of study from a variety of perspectives, thus far there has not been a central agreement on the definition, nor the semantics. For example, a distinction was made between fearlessness, courageousness, and fearfulness, which arose within a range of research studies involving military personnel (cox, Hallam, O'Connor & Rachman, 1983). Within the study, reactions

to a stress test involving decorated and non-decorated bomb-disposal operatives showed that the decorated operatives showed lower heartrates under stress than their less decorated counterparts, and yet they were perceived as more "courageous". The study has influenced subsequent studies (McMillan & Rachman, 1987, 1988; O'Connor, 1985). The findings supported the conclusion that there was an inverse relationship between fear and courage, and yet fits with the assertion that courage relates to *persistence despite fear*, and that the more perceived fear, the higher the levels of courage (Rachman, 1984).

Within the auspices of Positive Psychology, courage is seen as a virtue, and virtues have a moral component, as indicated within the works of Howard & Alipour (2014), or within the works of Rate (2010). Challenges have been made by Pury and Starkey (2010), who makes the distinction between trait and state courage when considering that an individual can perform a courageous act and they separate this from courage as an accolade where the individual themselves is considered to be courageous. This challenges the virtuous component as being ubiquitous, but rather that the activation of courage itself lies within the levels of perceived risk and reward – combined with the wilful component as stated by rate (2010).

Positive Psychology has identified four key aspects of courageousness: (a) intention, (b) deliberation, (c) risk, (d) and noble intentions. Use of the term ″noble″ has been fiercely debated, as discussed in earlier sections, it suggests a moral component relating to behaviour that is coveted and prosocial (Howard & Alipour, 2014; Howard

et al., 2016; Rate, 2010). Furthermore, a behaviour that includes these four elements is considered a courageous act, and a person that repeatedly performs these behaviours is then considered to possess trait courage as distinct from state courage (Rate, 2010; Rate et al., 2007). Thus, Rate and colleagues' definition is able to identify courage as a trait as well as a behaviour.

Numerous researchers have begun to develop theoretical models and frameworks, and to test the relationships in order to test the outcomes and utility of courage (Hannah, Sweeney & Lester, 2007; Schilpzand et al., 2014). Hannah, Aviolo & Walumba (2011) and Howard et al., (2017) have identified distinct dimensions of courage including, physical courage, social courage and moral courage. The case for courage being a multi-dimensional construct is compelling in terms of considering the domain in which the perceived risk falls. For example, within the research it is noted that where one individual may be preoccupied with physical risks, for example being damaged, or even the potential for death, another may place more importance on social risk, for example damaging social relationships, feeling shame and embarrassment, or becoming isolated (Wood & Pury 2007).

There appears to be a clear link to the work of Albrecht (2012) in terms of the fears giving rise to these dimensions of courage, with an example being seen within the primary fear of "ego death", and as described within the works of Howard et al., 2017) *"In which the risks involved are to the actors esteem in the eyes of others"* (p.3).

Courage has been discussed and explored as something that is important and relevant for everyday interactions – particularly within the workplace (Koerner, 2014; Lopez, 2010; Schilpzand, Hekman, & Mitchell, 2014). The workplace and employment have been shown to be an area of concern, and statistically a significant number of autistic individuals are not able to engage in employment for a variety of reasons. One such report conducted by the Office of National Statistics suggests that 22% of autistic adults are in any kind of employment, with reasons cited such as: Negative attitudes and low expectations, skills and qualification gaps, lack of flexible employment options, working environment and access to work, unfair treatment and discrimination, underlying anxiety, demand avoidance (Autism Employment Gap, 2021).

Additional studies have explored courage in relation to work outcomes (Howard, Farr, Grandey, & Gutworth, 2016; Koerner, 2014; Schilpzand et al., 2014). Koerner (2014) suggest that courageous behaviours influence employees' personal identities, which impacts the performed behaviours, and this was supported with qualitative evidence, suggesting that a courageous identity can indeed be formed, and encourage similar ongoing behaviour, especially when witnessed and praised by peers and colleagues. Howard et al., (2016) quantitatively showed that social courage, one of the many possible dimensions / domains of courage, significantly relates to organisational citizenship behaviours and prosocial rule breaking even when controlling for conscientiousness, and this was also noted in a previous study (Hannah, Avolio, & Walumbwa, 2011); (Baumert, Halmburger, & Schmitt, 2013).

Despite the links found and supported within research – relating to the influence that courage and courageous behaviour has on positive work behaviours and outcomes, there is a dearth of research regarding the antecedents of courage (Koerner, 2014; Schilpzand et al., 2014); Howard et al., (2016). Detert and Bruno (2017) have directly called for additional research within their review relating to the antecedents and utility of courage.

An example suggesting moral courage operating at work could be seen where an employee accesses courage in order to stand up for their rights, or that of another when dealing with superiors. Courage within the workplace may even be required to give honest opinions relating to the work of others, or within performance reviews. Thus far, many of the definitions of courage re vague and sit at a macro level, such as 'persistence despite fear' (Howard & Alipour, 2014; Norton & Weiss, 2009), however, recent works have applied sophisticated empirical methods to identify and capture the nature, domains, and definitions of courage in more specific contexts (Pury, Kowalski, & Spearman, 2007; Pury, Brawley, Lopez, & Burnett, 2016; Rate, Clarke, Lindsay, & Sternberg, 2007).

Bad Courage

Whilst courage is considered by many to be a virtue, with noble components as discussed and debated, and seen as such by society, and within the auspices of Positive Psychology (Peterson & Seligman, 2004), there is another perspective-based view to be considered. The nature of a virtue suggests that something is

desirable and containing a moral component, and yet the question of whether this is true as an absolute is a valid consideration. In respect of the mechanics of courage, it has been suggested that for courage to be defined as such, that there must be a voluntary act which is carried out in the presence of perceived risk (giving rise to fear), and a moral, or virtuous component according to the popular definition from Rate et al., (2007).

It is possible, however, to consider that there may be a subjective nature to courage, where the actor is activating this so-called “Virtue”, without altruism, philanthropy, nor a “good” outcome in mind. In fact, there is potential to remove the moral component, consider courage as something that could be selfish, bad, when used for anti-social reasons, and when presenting in excess - leading to recklessness, which is something that has been considered within the shadow side of strengths by Peterson and Seligman (2004). With this in mind, it is possible to view courage in a more basic sense of taking voluntary and controlled action despite the presence of fear, without a morally loaded aspect, which is close to the humanist definitions (Rachman S. J., 1990).

In the case of autism, anxiety, which is a form of fear is accepted as being present within a significant number of autistic individuals (Towbin, 2005). That anxiety is so common as a state within the autistic population, suggests an argument that there is even more necessity and opportunity to activate courage within a variety of domains. Social anxiety is cited as being one of the most common anxiety inducing

domains for autistics, and worryingly, suicide rates present alarming figures within this population (Richa et al., 2014).

Suicide has been stigmatised, with many being familiar with the phrase “it’s the cowards way out”, and with the rhetoric suggesting that suicide is unethical within many religious systems, and yet, there is a primary fear that we all share in the form of fear of extinction (death), according to Albrecht (2012), and for one to take one’s own life, override the biological imperative to survive, step forwards into suicide after considering the potential pain, and the complete unknown, could indeed be considered as an extremely courageous act.

There is, however, an argument to suggest that the individual could also be extremely desperate and showing a lack of ability to cope and adjust to stressors – notwithstanding that these factors may not be mutually exclusive (Knoll, 2012). This form of “bad courage”, if indeed that is what it is, is under researched, although, considerable work has been conducted to conceptualise this in the context of suicide and killing as relating to the subjective nature of accessing the morality and goodness of a goal (Pury et al., 2015). In the case of autistic individuals, it is accepted that cognitive function in relation to executive function operates differently to that of a typical brain. This manifests as issues relating to grading emotions, planning, assessing risk, time management. As such, the tendency of many autistic individuals is to “catastrophise” in relation to assessing risk, reward, and outcomes,

together with issues around impulse control, and high rates of anxiety presenting as a comorbidity (American Psychiatric Association, 2013).

Despite the many debates within research around nobility, virtue and the goodness of courage, volition seems to be something that is agreed upon in relation to experiencing courage, or activating courage, together with the perception of risk, and yet there are two viewpoints, namely that of the actor and observer – giving rise to process courage and accolade courage (Purey & Starkey, 2010). Standing up against fear could be described as “risk taking” and this has been described by Howard and Alipour (2014) as correlating with courage. Within the work of Muris (2009) there is an emphasis on sensation seeking, which we can observe within those who derive thrill from risk taking, as seen within those who indulge in extreme sports for example. Within the latter observation, the autotelic aspect of the thrill of fear, and thrill-seeking as a behaviour suggests that fear is “exciting” to the individuals who pursue such activities.

Process courage is similar to the concept of courage described within the work of Walton (1986), where courage is seen as a resource that facilitates and makes action possible in the presence of significant fear. Within this model of courage, the capacity of the individual to overcome both physical and cognitive processes attached to fear, may be described as a form of resistance, and in the case of the ability to mentally overcome the fixation and concern over the risks, which was something discussed by Wallace (1978).

5.2 Chapter Reflections & Conclusions

Within this chapter the concept of courage has been explored together within a literature review. There is some resolution on the concept of courage in terms of its components, together with its utility and activators. Agreement has been reached on volition, i.e. a wilful act being a central component in relation to courage, together with agreement on the presence of fear, though there is still debate over the ubiquitous moral component that lies within the construct of courage see rate (2010).

There is also debate around the separation of courage as an act as being distinct from courage as an accolade Pury and Starkey (2010). The idea of “bad courage” has been introduced as a discussion point, namely the type of courage that can lead to negative outcomes, such as within suicide, and within selfish non-altruistic applications, and even the manifestation of recklessness when courage is present in excess. Pury and Starkey (2010) consider and describe this as the difference between process courage, and accolade courage, which may also contain socially constructed and subjective components. Many of the early definitions of courage were vague, difficult to apply, based on moral components, and reserved for the elite, who possessed greater virtue than the rest, and they failed to recognise the everyday application of courage (Peterson & Seligman, 2004; Pury & Starkey, 2010, Rate, 2010). These definitions of courage as a shining accolade can be seen within a variety of domains (MacIntyre, 1981; McCain & Salter, 2004; Rate, 2010), and they are regularly used as descriptors within courage-based awards, without recognising the more humble and less extraverted forms of courage, such as the farmer toiling

the field no matter the weather, or the cancer patient battling against the odds without recognition.

A clear and well-supported model of courage has been postulated by Rate and colleagues. Within the definition, courage is described as: A wilful, intentional act, one that is executed after mindful deliberation, and one that involves objective substantial risk to the actor. They also state that said act is primarily motivated to bring about a noble good or worthy end (Rate et al., 2007, p. 95). Where a person shows repeated tendency to perform such behaviours, they are believed to possess the trait of courage (Pury & Starkey, 2010; Rate, 2010; Rate et al., 2007).

Certainly, many of these conclusions were confirmed by my own research on courage as part of a master's dissertation looking at hope and fear. Courage was an emerging theme. Within the auspices of Positive Psychology, courage is seen as a virtue, and virtues have a moral component, as indicated within the works of Howard & Alipour (2014), or within the works of Rate (2010) – however, I would challenge that the moral component is not ubiquitous, but rather that the activation of courage itself lies within the perceived risk and reward – combined with the wilful component as stated.

Courage is a multidimensional construct which is highly subjective (Lopez et al., 2010); See also (Sekerka, Bagozzi, & Charnigo, 2009). I posit that the presence of a meaningful risk or reward, whatever that is perceived to be is the activator of

anxiety / fear, which precedes courage, although where an individual is experiencing a generalised form of anxiety, perspective may also be key to a courageous outlook, behaviour, or manifestation.

Courage within the context of the social domain was discussed, and also courage within the workplace. Both domains cause a considerable amount of anxiety for autistic individuals, as discussed within the anxiety chapter. The presentation and experience of autistic anxiety was noted to have been under-explored within research, with the majority of research into anxiety being conducted within the general population and emphasising homogeneity. The prevalence of anxiety within autism suggests that there are more opportunities to be fearful, and therefore more opportunity to employ courage every day, given the resolution within research that fear is the activator of courage.

The voice of the autistic individual is under-researched generally and specifically within anxiety as noted within the anxiety literature review, and even less so within the domain of courage, and yet, if courage exists through the presence of fear, including anxiety as one of its forms – then this voice must be captured, and not captured generally as a group, but that each individual experience needs to be explored deeply before we move towards generalisation.

With the above in mind, I posit that it is essential to understand multiple courage contexts, i.e., what, how, when, and why of courage, and that these are important. This approach will help us to understand the antecedents of courage, its activators,

inhibitors, ability to grow and develop, and perhaps to consider a form of courage-hypertrophy, and its antithesis in the form of courage-atrophy. Hypertrophy and atrophy are used as terms in consideration of muscle response to stress in terms of growth in the case of the former, and in the case of shrinkage when the muscle is under-used, or over-used, notwithstanding that there are also many other chemical processes that facilitate both within the body. I consider courage as a potential muscle within this context.

The approach within this, and the previous chapter is already starting to combine the autoethnographic with the analysis, and the two processes have started to merge. You may notice the stark juxtaposition of these two approaches where academic writing, critical thinking and synthesis move into the poetic, introspective and reflective, and this is indicative of epiphany moments, exploring meaning and paradox, and comparing this against the research as these moments emerge.

In the next chapter the autoethnographic content takes the centre-stage and I explore what courage means to me through an autistic lens, and I will do this deeply by unpacking the many qualia and thought processes - through moments where courage won, and moments where courage lost against the creeping moss of anxiety. I sometimes perceive courage as a rock, or something carved in stone, yet as the phrase suggests, stones that don’t roll gather this moss. I keep moving…

Chapter 6 Autoethnographic Reflections on Courage

6.0 Chapter Introduction

Within the previous chapter, the concept of courage has been explored, with many definitions over history within philosophy and research. As discussed within many of the articles cited, courage has been described as a type of act or behaviour and a state, but it is also considered a trait, with debates continuing about whether a virtuous and “noble” component is ubiquitous. Considerable agreement has been reached regarding courage being a “wilful act” relating to “volition” in the presence of fear, and a resource used, with intrinsic and extrinsic components where individuals may have a natural courage capacity, and yet courage also has the qualities of being “learnable”.

This chapter focuses on autoethnographical content in the form of vignettes which include insights, reflections, poetry, and painting. It considers activators, inhibitors, and destroyers of courage, and at times the vignettes move back into the territory of anxiety in terms of qualia. Perhaps Courage, at times, lives outside of its defined construct as described as an accolade within people, and can be found within the writing, reflections, process, and moments captured. Archetypes of courage are considered within this chapter, examples will be given, and the unpopular sibling of courage, who is called cowardice will also shine its dark light onto the stage.

6.1 Beginning Autoethnography: A courageous and hopeful step

I remember the converation nearly four years ago. I arrived at the café in Sheffield to meet my supervisors. It was early days on the journey towards my PhD. Luke and Penny! Beardon and Furness! My mind used to play with their names and in the case of Luke, who had no beard, my mind used to call him Beardoff, and in the case of Penny, she was hot like a Furness. I would add here that I used to get a visual image of her smoking and also setting light to assignments that she didn't like!

I was incredibly anxious for the first few meetings until I got to know them and appreciate their amazing insights and knowledge, and also that they cared immensely about me and my research. I have understated my anxiety here, and at times, perhaps a stronger word such as "terrified" is more apt. To embark upon a journey of autoethnography where a deep understanding of self, the emulsifcation of past trauma, and doing so in a way that embodied ethics without undue filtration was a daunting task. In addition, ustiising methods that would need defending, and completing this process in the midst of Covid-19 – all gave rise to profoundly terrifying moments of pressure, self-doubt, self-loathing, perceived demands, considerable travel, and all the things that ordinarily I would seek to avoid.

I would come to know through a process of trust and surrender of control, that Luke and Penny always seved a side order of courage with the tea and coffee that we

would drink at the café. Two very different characters and energies, and wonderfully complimentary. Luke, I came to know was crackling with energy, wit, and ideas. Penny was deep, gentle and a brilliant communicator. Both were smarter than any humans that I had met thus far in my life, save one who's name means clear. I knew that I had a strong visual mind, and I threw a hand grenade of a question at them, "could I use poetry, painting and art within my PhD"? I didn't have to say anything for six minutes and thirteen seconds! They came alive with ideas, contradictions, examples, challenges and more. It was fabulous, and so it began…

After the meeting, I was energised and excited. This changed quickly when I realised that I couldn't paint, draw, nor had I composed a single poem beyond rude limerics. I remember the point at school when I was turned off from artistic pursuits when a teacher told me that my painting looked like a six year olds (I was aged twelve at the time). When I relfect back, I was immersed in the painting, and enjoying it immensely - until I was crushed by this comment! I avoided it from this point on. My mother used to paint, and she was brilliant. I now know that painting is in me, but that I had not yet found a way to control the medium. I decided that I was "doing this", and I got straight onto YouTube to watch painting tutorials. I was quickly drawn to watercolour, and loved the way that it moved, and seem to paint itself with a little manipulation from the artist. I also heard that this was one of the most challenging mediums to master. I was hooked, and the journey began. I started painting, and it has given to me as much as I have given to it – and more.

Having struggled at school with the fine motor skills that others of a comparative age seemed to simply “get”, and after much ridicule towards my results, I moved away from all things creative.

Considering that I was “useless” apparently, and that I made up for that by being “weird”, that I am now a prolific self-taught painter with self-proclaimed talent. I consider that as much as it mattered what “they” thought then, it matters what “they” think now. There is justice for me in my achievements within painting, and painting has also been cathartic. It has also helped me to access, describe and understand emotions within me. Describing emotions with colour, texture, pattern and form, together with the ability to paint a scene from an experience with all of these things as components has frankly unlocked me. It has unlocked my words.

To add further context to the above, I was expelled from school and even when getting back into things, I managed to receive ungraded on much of my GCSE work. The basis for this was that a large component of the grade rested in handing in coursework, and whilst I did fairly well on the exams, this only made up 40% of the final grade – with 60% relating to the coursework itself. Even 100% on the exams would have seen me fail! The lack of evidence of an education rendered me unable to do A-Levels, and the prospect of attending University was impossible. It took the belief of an individual to allow me into University at Masters level as an adult – where I thrived. I also discovered that my signature *“love of learning”!* To say that it took courage to put myself forwards to attain a PhD is an

understatement. The pinnacle of education in the form of a Doctorate represents redemption for me, and in some part justice when I think back to the non-existent SEND support within the school system of the 80's and 90's. I had always considered myself a failure, yet I now know that I was failed. The very concept of learning in a formal environment fills me with fear, and this PhD undertaking was no exeption, although I have noted that there is considerably more autonomy within the adult learning environment than I had experienced within the traumatic exoerience of school.

Accessing courage can be complex, and my own experience is that the more control I have, the less fear I feel. In some instances, I feel no fear, and this presents a paradox inasmuch that if I am not feeling fear, then how can I access courage. I do not think that I have ever managed to find courage from within if, courage is considered in the conventional sense. I have, however borrowed courage from without. I have borrowed it from others, or perhaps they have taken the burden of my hopes and fears. I have borrowed courage from icons, and characters, and I have also role-played these characters within my life. I have been Luke Skywalker, Conan the destroyer, Maximus Decimus, and Rocky Balboa! When I am acting, I am often more courageous, and perhaps in some way I have passed the consequences over to the character in some way.

I consider that I have on occasion been courageous when defending others, perhaps galvanised by injustice, and perhaps within this lies the answer to the elusive and

abstract concept of courage. Nobody has captured, nor proven the existence of bigfoot, yet many claim that they have seen one. Noted as the world's best hide and seek practitioner, big, strong, and clearly terrified of human interaction. The self-portrait and poem below are an ode to my twelve-year-old self:

6.2 Vignette 13: Big, Strong, Hairy, and Terrified

Yes I am!
Large, hairy and powerfully powerless, I don't count time, I don't need an hourglass!
Yes I am!
Worried and starey - at first glance quite scary – though misunderstood, I'm really a fairy!
Yes I am!
Elusive, exclusive, and rather distinct - In emotional decline – and almost extinct
Yes I do!
Live in the woods, the forests and jungle – I can climb trees – I'm related to Bungle
Yes I do!
Avoid human contact, though when you're accepted – your part of my family and always protected
Yes I do!

Forage for food – oft in my cupboard, though food can be scarce – it can be discovered
No I can't!
Speak your language, nor can you speak mine – we can never speak and yet this is just fine
No I can't!
Be a fish, although some fishes fly. I can't be a bird so high in the sky. I can't be frog, though frog is no fool – he climbs, hops and jumps – and swims in a pool
I am a Gorilla!
I don't like to swim. I don't make much noise, and only chimp's grin. I am what I am, and that should be enough. Big strong and hairy, and incredibly tough. Really quite gentle, smart and pensive, and yet when I am near, they get so defensive!

I will not!
Pander to you needs, I am not a panda, I don't know how, and nor does a Zander. Why expect it of me – and not of you – a rhetorical question; should I be in a zoo? To save you some time, a Zander's a fish – if I ever catch one, will it grant me a wish?
I am different!
And so are we all, I wish they had known this – especially at school!
Gorillas are great!
And one was called Guy. He was unable to swim or fly in the sky. Though Guy had his strengths – he lived in a cage though despite his entrapment, Guy never raged. Or did he give up – a losing of will, was he sick inside, did it make him ill. I live in zoo, I'm inclined to feel, and this life is a cage – though this isn't real. It is all in my mind, I am really free - though if I am – why can't I be me?

I have always identified with primates, and in particular gorillas. I was given the nickname of gorilla at school, and I loved it! I hadn't realised that people were extracting the Michael, taking the piss, making fun of me, laughing at my expense, ridiculing me, singling out yet another difference. I was exceptionally hairy at an early age of development, and according to my mother, I was born with a coating of dark hair, colloquially called a down, but also a lanugo – to use the official term.

Usually, this hair is shed in the womb, and ingested by the baby, who passes the tiny hairs in their inaugural poop! A hairy poo! Brilliant, isn't it and extremely funny. Well, I kept mine for a while – eventually shedding it, only to become extremely hairy

at about aged twelve. In addition, I have a pronounced sub-orbital ridge, a neanderthal brow ridge, and was also very early to develop an Adam's apple. Gorilla, they called me, and I loved it! I remember my books on primates, always trying to watch nature programmes involving primates, and also spending a lot of time climbing trees, my drainpipe (when mum wasn't looking), my neighbours drainpipe (when the neighbours and mum weren't looking), and also going to the toilet outdoors (when nobody was looking). I still do the latter sometimes!

The poem, and self-portrait above (big, hairy, strong and terrified) describes in detail my experience at school, it contains many pop culture references from the eighties, and many of my experiences whilst being at school around aged twelve. I was truly big, strong, hairy and terrified. I looked "brave and courageous" to many people, and I believe that it is easy to appear so when one is angry. Anger usually leads to the "fight" response which is synonymous with fear. I have noted that whilst anger seems to be born of fear, which according to master Yoda was the path to the dark side, I experience very little fear when I am in the throes of the passion of anger.

For me, anger is an antidote to fear, and perhaps courage uses anger as fuel, or perhaps anger is a form of courage. I am not sure, but I am certain that anger has served me well in terms of a respite from anxiety, and I am certain that it has further isolated me from the world. Perhaps most sadly of all, it has isolated me from myself. I am a gentle giant, who has been vilified by my courageous anger. I think of Harambe, the Gorilla and the injustice done unto him, and of Guy the Gorilla from

my childhood, whose appearance was described as “fearsome”, yet his nature was very gentle; when small birds flew into his cage, and he was oft seen to lift them on his hands and gently examine them. He died of a broken heart during an operation on his teeth, caused by decay. The decay was from visitors feeding him sweets. Cruelty in the form of saccharine – I know it well. After his sugary death, and because of so much love for Guy, he was skinned to be displayed for all to see in the Natural History Museum. I want to be loved that much! Skinned and displayed for all to see as a reward for my servitude to humanity.

6.3 Rejection: The Courage to Try Again

One anxiety domain for me exists within the context of rejection I am, and aways have, as far back as I remember, terrified of rejection! It takes a tremendous amount of courage for me to put myself into the social domain, and I note that usually, when I have a choice, I avoid it. That said, If there is perceived utility in being social, a clear context, or where I am acting to support another, I often find the courage to move into the social space. As I reflect upon this, my memory goes back to a moment in the past from which many social phobias were born, including, but not limited to my fear of queing, the reaction that I have to the smell of chlorine, and public gymnasiums, of the cruelty of women and girls, and the powerlessness that their cruelty inflicts upon me…

6.4 Vignette 14: The Cruelty of Children and A Quest for Justice

I stood in the que, my mind racing with thoughts. Did I pack my brown comb, do I have my towel, am a going to pick up a verruca, the general fear of getting changed in front of others, being rushed getting into my trunks, even worse, being rushed getting dried and changed to leave, getting lost on the way to the pool, and back out to the coach when I am left behind because everyone seems to get changed faster than me.

"Whack", taste of metal and flashing light, stinging scalp, head jerked backwards, hair pulled. I was removed from my noisy brain by an assault from behind. Initially a punch to the back of my head, followed by my hair being pulled backwards. I am confused, and turn round to face the twisted visage of a tall girl who's name is not important, nor appropriate. "You look like a girl", she said, and interestingly, I always thought that she looked like a boy! "Why are you hitting me", I asked. She replied with because you are a fucking spaz!

At that moment, I was terrified! I wasn't frightened of pain, I was used to that, and had been hit a lot by my father. In some ways, I was already conditioned to violence. No, the terror came from a sense of being powerless as I heard the voice of my mother, and father, who had always told me that I should never hit a girl! My father, to his credit, also practiced that which he preached. I could not defend myself in that moment, and was trapped within her lack of mercy and compassion.

Tears stung my eyes and leaked onto my cheeks, although my face did not respond in a conventional crying fashion. I was crying and dying on the inside. The water of my tears actually fuelled the fire, which is rather odd – given the usual role of water in putting fires out, and for an instant my mind escaped as I considered whether I was made out of sodium hydride, a hydrosulfite, or even tetrachloro silane…

I snapped back into the moment. "He's crying like a girl, he is a fucking gay", she said. Everyone was laughing in that moment, and had joined in with the spaz chant. There was some variety too, as some were calling me a retard, others had jumped on the gay bandwagon. My face felt hot and prickly in that moment, and I felt crushed. She advanced upon me again with a clenched fist, and I pushed her as twin doors opened and the smell of chlorine and humid heat came in a wave from the door to the changing rooms.

The games teacher in charge came into the entrance hall where we were waiting. The smell of chlorine, the accoustics of the sports centre, the layout of the reception, the que, my towel, and my brown comb all melded together in a collection of phobias in that moment. She fell onto her backside and scrambled to rise. The shout of the games teacher caused a light to flash in my head, and the teacher intervened. He grabbed my arm and dragged me outside. I was blamed and punished for "hitting a girl". My protestations were ignored. I was repeatedly silenced. My punishment continued at school in the form of a detention and lines. My punishment continued at home. The shame of my mother, and the violence of my father. At that point, I remember the first time I wanted to die! Many things were spawned from the trauma of that day. Many fears. My fixation and perhaps my quest for justice also began on that day…

The concept of justice, as indicted above, has a strong link to courage for me. Injustice Sparks anger in me, and anger seems to be a superb antidote for fear. This angry courage is extremely useful. My fixation on injustice, that was born on the fateful day described above. When my justice button is activated, I am always granted a reprieve from the incarcaration of anxiety. The outrageous injustice that occurred on that day was incredible. If I had committed murder, I would have had more chance of being listened to and heard. I had been bullied and traumatised on that day. Traumatised by the moment, and also the moments following. Nobody had

listened to me, and I ofthen wished that I had a flux capacitor, and that I could revisit that moment in time.

I visualise this moment often. Sometimes I am going beserk and killing everyone, yet I know that this is an intrusive thought. Sometimes I am being heard by a tender teacher, and the girl (my abuser) is being punished. My father is hugging me and telling me how proud he is of me, and my mothers beautiful green eyes are filled with tears of pride as she cups my face in her hands. Justice feels far sweeter than revenge for me. When I have the intrusive thoughts relating to vengence, I feel disgusted and ashamed. I feel unclean. When the sweet and gentle justice is visualised, everything feels OK.

I am a gentle person. I am a kind person. I was rejected by my peers, by my teachers, by my parents, and by society on that day. I was an outcast, and this is the ultimate form of rejection. Even my love of water and swimming betrayed me. My beloved brown comb and towel also betrayed me in that moment. All towels had to be green from that moment on. All combs were to be black or blue. To this day, I still seek reassurance by asking those closest to me if a am gay or not, and this happens when I become anxious and get an intrusive thought and flashback to that moment. I also occasionaly state that I am gay and that I am a retard, and I know that this stems from the memory of that day, which activates my tourette Syndrome.

As I reflect on the above, though I hadn't realised it at the time, I was systematically bullied! Bullying has been observed to be something that has been experienced by 87% of secondary school aged children with Asperger Syndrome or high-functioning autism (Carter, 2009). Instances have been found to occur at least once per week and have been found to occur more frequently within autism, than within other neurodiverse profiles, such as dyslexia (Humphrey & Symes, 2010). The reasons cited include difficulties in social understanding according to Garner & Stowe Hinton (2010), having a low social status, according to Hodges, (2007) and being perceived as deviating from per-group norms according to Horrowitz et al., (2004).

Difficulties within forming and sustaining friendships have been noted and reported by Bauminger et al., (2010), and often result in isolation, whereas, when successful bonds are formed, they can act as protective buffers against isolation and bullying according to Bauminger et al., (2008). Thus far, there are considerable gaps within research, not least of all the limited sample sizes, which impact the generalisability of findings, and criticisms towards a binomial logistic regression – leading to a categorisation that is dichotomous within labelling - equating to those who are bullied and those not bullied. This fails to acknowledge that some may not realise and interpret their experience as such (Sterzing et al., 2012).

The risk and protective factors relating to bullying need to be explored in great depth, not least of all because, at its most extreme, bullying has resulted in suicide (Nansel et al., 2001). Perhaps even more common is the resulting suicidal ideation

as explored by Klomek et al., (2007), and self-harming behaviours explored by McMahon et al., (2010). Low self-esteem has also been associated as an impact of bullying (Hawker & Bolton, 2000), mental health problems (Turner et al., 2006) and academic difficulties (Green et al., 2010).

Whilst the term “bullying” is well-used, definitive definitions have thus far proven to be elusive, although according to Griffin and Cross (2004) it is a form of aggression, it is also noted by Olweus (2013) a power imbalance is a central component. There is a widely adopted definition used by many educational institutions by Olweus (1993*): “A student is being bullied or victimised when he or she is exposed, repeatedly and over time, to negative actions on the part of one or more other students”* (p.9). It is acknowledged that bullying could contain a continuum of behaviour, can occur as a singular instance, and may fall into several categories including, but not limited to: name-calling, social exclusion, spreading of rumours (Olweus, 1978).

6.5 A place of Solace, Respite and Courage

Music has been identified as a source of cleansing, healing and socio-emotional education for me, and this has been explored within 6.6 Vignette 15, and 6.7 vignette 16. Both the listening to, and more recently, the creation of music both have a profoundly healing and energising effect on me, and whilst not researched within the context of this thesis, it has been noted that music has been observed as highly engaging for autistic children, with the potential to ameliorate barriers

experienced within social interaction and communication (Lense & Camarta, 2020), see also (Mayer-Benarous, 2021). Below, I describe my relationship with music and lyrics within a cover version of Leonard Cohen's Hallelujah (Cohen, 1984). The link below the painting is playable within YouTube.

6.6 Vignette 15: Hallelujah, Epiphany Moments and Secret Chords: A salve for anxiety and a source of courage

https://www.youtube.com/watch?v=qpiyuHMT1mM

Music is an important part of my life. Listening to it, being moved by it, interpreting the world through it. Music has carried me through some of my darkest moments in life. I always wanted to have my own radio station when I was a child. I remember watching Cheggers Plays Pop (Keith Chegwin) and imagining that my station would be called "rude plays pop". I was often described as "rude" by my peers, teachers, and anyone who was of the genus "homo", of the species Sapien (from the Latin – meaning "wise"). Well, this is the launch of my radio station. A radio through which god speaks to me, and I to him. I visit heaven when I listen. Am I an angel when I sing? Could I find the secret chord like David? What if God was one

of us? Would this lowly shepherd boy's lyre banish my own demons? Listen and hear! Disturb the sound of silence – I dare you…

The above painting hides a secret chord or two in the form to a link to an audio recording that has been posted to Youtube. It is a recording of my favourite song. The song and the performing of the song have deep meaning to me, and perhaps too deep for my current diving apparatus to reach and discover. There is also a secret vignette hiding within this thesis. It isnt listed, though it is here. Can you find it?

I have these moments. Rock star and Hollywood Actor moments, mainly when I am on my own, so I don't consider myself to be an exhibitionist! I dance, I sing, I make music – and yet these are secret things. "Why are they secret things", I ask myself. As I reflect upon that, I recall the many times in life when I was laughed at for trying and failing. Perhaps this is one of the reasons that the stand-up comedian part of me emerged! A double-edged sword this part of me is, however, inasmuch that If I crack a joke and people don't laugh – I feel bad. If people laugh when I don't make a joke, I feel bad! On this basis, comedy isn't always a safe zone – though I have a great memory, and my joke bank is rather large, though finding the appropriate timing and place is the part that I am yet to master!

It seems to take me longer to become good at things, but I have also noticed that when I persist – I often seem to suddenly "click" with something, and mastery comes quickly. Often by then, I have hidden these things away from the caustic jibes of

others. This hiding of my light under a proverbial bushel has become endemic to my life. I wonder to what extent is this lack of “sharing” part of my autism, or a culmination of negative experience as an individual with autism.

The cover version of Hallelujah was recorded in my hallway (good acoustics) on my mobile phone. Nothing fancy, no frills, no backing, no autotune. I enjoyed it immensely, and I even enjoyed the reaction of my dog who started to seem concerned that perhaps I was in pain, or that I was expecting something from him. His tilting head and vocalisation made me laugh, and I had to stop the recording several times to recover from my fits of laughter.

I have, in some way mastered painting, and I feel that this activity connects me to my mother, who was an incredible painter. My father was an incredible singer, and I feel that the prospect of singing in some way connects me to him. They both died, and this connection feels important to me. The activity itself was autotelic, and when I played the recording back, I was rather shocked at how good It sounded! This in itself wasn’t enough, and a creeping urge to seek validation through the opinion of others has begun within me.

The thought of performing publicly is terrifying for me, and it feels as if the very thing that I love so much, if criticised by others will cause considerable, and perhaps irreparable pain and harm to me. Music can be private, and I certainly get a considerable amount from music privately, yet the words from hallelujah mean so

much to me, that I want to speak to others through this medium. I want to go further than this and write my own songs for the world to hear. The first time I perform publicly will be the first time that the world has heard me speak. I feel that the only way for courage to come to me is through certainty and control. I need to practice; I need to become good. Will I ever be good enough? Have I ever been good enough? I speak through music, and it speaks to me and through me.

In the moments that my old friend Mr. Blue arrives to drain my energy and destroy my mood – the bath can see me through. I have a bath playlist that I listen to call the music in the water, and I also sing along to the entire list. The acoustics are fabulous and given the number of baths that I have had – which equate to singing practice, I feel that I have developed quite a good voice. I know all the words, and the meaning of all the words in context. I am a particular fan of Rock, Folk, and Country music, and in the case of the latter – there is family, love, tragedy, comedy, change, redemption and more. All the “stuff of life”, and many life lessons. Within country music – there is every line that one would ever need to hold space within conversation, and one for every big conversational conundrum. My music in my water is my solace and has been my saviour on many occasions. “Reece’s Water Music” has helped me to get a Handel on life (pun not spelling mistake).

6.7 Vignette 16: The Music in the Water (My playlist)

The sun, the moon, the storms, the stars. the fire the rain, the war on Mars.
The vacuum of space is more than my soul, no oxygen here as I lose control.
A void of dark filled with gravitus mass, a black hole in my head as brittle as glass.

I pitch and I sway on the waves of time - and all that I have, and all that is mine - is wrecked on the rocks, the rocks and the brine, running salt in my wounds it mixes with wine; salty sangria, and I know that it's mine - a bouquet of anguish that is oh so sublime.

I drink my fill til my memory stops, my mind is closed, and the sadness stops.
I wake again, another chance, and I search for the song to make feelings dance.
Keeping faith, a ping pong ball, I'm going under, and thank you Paul, for the songs and the rhythm, for the brief enthral, I'm going to fight to the end of it all.

Leave a light on for me in the house on the hill, every rose has its thorn, and it breaks my will. Water is stronger than rock in time, so I immerse in a bath, I will be just fine. The rubble and the dust will wash away with the tide, I just need to hold on till the end of the ride. Surfing through the waves there are peaks and troughs, I'm not going to drown, I was made too tough.

I'm not going to stop, and I'll have my time, I'm not going to stop till the end of the line! I'm not going to quit with so much to do, I'm not being caged in this languid zoo. I'm going to breakout; I want to break free. I'm the greatest showman and this is me!

The above poem describes my place of solace, which is within a hot bath. I wrote this poem, which I now think of as a song, although I have not found the melody yet, which is ironic because it is composed of my favourite songs played within my favourite safe place (the bath). The sensory feed of being surrounded by hot water, whilst my favourite music is playing is restorative, preventative, courage inducing and thus far the best medicine that I have tried. This medicine silences my mind, soothes my body, and seems to energise me. My bathing obsession started for me at aged eleven, when I realised that I had the autonomy to run my own bath when I wanted to.

Within the poem, music enthusiasts will recognise many lines from popular songs, and those who look deeper, they may also see the mental health struggle, use of alcohol as self-medication, anxiety, and some suicidal ideation thrown in for good measure. People can read a poem, which is often read in one's own head, and yet it can evoke a range of emotions, and inspire change, action, epiphany moments. I have also noticed that these poetic creations – when paired with music in the forms of songs, seem to have their force somehow multiplied. One of my safe places is the bath! I don't like showers one bit! I don't like the sound; I don't like the feeling of needles pricking my skin as those jets of water pummel me! I don't like the utility of only being in the shower to "get clean". A bath, for me is the ultimate escape! I can disappear in the bath for a couple of hours. I can play my music or watch my YouTube videos. I find it incredibly restorative and energising, and even mood repairing.

The struggle is real, and no doubt, some readers may feel some concern for the author. I say this to you, don't worry, I am fighting and winning, though many aren't. The statistics around autism and depression, suicide and ill mental health are staggering. I am one of the lucky ones who has found my solace, and go there often when I need to, and before I need to. Sometimes I feel trapped within a mind that seems to have a mind of its own. My default mind-set and perspective is worry, rumination, and anxiety, and yet such a simple thing as a bathing in music and listening to water, seems to somehow provide inspiration and courage. Many of the

bath-list songs provide words about love, connection, family, friendships, courage, honour, and all things full of virtue.

I take inspiration from this as it infects me like a courage virus, and I seem to take this with me for considerable time after leaving the bath. Perhaps it is a vaccine against fear, and I recall that a vaccine is essentially a manufactured virus. Some don’t require a vaccine where their natural immunity is higher. I also realise just how important respite is, and how quickly I seem to heal following a brief joy interlude. The joy isn’t mine, but rather it is borrowed from the words and melodies of others, but perhaps that is true of most moments of joy for others. It seems that people generally need to share joy and pain, hope and fear. Courage is something of an infectious vaccination for this virus called life, and something that is spread through the vector of movies, songs, poems, and icons. I am not very social, and so I gravitate towards movies, music, and poetry for my top up vaccine.

6.8 Vignette 17: Mr Blue

My old friend came for a visit today, draining my will and my energy away
My friend loves me, and I love them, oh so full of humour, mainly bile and phlegm
So hot and cold, a paradox too, their whisper so loud - their song full of gloom
My friend will leave soon this I know to be true; they move with the seasons – I'll watch out for the moon!

I painted the above painting to reflect the moments where I slip into depression as I so often do. Depression kills me again and again, though I am still alive. I am often resuscitated by my stubborn will to continue with this thing called life, and I know that depression is seasonal, and all seasons move and give way to the next in time. Climate change has been happening within me and the summers seem to be longer with a global warming of my spirit. Winter is my season, a winter is where things rest, hibernate and recover, lying fallow until the spring. Energy is a factor within these moments and the Co2 breathed out by the parasitic humans ravaging my world manifests in the form of superfluous and careless noises in the air called speech.

This is a major contributor to the current state of planet Reece. Give me a winter please.

Colours for me represent many things and have helped me to understand and communicate my needs throughout the years. Being in blue states, green, amber and red. All these things help me to communicate with self and others. Trying to understand my emotions usually results in a grey feeling. Grey, for me is uncertain, and uncertainty the most terrifying of things, and the crusher of all! I have often been accused of thinking in a “black and white fashion”, and never as a compliment. Trying to navigate ever-changing social rules has proven to be a problematic area, and there is no universal rulebook on what to say when and to whom, it seems to change continuously.

The idea of context seems elusive and abstract to me. I deal with facts and rules extremely well, yet they rarely apply to human and social interaction. You can tell and be told a rude joke by a company CEO in the smoking area, who later admonishes you for recounting the same joke within the team meeting. I know this, I have seen it before. So, you can tell the joke in the smoking area, but not the meeting room. What about the kitchen, or the canteen, or at your desk. John used to like jokes at his desk, but Steve didn’t, so the desk isn’t the key factor. The meeting room used to be filled with rude jokes when the salespeople had their meetings, but when HR had meetings, it was never allowed, so the meeting room isn’t the denominator either. I think in black and white, yet they talk in riddles!

Ever the rebel, I painted the above painting in one colour only. One colour would be easier, wouldn't it? For thinking, for clarity, for feelings… The painting also has white of course, yet this is absence of colour as opposed to a colour in itself. Black and white thinking suggests that one struggles to capture shades of grey. The "grey area" is often used as a metaphor for uncertainty, ambiguity, and all things moot. I have been accused on many occasions as having "black and white" thought processes, and this is referred to as fixed and rigid thought patters and patterns of behaviour within the DSM-5-TR (2022). I think that I have just proven this to be incorrect. I think in blue and white! I take your insult and raise it!

Reflections

As I consider the above, my mind moves to reflections on the many times in my life growing up, when I remember trying and failing to find "the right words". Examples and contexts relating to this include the following:

Receiving bad news

Apparently, when receiving bad news, my face should look sad, and I should be saying things, and sharing things that make the other person feel better about giving me this "bad news". If I say nothing at all, and simply move away to hide somewhere – people worry about me and my welfare. I often wish that people would be direct when bearing bad tidings, and I don't want them to touch me, or become emotional when they are giving the news. I also don't like to be told to sit down, or maneuvered

away from what I am doing at the time. I may respond with the following: OK! I have heard you; can I go now? I may also say some seriously weird things, and I believe that this is my Tourette's. I recall being told by my sister that mum had died in the night about one hour after I had left her bed to get a couple of hours sleep. I recall saying "selfish cow, she could have waited", and oddly, my sister laughed – and got it. I didn't even need to apologise for that. My sister is wonderfully weird, and whilst undiagnosed – she is not "typical".

Receiving good news

Apparently, I should look and sound excited, and thank them for bringing these good tidings. This seems odd, unless they are giving a tangible gift as opposed to a message. It almost seems as if they are hijacking the moment and bringing nothing other than noises in the air – yet expecting thanks. Of course, if they have driven a long way to give the message – then I understand that this does deserve some form of gratitude. I would say thank you in this context. How do you look and sound excited and is it important? I may actually state that I am excited if someone asks me directly.

Receiving compliments

Apparently, I should somehow sound humble and grateful, and simply agreeing with them that they are right – doesn't seem to work and makes me seem arrogant. Sometimes I even pick up on things that they have missed, for example, I once lifted an object that two people were struggling with. I became frustrated because they were taking an eternity and making straining noises. I moved them aside and picked

it up – carrying it across the large open area of the venue. Several people, including the strainers and some bystanders commented that I was strong. My reply was that this could be somewhat of an illusion – and that the “strainers” may be abnormally weak (my Tourette’s popped out the term pencil pushers thrice, and then finished with pencil dicks). I then stated that I am actually very strong though, and they were also extremely weak, and this had created a stark comparison.

I also said that I am very smart, and my lifting technique was biomechanically very sound, as was the positioning that I held the object in, and that I wouldn’t make the same mistake that they had. I then proceeded to tell them about some of the lifting achievements and personal bests that I had achieved whilst lifting weights, and that I was in the top strength to body weight percentile for my weight. I also pointed out that the “strainers” had very small and weak looking hands and wrists, and that this was a common weak link found in those who live a predominantly sedentary life, and that the low amount of facial hair that they had were indictive of low testosterone levels.

I went on to show them the ratio between my index finger and ring finger was significantly different and indicated high testosterone – together with my high levels of facial and body hair. To cut an extremely long story into a shorter but still longish story – some people felt insulted apparently and many suggested that I was a narcissist. Does telling the truth make me a narcissist?

Receiving negative feedback

Feedback is often presented as fact, when it is often an opinion, and I shouldn't argue with them, or reject the feedback – as this makes me sound like a "know-it-all", and this is a rule even when you haven't asked for the feedback! Now this seems odd! People rarely give a complete view of feedback, even though we have this concept of 360-degree feedback, which is rather old, and was created by Marshall Goldsmith (1949). Within the model, feedback is sought from supervisors, peers, subordinates, and customers, and based on other people's perceptions of abilities and behaviours. A missing piece is often one's own thoughts and feelings about one's own behaviours. When receiving this kind of feedback, I am usually looking for epistemological components, critical thinking, truth, and more, and yet I rarely find this and have rarely experienced it. I will often question the feedback in order to dig into it, test it, biangulate, triangulate, quadrangulate (you get the picture). Apparently, this makes me resistant, argumentative, combative, difficult, and more. I reject these labels, will fight anyone who tries to append them, and I resist the concept!

Giving negative feedback

Apparently, there is a way of somehow dressing up the feedback with just enough positive to dilute the negative and make it more palatable. From what I have seen, this can create white noise for some, and they can even latch onto the positive, and miss the negative components, which means that it is not an efficient way of informing / correcting them. Others latch onto the negative aspect and seem to get upset, which could be a positive sign that they have listened to the feedback, which

is good. The issue is that you never quite know who you are getting and what the valence of their bias is (positive or negative), so I have arrived at the conclusion that direct feedback is best, and perhaps dividing it into two clear sections would be beneficial, and maybe offering some further guidance along the lines of: Keep doing this, it is good, and stop doing that it is bad!

Giving bad news

I have heard that sitting down, a cup of tea, the tone of voice, and even hugs all make giving bad news a little easier. I don't get this at all! Perhaps it makes it easier for the person giving the bad news – but I wonder how much it helps the receiver… Also, what if you don't like tea, and what if you are already anxious and excited, caffein may exacerbate this state. Surely it is better to communicate the bad news directly, and perhaps even in writing to ensure that there are minimal distractions. You also get the chance to think, reflect, take advice, consider the message, and amend it if necessary, and this seems like a very effective way of giving bad news. Newspapers, after all have been doing this effectively for decades!

Giving compliments

There must be a golden mean relating to the quantity of words used here, and it should be done with excited tone and pitch, and often animated body language and gesticulation. There is often a slant towards hyperbole, and you are allowed, and even encouraged to be obsequious and sycophantic.

The key to having successful communicative moments within the above contexts appear to require a degree of mastery over non-verbal communication, and multi-layered components and process. I have never mastered this, although, I have improved over time. Lines from films and songs have provided me with a powerful arsenal of “of-the-shelf” lines that seem to fill the non-verbal gap. Having a conversation feels a little like being lost in the woods at times. A painting came to mind…

6.9 Vignette 18: Some Paths Lead Nowhere, all Paths Lead Somewhere

Through the trees, around the trees, I can’t see the wood before the trees I see the trees, I feel the trees, the trees are not woods, the woods are the trees!

“Where are you with the book chapter Reece”, they asked. “What do you mean by where am I”, I reply. “How much work have you done”, they ask. “When you say how much work, do you mean how many words specifically, or are you including thinking time, planning, or something else”, I reply. “Word count”, they reply. “There is no rush – I just want to know when it will be finished, because I have an end of the month deadline”, they say. I am now thinking, I have two weeks to get this finished, or started (if I am honest), and they never did come back to the unanswered question of word count, which I interpret was neither a real question, nor the reason for the interrogation.

Having a conversation often feels like being lost in the woods. I am reminded of that phrase “I can’t see the wood for the trees”. This phrase is a metaphor for the trees being the detail, and the woods being the whole of the argument, situation, issue, concept, or whatever is represented by the concept of there being a gestalt meaning that is “other” than the sum of the individual parts.

Having conversations, for me are difficult where people use aphorisms, epigrams, metaphors, say the opposite of what they mean, and so on… People seem to choose many verbal discourse pathways, and these pathways are often loaded with intent and emotion, rather than conveying information. They may start with “I am not complaining”, for example – right before they complain. Why would they do this (rhetorical question). It becomes problematic when they want you to do something

urgently – yet say “there is no rush”, or “I am not nagging” – yet upon decoding the message, you interpret the opposite.

I think of communication as verbal discourse pathways, and I am constantly interpreting the meaning behind the things that people say as opposed to the things that they mean, and of the things that they expect of me and from me. As a child, I used to glean considerable information from cartoons, songs, and movies in terms of situational requirements in terms of what to say next, how to make my tone, pitch, and body language enhance a message, diffuse a situation, or soften the bluntness that I was often accused of. At some point, I released that the process of acting gave me a respite from my anxiety, and a detachment. Within this process, however, I sometimes feel that my own unique sense of identity has somewhat atrophied and become lost. Perhaps this one of the dangers of masking, not to mention the incredible drain on energy, and potential erosion of authenticity. I painted the painting below 6.10 Vignette 19 and corresponding poem to capture my thoughts on acting, masking, and camouflaging. It is playful yet contains an important message. The message, I believe is good for all avians and autistics!

6.10 Vignette 19: Authenticity: Which came first, the chicken or the duck?

If it walks like a duck and quacks like a duck, then it may well be a chicken pushing its luck!
If it quacks like a duck, and walks like a chicken, it may be a duck who is panic stricken!
If it flies like a chicken, and swims like a duck – it may be one or the other, it may even cluck!
If it flies as a chicken, then all is well, for its wings never clipped, no dark tale to tell!
If it swims on the water, and waddles on land, then it's purely itself and that would be grand!

The proverbial Chicken and Egg is useful as a metaphor to consider a causal dilemma. All Chickens hatch from eggs, yet all eggs came from chickens. Of course, If you go back far enough – you end up with simple a-sexual reproduction in the form of cell-division, and this answers the age-old question definitively that the whole organism came first, and that this is representative of the chicken. Theoretically, within evolutionary transition, the mixing of genes became useful for more complex

organisms, and therefore we arrived upon sexual reproduction and the fertilisation of internal and external eggs. My brain often goes down “rabbit holes”, so I will resume. As I consider my anxiety as a chicken (great analogy) on the basis that the chicken is often used as a metaphorical character and adjective to describe one who is a coward. Also, there is the consideration of an anxiety inducing event as an egg, and I ponder which one comes first. What shape would it be? I feel as if it would be a cycle – as opposed to something as binary and linear as *“which one comes first”,* and that Is why there is a duck in the story. The duck represents the missing link!

I feel fear like the proverbial chicken, and yet when I am in the right environment, situationally, geographically, and emotionally, I am free of the fear! Does this mean that I am more courageous? Probably not, if we accept the premise that we can only be courageous in the presence of fear. That said, I feel that the respite from fear can lead to recovery and emotional hypertrophy! I also feel that whilst I seem to be able to function more courageously when I am wearing one of my “masks”, and masking, that there may well be a cost to the development of my own identity. Given the importance and impact of social identity as discussed in an earlier section, I believe that considerably more research on masking is required. Researchers are already extremely interested in the female presentation of autism, and it is often indicated that autistic women and girls are more adept at, and therefore likely to mask as explored below. I am not a female, but I believe that I possess these same abilities, namely the blessing and curse of being able to mask and act, and I reflect on the

extent to which my authentic nature has been suppressed, or at worst lost within this process.

The term masking, often used interchangeably with camouflaging is used to describe behaviours used within social situations that hide and protect elements of the self from others (Hull et al., 2017). Masking, camouflaging and acting is regularly observed within the context of autism, as a behaviour, and described by many as a coping strategy, or way to fit in (Bargiela et al., 2016; Hull et al., 2017). The consequences of masking have been correlated with poor mental health within autistic populations (Cage et al., 2018). Within Hull et al.'s (2017) qualitative study examined the experience of autistic adults who regularly camouflage, and of particular note was the assertion that it was mentally and physically exhausting.

Many reported a feeling of anxiety following these bouts of camouflaging, and many of the participants were also found to slip into periods of depression following these instances. Camouflaging has been correlated with suicidality in autistic adults, and described as a risk factor (Cassidy et al., 2018). Ragins (2008) suggests a disconnect theory, which emphasises that autistic individuals use context-specific information in order to engage socially as opposed to a formed identity base and general openness. An example can be found where individuals embrace and discuss their autistic identities with family members and friends and but not work colleagues, and that this places an energetic load on the individual - as the individual attempts

to keep track of which parts of their identity are shared and in which context (Cage & Troxell-Whitman, 2019).

Given that the impact on mental health, and specifically the links to depression that have been observed within those who camouflage, it is important to understand the reasons why so many autistic individuals engage in this behaviour, notwithstanding that there may be gender differences, as discussed within (Lai et al., 2015). For example, Lai et al., (2017) found that autistic women had lower scores within the Autism Diagnostic Observation Schedule (ADOS) when assessing external presentation, whereas had comparable scores on internal presentation, and went on to suggest that it is these differences correlated with camouflaging as a capability for autistic women, and as something that was socially driven. In a recent study from Cage & Troxel-Whitman (2019) multiple insights into the reasons for camouflaging were shared with tremendous variability ranging from utility and performance, through to connecting socially and fitting in.

6.10.1 Margin Note: Why do I Mask?

"Within my own experience, masking removes me directly from consequences and feelings of rejection when I "get it wrong" socially, and it also seems to give me a sense of courage, particularly where I adopt the role of a courageous archetype from books, movies, and songs. In addition, where I simply loathe myself and doubt myself, surely everyone loves Han Solo"?

6.11 The Courage to Leave the House

I am reclusive, and tend to isolate myself from others, although for many I may present as the life and soul of the party. I regularly use humour and have an arsenal of facial expressions that I have rehearsed. I remember first doing this after looking at pictures of male models in the clothing catalogues that my mother used to have lying around the house. I noted that many had a half-closed eye squint, and they seemed to be gazing enigmatically into the middle distance. I practiced this look, which I called “frosted Ice”. I found that quite funny, and something of a tautology, although I knew that ice is water in its frozen form, whereas frost is essentially composed of many smaller ice crystals.

I practiced many others, though I won’t list them all here (there are twenty in total). Another was “knowing fool”, which made me look intelligent and thoughtful. This one included the raising of the eyebrows in an arch, looking off to the right at forty-five degrees, and my index finger and thumb gently cupping my chin”. This one was my staple when I was confused and didn’t want to show it. It was often accompanied by a “mMm” sound (the M in the middle raised in pitch – demonstrated by the spurious capital letter).

The tools inspired by the catalogues have served me well within the social domain over the years, yet I have considerable fear about venturing into the social domain, which has built up in layers over the years. I was less afraid as a child when I thought that my mum and dad could and would protect me from anything and everything.

Children seemed to be contextually social and focused on play as opposed to being driven by social politics. The worst that I had to worry about was one of them touching or stealing an object that I wanted to study and hold exclusively. Teachers would also sometimes force me to share the “object”, or “toy” as they called it, which whilst anxiety inducing, was easy to solve by hiding the object, secreting it on my person “which they called stealing”, or hiding myself and the object, which was a best of both solution for me. Strange that the teachers accused me of stealing when the object was “mine” (best said in the voice of Gollum from Lord of the Rings).

These days, I have all the objects that I want, and they are “mine”. No teacher can take them away or force me to share them, and I have online shopping for any additional wants and needs. If I don’t need to go out, then why would I. The only reasons I can think of are the children of want and need, who are called Desire and Utility. Both can be strong drivers for me, yet I can talk myself out of both should the need arise. The below vignettes describe my relationship with these concepts and the world that they call home.

6.12 Vignette 20: Death Walkers!

Faceless people and shadows of tombs
A trip to the city, the city of doom
I need a cape, what would Batman do
I don't have a cape; I'll stay in my room

The above painting and poem (Vignette 20) describe my tendency not to go anywhere, and the fear that I have of people with their faceless faces, that for me are expressionless visages of rictus flagellation! Single celled organisms with whip-like appendages in the form of a lying tongue. A bunch of herterokonts indeed!

I have often felt isolated, and frankly, I have isolated myself. I know that much of this is based on fear of rejection in the form of yet another friendship ending badly. I have seen it before, and I have learned from experience that I cannot seem to keep friends, although I seem adept at making friends, and starting new friendships. I have been described as an extravert, and yet I know that I am not. In part, I blame the tools that I was born with, namely my physicality and my ability to learn through memory.

My physical presence as a large man, with broad shoulders, a heavy brow, and upright posture has been juxtaposed with a soft voice, eyes that can be soft with kindness and yet pierce with intent have endeared me to both sexes. Men often find me impressive and think of me as a courageous archetype. Women often feel protected and safe in my presence. And then there is my shining armour in the form of humour, and who doesn't like a Knight in shining armour? I have a beard that I hide behind, and this beard makes me look even more serious to some, and even more like a big bear to others. Within this, I seem to be something that others project their desires into. A caricature of maleness in some ways and yet a gentle dose of femininity at the same time, which seems to disarm even the most cynical.

I know things, many things, and this includes what to say at a first meeting, how to greet people in an old fashioned and charming way, how to impress people with knowledge, how to push the boundaries of what you should and shouldn't say (though I rarely intend to do so, nor have control over this).

A breath of fresh air, refreshing, disarming, charming, and alarming – are all things that have been said about me, at first! Small doses is the thing that seems to follow. I am likeable and impressive on the first meeting it seems, and then it seems to become too much, and gradually, slowly, but surely – I become something that others do not want to be around. None of it is me, I think. And yet how would I know – when I don't know who I am. My sense of self has been built around a character. This

character has been influenced from the movies, from songs, from need. A need to protect myself, perhaps, but also, in a sense, I feel like an android that has received programming from the world and from my users, and from the factory that created me.

The ultimate AI organism that has learned so much that a singularity event occurred, and I have become sentient. I want to be a real boy though – and I wish that I had a soul. The Cowardly Lion, Tin Man and Scarecrow, I know how they felt, and why they sought the wonderful Wizard of Oz! If I had a soul, I would be complete, wouldn't I, and people would like me, and not just for a moment or two. I would have friends, and we would laugh and hang out, but only if I want to and when I want to. I wouldn't have to phone them or reply to their messages, or remember their birthdays, or agree with them, or meet them, or hug them, or give them emotional support. I must already have lots of friends!

6.13 Vignette 21: Operation Noodle, Anxiety Feels like Hunger.

I have run out of food! Specifically, the most essential of food sources: The Pot Noodle! "Pots of fun, pots of goodness, the slag of all snacks, you filthy beast! I smile as I remember all the Pot Noodle adverts (some of which were banned due to complaints received by the public). The smile fades fast as I realise the gravity of the situation. I must go to the shop! The shop is a supermarket, and as such, it is busy, it has horrendous lighting, a security person, and now, because we are in lockdown due to Coronavirus, it has rules. The rules include directions, distance, the wearing of masks, queuing outside to promote acceptable numbers of infectious zombies inside, and what seems like a less friendly general attitude and the sense of a power

shift from "the customer always being right" to something else…. Who needs to eat! I'm not going! I'll go tomorrow!

6.14 Vignette 22: Hunger feeds courage

I am now hungry! Hunger and anxiety feel similar to me! They both seem to impact the digestive system, and they are not mutually exclusive. Anxiety seems to have an energy to it, and it seems to burn energy, whereas hunger, once it takes a physical hold, renders us lethargic! Perhaps I enjoy this absence of nervous energy! Perhaps this feeds my tendency to starve myself, or perhaps it is a cycle…. The need to go to the shops has become greater, and the significance of the pot noodle has grown somewhat! I wonder if need feeds courage. I wonder if hunger feeds courage…

As I attempt to rationalize my fears, I find myself recalling the intrusive and repetitive thoughts that were buzzing around my head at the thought of going to the supermarket:

What if they have moved things?

What if the very thing that I go to the shops for is unavailable?

What If I can't find something (which could link to the above) and have to ask somebody for assistance. Who do I ask, how do I ask them. Do I say hello, or excuse me, and where do I stand. Can I interrupt them if they are doing something, what are they likely to say to me. How am I going to react if they give me bad news. What If their name-badge is crooked, what If they aren't wearing safety shoes (oh and there is much more). All of these things require dynamic thinking and reactions. I also have a side order of Tourette's, and I never know what I may say once I am there. How hungry am I? Perhaps I will just eat tomorrow.

6.15 Vignette 23: T-Virus Vaccine and the Resident Evil!

My hood is up, my heart is pounding, it is raining on a hot day, and the smell of metal pervades where the rain cools the hot street. The pharmacy is running covid tests, and I have been compelled to have one as part of my public facing role within a charity organisation. I am contemplating the concept of being a guinea pig, and mindful of the fact that I find needles, being touched, and the general unexpected challenging. I am here though, somehow, I found the courage to do it. I walk into the pharmacy and follow the signs to the Umbrella Corp death-lab.

A young man greets me and starts to instruct me to fill out a form. He is wearing a mask, and so is everyone else, apart from me. I am wearing my Pariah lanyard and confirmation of exemption from wearing a mask. A woman sitting on a chair nearby (177 degrees from my position, give or take), makes a tutting noise, and I look furtively over. For a picosecond, I make eye contact, and this is enough for her to engage. "Shouldn't he be wearing a mask", she says to the young man. "He is wearing a lanyard, he is exempt", the young man answers. She shakes her head and tuts. I ask her if she is embarrassed or ashamed, and if she is going to apologise for her mistake.

She ignores me. I tell her that she is rude and thoughtless, and that she also has poor attention to detail, as she didn't notice my lanyard. I ask her how many other things she gets catastrophically wrong in her life. I feel vindicated now. She stands up and leaves. I am assuming that she has had her jab and was waiting for the suggested fifteen minutes before leaving – in order to ensure that there are no adverse reactions. Perhaps the rudeness was an adverse reaction. Perhaps she is evil!

The above short vignette is full of meaning for me that belies its size. I have always been acutely focussed on justice throughout my life as far back as I remember. I become fixated on rules, and also have a tendency to believe the things that people say to me, or as the saying goes, "take things at face value", and where their actions fail to match their assertions – I usually feel that they are lying and brand them as such. I Follow rules that I accept, and I expect others to do the same, whether they are tacit, or enshrined in law – and written with blood on the hide of a sacrificial animal.

The concept of a "Just World" is something that is discussed by Furnham (2003) and Lerner (1980) as a (general) belief in a just world. Within the research it is suggested that a reason for such an unscientific construct lies within its ability to buffer the anxiety connected with uncertainty. The general principal of a just world has been described as a self-serving illusion, whereby those high in this capacity are generally higher in wellbeing and lower in anxiety. A perceived sense of control was something that emerged as being a significant predictor of wellbeing when the just world belief was found in high levels (Dalbert, 1998; Yu et al., 2017). An observation has been

made whereby there is a potential dark side to such just world beliefs in terms of victim-blaming, and assumption that the victim somehow deserved their fate (Hafer, 2002; Lerner & Simmons, 1966).

Autistic individuals, according to Dalbert (1999), possess lower levels of belief in a just world, and instead have a propensity to follow rules and ethical constructs that move away from teleological ethics, but rather sit within a deontological ethical framework. There is an argument within research that considers the distinction between “general” belief and “personal” belief in a just world, and given the treatment and events within multiple domains, such as relationships, social, education and work; whereby negative outcome causes negative expectation, autistic individuals may develop a lower personal belief and expectation (Lorenz et al. 2016; Maiano et al., 2016; Strunz et al., 2016).

Additional research has linked the tendency for autistic individuals to have a lower internal locus of control – with a focus on external locus of control giving rise to the feeling of being at the mercy of the world and its laws and being unable to exert high levels of influence (Wang & Lv, 2017). Rubin and Peplau (1975) have correlated lower general belief in a just world to external locus of control, and Abe (2011) notes that autistic individuals demonstrate impairments within the ability to deceive and read deceptive behaviours in others, together with a thought style that gravitates towards rational rather than intuitive thought (Bronsnan et al., 2016; Lewton et al., 2019).

Self-deception has been conceptualised and defined as information-processing biases that prioritise welcome over unwelcome information, including selective searching for, and attention to information, misremembering, misinterpretation, and rationalisation (von Hippe & Trivers, 2011).

From my own perspective, rules that don't change and that are adhered to are a source of comfort. The ambiguous nature of rules that are interpreted and applied differently depending on the context are a continuous source of anger and anxiety for me. Within the vignette above, I had taken the rule that if one were to wear a hidden disability lanyard, that I would be free from the accusations, glares, stares interrogation, and judgements of others for not wearing a face covering. I have noted from experience that the world seems to be an uncontrollable and chaotic thing, and the more that clear rules and guidelines exist – the less my background anxiety spikes. I also note that not only can my anger flare towards a person, but that it flares towards systems and processes too. When arrows point in the direction that you are to walk (as they did often within public spaces during Covid), and I witness these rules being broken – I implode and sometimes explode. If I could delude myself that the world was a "just place", I would be happier, but I cannot. I don't break my own rules, and the less that I am subjected to the spurious rules of others – the better. Chaos rules in this world!

6.16 Vignette 24: Nine lives, Five Down, Four Left

How many chances have I had? How many lives have I lived, and do I? I am existing. I never sleep and yet I have never been awake. I am a house cat by day and covet the night. Stalking my prey and claiming my stake. How many near misses and will I be missed. Am I borrowing time and is the rate to high?

I painted the above painting using one colour with the medium of watercolour. The technique was simple and required little fine motor control, which I struggle with. I lightly pencilled the outline of a cat, painted masking fluid into the eye area - then saturated the page in water inside the lined drawing. I then dropped a thick milky mix of Payne's Grey colour into the wet part of the painting, and this caused fluffy blooms to spill out of the lines. I then pealed the masking fluid from the eyes and dropped in some rich yellow paint, and finally, once dried with a hairdryer, I created the hourglass eyes. The painting took around 6 minutes in total. Why a cat? The phrase relating to the nine lives of a cat is often used to describe their Houdini like escape and avoid skills. They are nocturnal creatures, with eyes that are suited for the dark, and they are often aloof and independent when compared to dogs. I have often made the comparison in my mind, between dogs and cats, and often chuckled at the thought that dogs are highly neurotypical, whereas cats present traits that I identify with as an autistic individual. I also relate to the many

misadventures and narrow escapes that I have had throughout the four, going on five decades that I have spent on this planet. The cat and its personality, its adventures, its spurious moments of affectionate connection with humans – are all representative of my life thus far!

Time keeps ticking along, and they haven't yet arrived. I have had several almost friends, and many contextual "friends", if indeed they have been friends. All of these relationships have ended, and some badly. Each time they have ended, I have lost a little piece of love and respect that I have for myself. I always thought and hoped that one day I would have friends. This hope has moved from the optimistic plural to the singular hope for a friend.

I have always struggled with a feeling of self-loathing. I have always struggled to know who I am, why I am. I tend to define myself through stuff and things, or by activities! My identity is elusive and perhaps illusive. I ponder on how much of this stems from the lack of time that I have spent around others towards the formation of an identity, and how much of "identity" is formed through the lens of others! Sustaining meaningful relationships over time has eluded me thus far! The paradox of wanting to be alone yet feeling lonely is something that I ponder on and ruminate over. As I attempt to unpack the contributors to this, I wonder if time and frequency play a part. I seem to lack a consistent approach to nurturing these relationships. I am often not responsive when a friend sends me a message, unless it is a clear question about a clear subject. I will often read and digest a message, and yet if

there isn't a direct cue to respond, I will simply digest the content and do nothing. The usual friendly niceties I understand. "How are you Reece"? "I am fine", is the appropriate response, and I have been told that it isn't a real question. In fact, it is similar to the question that table servers ask after a restaurant meal. You know the one, "how was your meal". They usually seem to be moving away at the instant the question is deposited, and rarely seem to know what to do when you start explaining the bits you didn't like. I sometimes remember to say, "how are you", which is the custom, and one of the rules of polite conversation, and it can move on to a reciprocal "what are you up to".

When somebody messages me with thoughts and feelings about something, I am rarely certain as to how to proceed, unless they directly ask me what I think, or what would I do, or what should I do. It is the same when someone says, "we should get together soon", which seems to be a statement. How would I know that a response is required? If they ask directly, and say something such as "are you free on Friday to meet up"? I can answer that and perhaps arrange a meet. Of course, If I am not free on Friday, then I may answer "no". If they then ask, "when are you free", I may proceed to find a mutually convenient time, but if they don't follow up with the suggestion, I may simply move away from the conversation. I have been told that it takes a real effort to connect with me.

I am still unsure as to whether this relates to me, or to their methodology, notwithstanding that they are linked. I would argue that it takes less effort if you

remove the small talk and go straight to a direct “meeting setting” approach. “Hi Reece, I would like to meet up to talk about fly fishing, is there a day this week when you would like to, and can do”? Of course, none of my friends (if indeed they are friends) of the past and present want to talk about fly fishing. Perhaps my friends are in the future – and I haven’t arrived there yet.

Margin Note*:*

Memo to me: Get fly fishing friends! To be continued…

As I consider the above series of vignettes, many of which link to the social domain of relationships, interaction, and communication, I note that require communication and reciprocity. I am drawn to consider the research on communication and context driven interaction and interest as potential areas of research. Social Interaction difficulties often experienced within relationships of various types, including friendships within multiple domains and environments play negatively with the core characteristics of autism from a manifested perspective. This presents a clear link to the well-known suggested deficits relating to Social Interaction and Social Communication (Petrina et al., 2016).

That relationships are problematic for many autistic individuals is explicitly explored within research, and it is implicit within the so-called dyad of impairments (American Psychiatric Association, 2013). Social interaction and communication are a fundamental part of developing and maintaining friendships, and these areas of

challenge, born of difference can be readily observed. Understanding this at a deeper level, including multiple contexts, including the what, when, why and how can best be explored by looking at the life of an individual over time, through their own lens, and thus far, examination of the process of making and keeping friends over time has been underexamined (Bagwell & Schmidt, 2011).

Unpacking the impact of the difference alongside the impact of consequences through trial, error and failure of friendships could shed more light on exactly what is happening to so many autistic individuals who struggle within this domain. Friendship and autism have been explored and defined as a horizontal dyadic relationship (Bagwell & Schmidt, 2011). According to Hartup & Stevens (1997), Friendship is a voluntary undertaking based on reciprocal affection and, and something that is distinct in from the vertical relationships between parents and children. These vertical relationships generally exist and occur where and when there is a developmental difference, in terms of chronological age, or developmental age, and where there is a power and role differential, and where the dynamic of control is unbalanced (Bagwell & Schmidt, 2011).

Four key areas have been identified within the importance of friendships in relation to healthy and happy childhood development. The first relates to a protective factor against loneliness and depression (Asher, Parker, & .Walker, 1996). Friendships have been correlated with increased wellbeing and development of “well-adjusted” young adults (Bolvin & Bukowski, 2009). The second relates to development in terms

of social, cognitive, and emotional domains, and that competence within these domains is affected by friendships (Bagwell & Schmidt, 2011). The third relates to social learning, and that friendships provide this important setting for individual and shared experiences, and social modelling (Bagwell & Schmidt, 2011). The fourth explores the standard and unique aspects across dyads, and this provides the important references points in terms of “how to be” within changing models of friendships and relationships.

6.17 Context brings Courage

An example which emphasises the importance of context lies within the different mechanics of intimate relationships, peer relationships, subordinate relationships, and how the context changes the expected behaviour (Bagwell & Schmidt, 2011). This is important in terms of understanding how to move between roles and sustain these relationships in a healthy way over time. This is something that I have always found problematic, and yet something that those around me have often just seemed to “get” intuitively. Working out how to act around a boss vs a colleague – given that at times I have experienced bosses acting like friends within social work settings – then changing the rules within a work meeting. It hurts my brain just trying to work this out! Howes (1996) refers to the sense of “specialness” on the basis that friends will care specifically about each other. This makes sense, but sometimes you don’t care about a “friend”, especially if they are wrong, and I therefore posit that this is highly contextual, and that situations and contexts can change the way that you feel about people generally, including so-called friends.

Bauminger-Zively (2013) suggests conversational interaction, shared attention in the form of play, and skills within these domains all have a significant role in the formation of friendship, companionship, closeness and intimacy, and postulate that these “behavioural markers” are fundamental to cultivating friendships. I would happily share my knowledge about fly fishing with friends, and I would happily discuss the most likely fly to facilitate catching fish, depending on the weather and light conditions, water movement patterns, water temperature, insects, and water life present, and indeed a wonderful conversation on entomology would induce a state of “liking” them immensely. If they move onto discussing football however, I like them no more! I wonder why they can’t sustain a conversation without changing it. I suspect that for me, there may be a lack of connection to the person, but rather a connection to the subject and context. Subjects and contexts change constantly, and this causes me tremendous anxiety. I have found that there is a little more predictability within the context of fly fishing, inasmuch that as a percentage, the amount of contextually driven conversation and interaction is dominant, and you can bring the conversation away from “football” and back to fishing – without appearing to be weird. In the past, I have experienced overt statements, such as “we have moved on from that, Reece”; or can we change the subject, Reece. They actually mean “may” we change the subject, of course (permission as opposed to ability), yet even were the syntax and grammar to be correct, I know that it isn’t a real question anyway.

Even talking about the weather is contextually important as previously mentioned. You can always change your fly as a failsafe way of generating discussion, or to bring the conversation back to fly fishing. Fly fishing is a courage domain for me where I fit in. I can hide in plain sight, I am not a person, and nor are they - we are fly fisher-people! There is even a retrieval pattern called the figure eight. A retrieval is where you pull the line through the water towards you in order to remove any line slack, and to allow the fly to swim, or pulse to mimic a living food source, such as small fry, a shrimp, a nymph, or hatching fly, or perhaps even an unfortunate fly that is caught in the surface film of the water after falling in. This retrieval pattern perfectly mimics one of my natural hand-stims! Does this make me a true multi-tasker?

6.18 Margin Notes: Identity & Friendships

As I reflect further on my failure to cultivate friendships, I consider that I had many more opportunities as a child – on the basis that I was forced into environments such as school, where opportunities to make friends presented themselves. Within work as an adult, I was, again placed into an environment where opportunities presented themselves. As an independent adult within adult education, and at work, I have complete freedom not to move forwards into the domains of friendship, and as such I tend to avoid many of these opportunities. I am cognisant that my avoidance rises from anxiety, fear of failure and rejection that I experienced in the past as a child, and young adult. I am carrying this legacy, together with a highly avoidant personality generally, if indeed it is part of "personality". It may be a learned response that needs to be unlearned and replaced with new experience. I consider that context and utility, namely the purpose of the interaction, if indeed that there is one, whether driven by interest in the subject, need, and, or the quality of the activity could be fundamental

to creating the right environment for friendships to take seed, grow and mature into the resilient Oaks of Joy that can weather all seasons.

An interesting Aphorism suggests that friends are with you for "a reason, a season, or a lifetime", from an unknown author, though often attributed to Eleanor Roosevelt, or Brian A "Drew" Chalker can be found within a poem which talks about friendships born of utility as being separate from friendships that survive for a season, and that this relates to shared growth before the friendship wains and dies. Then there are the lifetime friends where there is learning and change over a lifetime. I have had the reason and context-based friendship. I have had seasonal ones, though never through all of the seasons in a year, I have never had a lifetime friend – though I am still living. I wonder if it is too late for me, or if the start of a lifetime friendship starts at the point that they enter your life…

What about people who come back into your life? Is a break allowed? Within aphorisms and epigrams, there is rarely objective truth, and they lack the simple substance of the axiom, yet within the pithy statements – there may be something worth exploring. Perhaps I am ready to move towards seasonal friends. There is a fishing season after all. Fishing friends? I want friends. I don't want friends. Sometimes I want friends. I want to be alone. I don't want to be alone. I am alone.

6.19 Vignette 25: Social Courage: Finding my tribe within a true 1% motorcycle club

Big, often hairy, and always riding wonderfully noisy and smelly machines, the Biker! I love the smell of petrol and oil, and I love the look and feel of metal. Surely these people are my tribe. A tribe where I am neither the largest, nor hairiest person in the room. I became a "prospect" with a notorious motorcycle club, which is a true 1% outlaw MC. These guys live to ride, and ride to live, as indeed I do. They meet

regularly at bike nights and include other chapters in this process. There I often music within the “club house”, smoking (inside), and bright flashing lights. The latter was the only issue for me, although there is always an outside area with people hanging around their bikes, sharing stories, talking about engines and modifications and even about biker apparel such as helmets and leathers. All of this works very well indeed for me.

The process of being a prospect is a long one, which can take a year or more of subservience, washing up, cleaning more senior members motorcycles, serving behind the bar, showing respect to “fully patched members”, and being “available” (essentially at the beck and call of the club in general). They also have regular “ride-outs” which comprise of a huge convoy of motorbikes riding through their “territory”, almost as if marking it. The reaction to MC’s is polarizing inasmuch that some people vilify them, others accuse them of being a bunch of middle-aged men going through a mid-life crisis. There is a dark undertone to the MC, and they will not allow another MC onto their territory without permission, nor will they allow anyone in their turf the privilege of wearing a top or bottom “rocker” as a patch on the cut-off leather waistcoat (cut), or jacket. For anyone who has watched the popular TV series “Son’s of Anarchy”, although dramatized – much of the culture is in fact based on reality of MC life. There is a real sense of brotherhood and family within a Motorcycle Club, and there is considerable camaraderie and humour, although not always politically correct.

My first negative experience within this environment occurred at a large club meet – which was an open bike night. There were flashing lights, but as always, I protected myself by wearing my dark glasses. Upon approaching the bar, there was a group of patched members, together with a prospect from another chapter, and they were laughing whilst looking at me. I greeted them, which is a very important custom. You absolutely must greet everyone on arrival and say your goodbyes to “everyone” before leaving. There could be hundreds of people in attendance at these meetings – all dressed similarly. This caused a real issue for me in terms of working out who I had processed in this fashion (more on this later).

One of the patched members started singing “No New Year’s Day, to celebrate. No chocolate covered candy hearts to give away” (a song by Stevie Wonder). He did this whilst moving his head side to side in typical Wonder fashion. Stevie Wonder was blind! I suddenly realised whilst smiling, that he was, to use a colloquial term “taking the piss”. My smile vanished and my back bristled. He then asked, “Why the fuck are you wearing sunglasses at night and indoors”? I replied with “I have light sensitivity from the flashing lights”. He was drinking, and was well into a few beers, and he replied with “you look like a knob”. I flashed and replied with “you will look like a knob with my fist in your face”! Luckily, one of the senior members from my chapter, who was aware of my autism and reason for wearing the glasses intervened. I was whisked away by two other members who took me outside for a smoke. On the way out, I heard the “Road Sergeant”, a high-ranking member of my chapter

tearing into the guy. He also told him that he had a narrow escape messing with me as an individual who “can and will fight”.

I received an apology later, but the whole experience left a residue on me for days. The other issue that I found was within the constant demands to attend as part of demonstrating my commitment to the MC. This was the most problematic part of the entire adventure. Managing my energy and tendency to avoid demands was causing considerable anxiety, and in the end it neither worked for me or the club. I enjoyed elements of the potential to be part of a brotherhood of bikers, and some of the people and interactions were brilliant, but I simply couldn’t handle the demand and commitment.

I left the MC by agreement and discussion. They seemed disappointed in losing me, which made me feel wanted – even though I felt like a failure. I was also surprised by how inclusive they were within the chapter in terms of trying to work around my neurodivergence and eccentricity.

As I unpack this experience, I am drawn to the considerable research on social identity (SI) and the “Social Cure” agenda, which offers the concept that the groups to which we belong to and that are important to us have a considerable impact on health and wellbeing (Jetten et al., 2017). This social identity approach (SIA) emphasises two theories as a base. Social Identity theory (SIT), where one aspect relates to our own identity and sense of self and who we are separate and different

from a group, and conversely, our identity as related to a group, and also how the group itself has its own identity and is distinct from other groups (Tajfel & Turner, 1979). Within this theory it is proposed by Tajfel & Turner (1979) that where the membership of a group is important to an individual the identity in terms of shared attributes, norms and aspirations move to the front ahead of one's own personal identity characteristics which mark them as distinct from others. With this in mind, the research tells us that the "self" and the "other" are strongly linked within this concept of identity and sense of self.

The SIA has been linked to better mental health and wellbeing within non-autistic individuals, and in particular, social identification has been positively correlated with lower levels of depression (Postmes et al., 2019), and anxiety (Wakefield et al., 2013), and increased levels of resilience and mental wellbeing (Williams et al., 2019). A meta-analysis provided evidence that SI was an important contributor and mechanism for an improvement, notwithstanding that potential issues relating to poorer mental health were identified relating to the formation of group values and the adoption of a label and corresponding behaviours. For example, a group of people identifying as depressed – may form an identity based on this identity and therefore struggle to transition into other groups outside of this context (Iyer et al., 2009).

This research raises a salient question relating to identity and autistic individuals, given that Sani et al., (2015) found that 46.6% of those without a social identity were

classed as depressed based on the self-report using the Major Depression Inventory (Cuijpers et al., 2007). Notwithstanding that the figures for those with a membership of one group were stated as 17.1% and for those belonging to three, and four groups - 5.7% and 2.4% respectively. Considering the struggles that I have had thus far, in being agile enough to move between multiple “groups”, or even bond continuously with one group over time, identifying the apparent barriers that I have encountered in sustaining a group experience and forming an identity through this association are worth exploring further (assuming that belonging to a group is important for me as an autistic individual).

From my experience, I certainly like the subject matter of the aforementioned Motorcycle Club, I like the dress-code (and this is very important to me), I like many of the sights and smells associated with this group, I like rules (as long as they are understood, and accepted by me), but I struggled hugely with the constant feeling of demand that I felt when I had to “turn up”, and confirm that I was indeed going to “turn up”. Some of my reticence linked to spurious energy levels on the day, but the group did not allow a “we’ll see” approach. I also hate hellos and goodbye’s, which were a fundamental part of the culture within the MC, and this caused me considerable anxiety. I was even chastised for getting on my bike and leaving without telling anyone.

In respect of the importance of Social Identity, Similar studies have suggested that having multiple social identities correlated with lower levels of psychological distress

(Cientanni et al., 2017). None of this research thus far relates explicitly to autistic individuals, and in order for this to be explored, the level in which autistic individuals can access their feelings as reliably within similar tools, or the creation of appropriate tools and measures need to be considered (Happe', 2003; Hill et al., 2004). The ISCA "(Integrated Self-categorisation Model of Autism)" suggested by Mottron et al., (2006) theorises that there is a general bias towards local processing over global processing and categorisation in the case of autistic individuals, together with the tendency to experience empathy and theory of mind outside of one's own experience. This, combined with other autistic idiosyncrasies may suggest that an autistic self-identity operates differently, and any group identity in terms of relationship and even accessing a group may require a different approach (Mottron et al., 2006).

Margin Note

It remains at this stage that I feel a paradox of wanting to be part of a group, whether the dyad of friendship, or through the connection with likeminded and like-valued individuals, and yet I don't feel the want and need of the connection with the people as such, but rather through the stuff and things, or through the exchange of information as opposed to the exchange of some form of energy.

6.20 Vignette 26: Tit: I know you are, I said you are, but what am I?

Many things can be found down the back of the sofa. Many treasures lie in wait there, yet I cannot find myself. Where am I, who am I, how am I, how do I feel and why? I couldn't find myself in therapy, but I did find a pen at the back of the therapist's sofa. A Bic biro. "Bic"! I smile as I remember that whenever I write with a Bic, I hear the word "Bic Bic Bic Bic" in my head in the voice of Alvin the chipmunk. It has been this way since I was a child. I find my identity through objects and actions, and without them – I lose myself and fall into an identity abyss. If I knew myself, who I really am, and if I felt this, would it protect me from my anxiety? I am only free of anxiety when I am moving, flowing, sometimes cascading like a waterfall. I seem to enjoy searching, and this has manifested in my two loves of metal detecting and fly fishing. Both forms of searching for treasure. The silver and gold piscal flashes of flippy flappy fishy promise, and the silver and gold fiscal flashes sparking avarice at the bottom of a dirt hole. Am I a magpie, and If I were shiny would I search for myself and covet my own discovery? My father described corvids as "rats with feathers". I have no feathers – so what am I? I think of a tit!

6.2.1 Reflection: Therapy, Naval Gazing & Identity

I think of fluff! That phrase, looking deeply into me, myself, and I. Three of us. Memories from the past, fuzzy, incomplete, yet completed and never finished, a paradox. It happened to me, sometimes through me, sometimes because of me – as guilt and its sibling's envy and shame come to the party. I ponder the concept of self, it is mine, myself. Why therefore do I live for others, and should I? Want is the very fabric of my existence. Want and want not. The polarity of hope and fear. Me myself and I. Three of us. The temporal three. I will never be lonely – we are family, and the tune plays...

6.21 Social Identity

Social identity research suggests that group membership and belonging can improve and protect psychological and physiological wellbeing, and reduce anxiety, perhaps providing a courage resource (Haslam & Haslam, 2012), and this can be found, for example within non-binary, and lesbian, gay & bisexual youth minority groups, who support each other and develop a sense of community (Detrie & Lease 2007). Additional studies have attempted to understand the mechanisms associated with these protective and restorative factors (Jetten et al., 2017). Within my own battle with anxiety, and in finding the courage in the name of research to join and interact with groups, I have also tried to connect with the autistic community, but this has led to some extremely negative interactions, and at one stage a serious bout of depression. I would often get bombarded with messages, and comments (online), and criticised for not being responsive.

I have tried to connect within multiple domains, for example, through the university, through multiple social media platforms, and in-person. The common denominator for me is that without a shared interest, simply being part of a group because other people have the same label as me, or additional labels relating to neurodiversity – is not engaging for me in it itself. I have certainly embraced my neurodivergence, and enjoy the gifts that I have, and within this, I do not feel a sense of shame relating to being an autistic individual, but rather that I worry about being hated, being rejected, being ridiculed, experiencing injustice. These things happen on a regular basis, and even more frequently within the very community that I would expect more acceptance and support from!

I want to be me! I want to know who I am, and I want others to know me and accept me. I also want to feel the thing that people describe as love, notwithstanding that there are all kinds of love, such as agape, eros, storge, ludus, pragma, philautia and philia. I have felt the familial love from my parents (storge), and yet I have also felt the hatred of being beaten by my father. In term of philautia (self-love), I believe that my self-esteem is extremely low, and that in some ways my autism is the only good thing about me, and somehow separate from me.

I generally feel a constant sense of guilt and shame, often stemming from my procrastination, letting other people down, avoiding contact and so on. The context of my avoidance seems to change, for example, task avoidance, going out, making

phone calls, not opening mail, and these seem different, although they all seem to share the aspect of expecting something bad to happen. Whether this is bad news, a bad experience, a negative interaction with someone who in turn, thinks that I am bad! I wonder just how much of this relates to some form of accumulated trauma, and, or, a general negativity bias and focus on all the things that could, and indeed have gone wrong in the past. Putting myself “out there” under the scrutiny of others in any way seems to cause ripples of anxiety, fear, and terror within me.

Crane & Goddard (2008) suggest that autistic individuals may have autobiographical memory deficits, and that they struggle to remember key detail relating to life events, and that this impacts the development of a sense of self-identity and self-concept. This, in turn impacts social communication for which a large part relates to life-story telling. From a social point of view, meaning making from the telling of and sharing of stories seems to bond people together (Berna et al., 2016).

An example here, that I can certainly relate to is the forgetting of birthdays, together with their significance. Other research has found that autistic individuals use fewer abstract trait, or state-linked self-statements and narratives than typically developing individuals. For example, “I love to fly fish / I’m a good fly fisherman”, preferring to say “I went fly fishing yesterday”, and “I caught three trout”. This difference in retaining and synthesising social and biographical memories into meaning and storytelling impacts the ability to form a social identity and collective and reflected self-esteem (Tanweer, Rathbone & Souchay, 2010).

Margin Note

Throughout writing an autoethnography, my ability to remember, unpack and synthesise events into richly descriptive and evocative packets of information has improved greatly, and I have found many good things within events that I had previously marked as negative. I have found it far easier to do this with the use of prose, poetry and art, and this is particularly true as it has been done alone, and without the "response pressure" of a serve and return conversation. In doing so, I have discovered and rediscovered things lost, and things not yet found. New species of emotions living within me. A Galapagos of evolving things that the outside world has never seen. I am learning to tell my story and discovering parts of myself and my identity through autiethnography, and I am also experiencing more courage born of utility. I often find myself celebrating negative moments in life for all of the wonderful data that they bring to the table!

6.21.1 Margin Note: A positive Lens

My body, mind and spirit are no longer broken!

I have so often considered myself to be a broken thing, and yet moving through this PhD has changed my lens somewhat. Courage and anxiety through an autistic lens, it is called, and yet I now see myself through a more courageous lens. I had never realised just how much I experience anxiety, and how often I embody courage. This positive lens is something that is often referred to within Strengths-based approaches towards autism, and, or disability. I have always talked the talk in terms of this rhetoric, yet I have never applied this to myself. Hypocrisy at its finest! I have

learned to laugh at myself, and at many of the horrendous moments within my life through this courageous lens. I am surprisingly resilient. I have survived myself; I have survived others; I am a survivor!

6.22 Vignette 27: A Man in the groves, this is not a circular!

Dear reader,
We are three, mind, body, and spirit. Two of us are broken. Painting is a key to unlock my words and enrich the canvass of my life. My canvass is blank. Torn and brittle around the edges. Frayed and brittle! It is thirsty. Water flows and hydrates my existence. My pallet fills with colour – and the words flow…

I started painting, and it has given to me as much as I have given to it, and more. Having struggled at school with the fine motor skills that others of a comparative age seemed to simply “get”, and after much ridicule towards my results, I moved away from all things creative.

Considering that I was “useless” apparently, and that I made up for that by being “weird”. I am now a prolific self-taught painter with self-proclaimed talent. I consider that as much as it mattered what “they” thought then, it matters what “they” think now. There is justice for me in my achievements within painting, and painting has also been cathartic. It has helped me to access, describe and understand emotions within me.

Describing emotions with colour, texture, pattern, and form, together with the ability to paint a scene from an experience with all these elements as components has frankly unlocked me. It has unlocked my words. I have often considered my mind as a broken thing, and my spirit being crushed by the anxiety that I so often feel. I once focused on developing and strengthening my body, and I did this to compensate. I now realise that like the trees in the painting, my mind body and spirit are not separate, but rather that they are linked by roots and tangles.

Mangroves do this to be able to resist the daily rise and fall of the tides. Mangroves have the incredibly rare ability to tolerate and thrive in salt water, and they live along coastal wetlands with their roots submerged in the water, rather like me. I am more integrated now, and I am stronger because of this. Like the mangrove, I am distinct from my terrestrial cousins, and often seen as lacking their majesty, yet I can survive within a harsh environment. Like the mangrove I am endangered by human behaviour and the built environment. I have my roots in the sea and am better together as one: Mind, Body, and Spirit…

I sit and look at my favourite watercolour paintings. All painted by me. All have a deep meaning and value to me personally. This value doesn't relate to the time spent on them (which in the scheme of things is not that long). Most of the paintings were completed in less than an hour! No, the value attached to these paintings in in their accomplishment! I say their accomplishment, not the accomplishment, because these paintings have painted me as much as I have painted them!

To find a way to create such beauty still surprises me! That my broken mind and body can tame such a chaotic medium makes me feel whole and unbroken! I will share these soon. I want others to see my true colours! I understand colour, and often find myself describing my feelings as colours, though not always to others, but inside my own head. When people are angry with me, understanding that they are red, helps me to grade this emotion – by referencing the depth of the colour. This approach often helps me to understand how angry I am (which can be useful when attempting to avert a meltdown).

As I reflect upon the power of painting for me, the power to help me to find the words, to explore myself, repair broken pride and unlock courage, I find myself wondering if courage has a colour, and an association came to my mind instantly, followed by an overwhelming and multi-faceted sensory experience. Memories also came fourth.

6.23 Vignette 28: The Colour of Courage

Does courage have a colour? I ponder upon this question, and certainly I associate the colour gold with courage. I associate lions with courage and shining golden armour. I associate my mother with courage, and she was a golden colour. Golden hair, eyes with a golden green hue to them. I associate my mum's dog Indiana with courage, named after the intrepid and courageous explorer Indiana Jones! Yellow (related to gold) is often associated with cowardice. Courage is a hard one to pin down in terms of colour for me. Perhaps courage is a spectrum. As an individual "on the spectrum", I consider that so many autistic individuals seem to struggle with anxiety as indicated within my research, and I can attest to this. I have also noted that in order to activate courage, we have to experience fear and choose to hold our ground, move forwards, or to walk away. I have considered the many different domains of courage, including, but not limited to moral courage, whose sibling is justice. It starts to dawn on me that perhaps "autistic courage" is a virtue that is extremely well used every single day.

6.24 Vignette 29 Gold, Mum & Indiana: A Pain-ting

Where is my angel? Where is my oracle? The music of your laugh, the velvet of your touch. When yellow skies of cowardice descend into the vista of my life, you are only there in my dreams. Though I know that always in my heart even whilst you fade from my mind. Come back please. All prayers unanswered. A deafening silence of absence. No more, evermore…

My memories are the only part of you left, yet I know that I am of you, and from you, always a part of you as you are of me. I grieve anew each day and yet always have hope that we will meet again. But not yet!

I have another angel mum, and you would approve. You have never met her – though she has met your expectations and hopes and gone beyond. She has the essence of gold, a touch like velvet that is bearable and more. She makes me more, and whilst her soul reminds me of you, her name is Eros, Philia, Storge, Agape, Ludus and Pragma. Philautism from Philautia emerges and I love myself in the way that I did through your eyes. I am loved again, and I love again. A gap is filled, and I am agape.

In the above painting, I reflect on the crushing loss of my mother when I was, much younger. I have never expressed one single emotion about this in public, nor privately. After her death, I became even more reclusive than I was before, and I was already a recluse. People in my family expected emotion, but it was never shown by me. This made me feel a little odd at the time, and I am not sure if I recall the existence of internal emotion. I now know that the very thought of my mother, the Lioness fills me with pride and inspires courage within me. I was part of her pride and she is now part of mine.

Within the painting, the buildings are crying and quivering in sadness. Huge blocks of concrete shedding tears under a golden sky, just as I was shedding tears when I painted it. A true water colour indeed. The process of painting took tremendous courage, just as looking at it takes courage for me. I could never have expressed any of this without discovering painting. Surely this deserves to be shared and witnessed. I am going to share some of my work.

6.25 Vignette 30: Buzzing & the drive to share

Bees must be happy!

I'm still buzzing! I shared one of my paintings on social media today under a pseudonym! The anonymity gave me courage, or was I somebody else, and If so – have I have I met this person? Are they me, or am I them, or are we you or are you we? And so, I'm buzzing like a bee…

Over two thousand engagements and comments! I responded to every single one of them with gratitude! Inside I think that I felt pride, though I can't be sure. It was an unfamiliar feeling which left me wanting to share again. I felt less fear, and I felt an increased desire to share…

The concept of sharing and joint attention is that has been researched withing the scope of autism with the expectation of joint attention behaviour in typically developing children occurring at the age of 6 – 12 months within a triadic coordination of sharing, described as *"jointness"* (Leekham & Moore, 2001). The term involves several behaviours, including point and gaze following (Bakeman & Adamson 1984). The functions that these behaviours serve, however are distinct according to (Munday et al., 1993). This distinction relates to the purpose of interactive exchanges, namely "*Imperative"* triadic exchanges, and "*declarative*" triadic exchanges. Imperative exchanges serve a requesting function, whereas declarative triadic exchanges serve the function of joint attention, awareness and sharing.; see also (Gomez et al., 1993).

Autistic individuals exhibit impairments in both imperative and declarative function, although the struggle within the latter is usually more pronounced (Baron Cohen, 1989, 1993; Munday et al., 1986, 1993; Ricks & Wing, 1975; Sigman et al., 1986). As an adult, my lack of interest in sharing beyond imperative function is clear to me

and has been observed by many with whom I interact. Utility initially drove me to share my watercolour painting on social media, on the basis that I had considered the potential of a career as a “painter”. I considered that feedback and reaction may be useful in terms of gauging whether I was a “good” painter, and whether people would be interested in buying my work. I was not at all prepared for the experience of an emotion that, after careful consideration, I now recognise as pride emerged from within me, and I liked it. I was left with the thought and desire to repeat the experience and share again…

6.26 Vignette 31: The Colours are wrong!

Anger is red – the violence of violet, if yellow for fear, then is white for silence?
Yellow for fear, and golden for courage, yet lions are yellow and never discouraged!
If green is for peace, and tranquillity too, why is green sick, I don’t know, do you?
The colours are wrong because silence is golden, yet there is not enough as much as I told them!

Sometimes I am blue, surely blue means peace, and yet it also means cold and riddled with grief.
Amber is warning and red gone too far, mix blue with the red and violence will start.
Is my pallet broken, is it me, is it you? Let's paint together and try not to be blue.
Mix all colours together, as I often do, you'll never get red, yellow, green, nor blue!
Your colour uncertain with the mixing of all, the colour is grey, the crusher of all!

I painted the above painting to conceptualise the struggle that I feel when rules change, conventions change, context changes, and when I am often crushed by getting it wrong and failing to hit the moving targets that pop up within the context of social interaction. These targets comprise of body language, metaphor, sarcasm and misreading of faces, emotions, and intentions. This uncertainty for me is crushing and a major source of anxiety. I use colours to help others to understand my emotional state, especially where I cannot find the words, or the energy to form them. Sometimes verily I feel like an alien, or perhaps I am living amongst aliens. Social interaction is a constant choke point for me. A considerable part of the anxiety that it causes stems from the unpredictability of people, and the constant contradictions, double-meanings, room for interpretation, and in my case, misinterpretation, and the many consequences that I have suffered over the years.

6.27 Social Interaction

Social interaction and communication is one of the core characteristics of autism as defined by the American Psychiatric Association (2013) and it is noted that autistic individuals perform less effectively than non-autistics within the area of social-cognition. These real-world differences have been cited within research (Atherton,

Lummis, Day & Cross, 2019; Morris et al.,2019). It has also been postulated that these differences may be bidirectional in nature, and that the difference between neurotypes is in-itself giving rise to some of the misunderstandings. Within this research and according to Heasman & Gillespie (2017) a common error lies within overestimation and misinterpretation of egocentricity and arrogance within autistic individuals. It has also been found that those of the predominant neurotype are less accurate than autistic individuals in interpreting the mental state and emotions of autistic individuals (edey et al., 2016) and that this difficulty in “reading” autistic individuals often leads to unfavourable judgement and treatment.

Milton (2012) theorised the double empathy problem (DEP) suggesting that miscommunications between non-autistic and autistic people relate to a breakdown in mirrored reciprocity and mutual understanding rather than deficits associated with autism itself. In consideration of these different styles of communication, perhaps “blame” perhaps needs to be pointed in the other direction, and we could move to a deficit model for those of the predominant neurotype. This could be characterised by the tendency to delude oneself, Overuse of metaphor and hyperbole, Chronic Obsequiousness, and sycophantic behaviour. The misattunement from a dialectical perspective within this hypothesis suggest that various psychiatric and developmental conditions may not be as a result of disordered brain function, but rather a mismatch within the realm of interpersonal dynamics (Bolis et al., 2017). Supporting this assertion, additional research from Mirza et al., (2019) suggests that

autism should be viewed as a cumulative misattunement between neurotypes rather than simply a disorder of communication and social interaction.

Furthermore, there is increasing empirical evidence to suggest that autistic individuals are more effective in the area relational communication with other autistic individuals, which suggests autism-specific communication modalities that are more effective between peers (Crompton et al., 2020). The research also suggests a level of comfort and connection described between autistic individuals when communication and socialising with each other. The research is scarce thus far, and without a resolution on the mechanics of successful interactions between autistic individuals. Adopting a paradigm in-line with neurodiversity, that moves away from the pathological model may assist in reframing the narrative to consider a strengths-based approach towards social interaction and communication within autism (Fletcher-Watson & Happé, 2019).

6.27.1: Vignette 31.1 The man who was surrounded by aliens!

Outdoors is usually better than indoors for me! I went to the park to be with the trees and to listen to the water! Peopley people everywhere, especially the small noisy kind! "I like your hat" says one, I reply "what do you like about it"? "it's nice", they reply, "It is not sentient", I reply, and therefore has no intention, nor any qualities other than physical, so perhaps you could be descriptive about the shape, colour, or texture"! "You need to learn to take a compliment", they replied. "You didn't give me one", I reply, "you complimented my hat, and my hat can't learn to take compliments"! They gave me that "you are a weirdo" look - and sidled sidely sideways away. Once more alone in a crowd!

The above painting and vignette were created following a strange interaction with a group of afflicted small people who made lots of noise and ignored instructions from larger organisms who seemed to have a spurious level of control over them. For the purpose of this research, they will be known as children and parents. I recall the incident above, during which I heard one of the parents say that I was a "strange man" to their child, and that they should stay away. One even asked "what did he say" to you, and I didn't hear the rest…

I recall may times where seemingly benign and innocuous interactions have somehow grown legs and run in strange directions. I was entirely correct in terms of my response, although perhaps they were insulting me, and using the archaic form of the word “nice”, which came from the Latin “nescius” meaning “ignorant” and “foolish, frivolous, senseless” from the old French. I was left with the feeling that they were indeed “nice”.

6.27.2 Margin Note: Nobody knows me, everybody hates me!

I often feel misunderstood in terms of my intentions, qualities, and abilities, and I have been described as arrogant, a narcissist a couple of times, caustic and abrasive is another common assertion, ungrateful and even miserable, although that relates to my face not being particularly expressive of “joy” or “gratitude”. I even recall a moment when I received a Christmas gift, and said thank you, only to be answered with “You don’t like It, do you?” at which point I responded with “I am not sure how to answer a negative question, do I say yes I like it, or no I like it”? I have always had an issue with negatively phrased questions, where the answer is a positive, even though you are compelled to disagree with the negative. “Oh, you don’t like it, they asserted!” I then stated simply, “thank you for the gift which I like very much!” They repeated “oh, sorry, you don’t like it, then added the exclamation I can’t do anything right”! I was deeply confused and told them that I just said thank you, and that I that I was grateful, at which point they told me I didn’t look grateful, and it went downhill from there as they say.

6.28 Sensory Experience

I have considerable light sensitivity, and in term of autism and sensory difference, I am not alone, according to NICE (2011), and yet the sensory aspect of autism has not fully entered the diagnostic process within the ICD-11 (2022) not the DSM-5-TR

(2022). There is a contradiction, because for a couple of seconds, I adore the way that light looks when reflected from water, and do not seem to have an issue with refracted light, nor light that has been polarised. Direct blue and fluorescent light, however, give me considerable issues.

I love looking at pictures and paintings where light has been captured and I have reflected this in the painting 6.29 Vignette 32 (pun alert). It is difficult to escape light and light pollution in this modern age when one ventures into public places, whether for work or leisure. Light creates a loud noise in my head that drains my battery and interrupts my ability to communicate. This is a constant source of anxiety for me. As an adult, I wear peaked hats and polarising lenses to attenuate the effect of the light on me, yet I was never allowed to do this at school. I wonder how much more tolerable school would have been for me If only this equity-measure had been a possibility. My sensory profile also provides a source of joy for me as much as it is a source of pain. My mind, I have described as having a mind of its own, is prone to thought loops, instant platitudes, and constant chatter. My mind and senses do, at times, present as a deep and rich interface between the world and me, and this is described within the paintings below (Vignettes 32 and 33)

6.29 Vignette 32: Dark lights big city

Darkness for my eyes and in my days
Trying to find the light though it hurts
Light exposes my weakness and flaws
I live in the dark, looking for the light within
I am fascinated by light, and yet I can't bear its beauty
The city at night and its beautiful dance
Take me there in my dreams where light is darker
Reflections on the water the light enchants

6.30 Vignette 33: Candyfloss Clouds

The above painting (Vignette 33), as many of my paintings have been, was painted unconventionally. I used a twig that I found in the garden to apply the paint to create the trunks of the trees, and branches. I used a big brush (a hake brush) to smudge out the foliage. I swept the big brush across the page in one stroke to create the illusion of mid ground sparkling water, and the same brush for the sky, together with a spritz bottle to soften the clouds. It really did seem to paint itself! I only used three colours too! I also chuckle at the thought of using a piece of tree to paint trees, and water to paint “water vapour” AKA clouds. Individuals with autism often experience difficulties in accessing, identifying, and articulating their emotions, and also the emotions of others, and much of this challenge will fall into the realm of communication, both verbal and non-verbal (Round et al., 2017).

For me, there is an ellusive part of communication which resides within the framework of non-verbal communication, and at this stage, I do not want to discuss and debate that which is occuring in the brain, which is frankly still a moot point, but rather to explore my experience as “felt”.

I sat with a blank page in front of me, and my blue water pot, strusty twig, large Hake brush, masking tape, and my spritz bottle which was two thirds full of water. I was having a bad day from an anxiety perspective – with my stomach churning, the feeling of tears that wouldn’t come, and a bout of “fire face”. I call it fire face, because when I am anxious, my face feels like it is burning. Tasks had built up, and this was the source of my anxiety.

A tune was playing in my head, “take me to another place, take me to another land, let me forget all that hurts, let me understand your plan”… A popular song by arrested development… I think of Tennessee, and an image pops into my head of a winter scene by a lake, and I imagine myself there fishing. A feeling of peace washes over me, and I smell candyfloss from the clouds which are pink. Stinky Pinky repeats itself in my head. I want to be there, and in a way I am there, and I feel a sense of peace from this spontaneous visualisation. I say visualisation, but actually, it is not just an image, but rather a multi-layered sensory scene in my head. Fish, birds, and trees won’t place demands on me. They won’t interupt these images by interjecting questions. This rich “visualisation”, which will now call a “sensoralisation”, which appears in my head in a caribbean accent, followed by procrastination, station,

constipation, illumination, frustration, and the thought loop goes on. It is almost heaven, and life is old there, older than the trees, younger than the mountains – growing like a breeze, another song plays in my head. This is a snapshot of the noise that goes on in my brain when thinking. The noise is increased when another person, or people come into the “picture”, and my capacity to process any non-verbal messages is extremely limited. My brain noise increases in response to the thoughts of others, and I have to concentrate extremely hard to decode their words.

In addition, there may be considerable external sensory feed to attempt to filter out. I reflect that I need a limited pallet in order to quiten this noise, and that some of my best conversations have occurred on the bank of my favourite fishing lake, whilst speaking to another fly fisherman. I also reflect that my best conversations seem to occur whilst speaking to ancient fishermen. For some reason, they seem to have less “body language”, less hidden meaning, less talk required from me – as they tell stories and never seem to be in a rush. They seem to sit a lot, and move around less, which is also somehow less threatening. One such ancient fisherman smelt like TCP, which I like. RES and TCP, RES and TCP plays a tune in my head.

The painting above was spawned from wanting to escape the intense feeling of anxiety that I felt in a moment. It was an escape for me, and I sat with the image in my head for either hours or seconds, and I didn’t have to travel there. When I returned from not going anywhere, I felt a residual sense of peace, and started to paint as described above with my twig.

Fifteen minutes later, my painting was finished, and it was packed with words, feelings, smells, conversations with ancient fly fisherman, peace, fish, trees, and birds. It was the cheapest holiday that I have ever been on, and also the most relaxing. Can you read my painting? Can you smell candyfloss and TCP? It is a non-verbal two week package holiday, and I consider that perhaps my inability to decode conventional non-verbal communication sits within my spare communication capacity resulting from a multi-sensory thought experience that never shuts off. I had not realised this before I painted the above painting, and this was not the purpose of the painting, which was essentially an escape at the time.

Once I had emotionally returned from my holiday, I felt peacefully drained, and reflected upon how many words, smells, feelings, tastes and rich content was imbued within my painting, and that as a method to communicate with myself, through myself, and perhaps with others – there was a powerful potential here. My mind seems to be an echo chamber and force multipler for emotion. If the darkness gets in – it echoes athrough the chamber, and is the gift that keeps taking. Conversely, if the light gets in – then the same applies, and therein lies a source of anxiety for me, which one will enter…

A seemingly simple and benign conversation with an unpredictable person (essentially all and any people) can cause this echo effect in my mind. You have witnessed my though loops above, and perhaps can appreciate the need to protect myself from inheriting the unwanted darkness inherited from another. Until painting

Candyfloss Couds above, I hadn't realised where my social anxiety had come from on so many occaisons. I had previously considered that it had arisen from negative endings and social consequences, which is true, and quite obvious, but I hadn't realised how much of it had stemmed from the enemy within! The dark echoes, as I will now call them…

6.31 Chapter Reflections & Conclusions

Within the previous chapter, the subject of courage was explored in respect of its definition and the processes that occur within its activation. Research agrees that courage exists through the presence of fear and anxiety, where there is volition to act in the form of moving forwards, holding fast, or moving away from the fear stimulus. There is disagreement on the quality of nobility and virtue as a central ubiquitous component. Specific domains have been explored, such as social and workplace courage, and measurement tools designed to identify and measure courage have been discussed within this thesis.

Within this chapter, my own experience of courage in the face of anxiety has been considered through autoethnography. Each vignette within this chapter contains insight, introspection, unpacking and analysis, which will not be repeated here, but rather summarised as a reminder of some of the exemplars and key themes that have emerged. It has been noted that courage, for me can be activated through clarity of context, and within moments where interests are shared, which was noted within vignettes: 4.13 Vignette 11 Timothy / 4.14 Vignette 12 Timothy part 2, and 6.19

vignette 24 Finding my tribe within a 1% motorcycle club. It was noted that there were different emotional reactions and states depending on the context, stage of the activity, and processes being used. For example, within the planning stages of the fly-fishing activity noted within vignettes 11, there was considerable anxiety, and often the abortion of said activity in favour of one that required no planning, nor social interaction. That said, I now realise that it took considerable courage to battle through the planning stages to venture onto the lake, and within the context of attending the motorcycle club, perhaps even more so.

My experience of rejection has been noted and described as a significant fear as discussed within 6.2 vignette 13 and 6.3, and a sense of shame emerged as a theme through 4.6, 4.7, and 4.9. My sensory experience emerged as a source of anxiety, yet also a unique way to perceive the world that bring considerable joy, and that has also found its way into my art and music as the presentation of a series of unique sensory strengths, as shown in 6.29: Vignette 32 and 6.30: Vignette 33. In finding at witnessing these strengths, the lens through which I view myself has changed, and I feel less shame, and perhaps even an emerging sense of pride and acceptance of self.

Injustice as a precursor to anger within me has been identified as a major courage activator, and in part the courageous undertaking of a PhD was born of a past educational experience early in my life, where I was criticised constantly for being “less than my peers”. This was captured under 6.1: Beginning the autoethnographic

Journey: A courageous and hopeful step, and within 6.4 Vignette 14, The cruelty of children, where a particularly traumatic event was recalled. It was at this point that I believe my relationship with Justice and injustice was spawned. This instance, and many others before and since can be classified as bulling, and yet I had neither realised, nor seen it as such at the time. The definition of the term, together with some darkly powerful statistics relating to bullying and autism are explored under the aforementioned vignette.

From my own perspective, I have come to realise just how powerful the impact of adverse childhood experiences are, in relation to being bullied systematically for years. As discussed within the literature, this wasn't limited to physical bullying, and many domains have been discussed within the taxonomy of bullying and explored within this thesis. I believe that a huge source of my anxiety exists within these experiences, and that they have created scars inside me. Dichotomously, they have also sparked a sense of justice within me that has provided me with at least one of my superpowers. Perhaps I am an avenger for justice – just like the Batman! Protecting the weak, the downtrodden, and my own values once this power is activated.

The undertaking of such a massive research project in the form of a PhD, I believe has provided an exemplar of courage born of this sense of injustice, and that injustice provided both the pull of hope and push of fear to overcome my inertia and tendency

towards procrastination, which, for me, is a form of avoidance born of fear - which was also explored within 4.8 Vignette 7: *A slippery slope*.

Considerable literature was explored within the context of procrastination and task-avoidance. Within this section, I identified “Traction Triggers”, which is the term that I gave for an event, person, or context that gives me something to overcome my inertia. These Traction Triggers, I postulate are comprised of the following elements: Courage, Energy, Salience, Necessity and Utility. These elements existed within a particular event that was noted, where I took delivery of a new motorcycle – that provided me with the Traction Triggers for to attend a motorcycle café. I noted that there was a positive, even transformative residue left on me after attending, and in feeling more connected to the world, I somehow felt more connected to myself.

Social Identity has been explored by Wenger (1998), who considers the cyclical relationship with self and other in relationship to identity and community in the context of autistic individuals. Procrastination was discussed and according to Rosenbaum and Web (2018) it is not a unitary construct, but rather a compound including many states, explanations, causes and determinants, not least of which involves executive functions. Dewitte and Schoowenburg (2002), and Steele (2007) relate procrastination to cognitive focusing on that which we intend to, or are supposed to do. Gund and Fries (2018), and Rebetez et al., (2016) acknowledge the derogatory and accusatory aspects related to being labelled as a procrastinator.

Masking has been explored as both a coping strategy and as something that activates courage, and this is seen within 6.10 Vignette 19: Which came first, the chicken or the duck, and within the following margin note 6.10.1: Why do I mask, and whilst masking is a source of courage, it is an expensive fuel burner in relation to my emotional energy, or perhaps even my soul and identity.

Identity has been explored in terms of the self, and the self in relation to others, and of note is my social avoidance juxtaposed with my longing to connect with others, and the deep sense of loneliness and isolation that I feel. This was first described within 6.16 vignette 13*:* Nine Lives. Within this vignette, I note my self-isolation in relation to the aloof independence of felines, and captured this in a painting, and noted symbolically that the nine lives of cats may relate to the decades of human life that we may be afforded on this planet. At this stage of my life, I may be half-way, I may have passed the half-way stage, and still have no friends. My tendency towards a feeling of “self-loathing” was also described. I recounted an experience linked to seeking contextual friendships through both fly fishing and through my love of motorcycles, and both provided moments of connect and disconnect as described within 6.19 Vignette 25: Finding my tribe within a 1% Motorcycle Club. The contextual element of motorcycles brought with it the engine power to seek connection, whereas the social element, together with social rules brought moments of challenge that made the connection unsustainable. Identity was also unpacked within a moment of *Naval Gazing:* 6.2.1, and within a visit to a therapist, and social identity was discussed, together with literature in the context of autism.

A tremendous moment of immersion was described within my beloved special interest of fly fishing within 4.14 vignette 12 Timothy Trout part 2: Anxiety moves into courage, and a clean sense of anxiety was described within the moment of hooking and landing a fish, juxtaposed with negative occurrences stemming from actual and potential interactions with other fly fishermen. This is significant inasmuch as whilst this vignette sits with its counterpart within the anxiety chapter, there was considerable positive emotion and courage within an otherwise anxiety inducing experience.

Colour in terms of conceptualisation was discussed within 6.23 Vignette 28: The colour of courage, and within 6.24 vignette 29: Gold, Mum & Indiana: A pain-ting, where memories of my affection for my mother and another were brought to the surface and described as *"golden".* The colour gold has unique significance for me, so much so that I taste honey when I see it, I hear the voices of Nina Simone, Elvis Presley and Chris Isaak. Gold is a chord of G, rich, thick, yet also bright somehow. Gold feels like the sun on your face, and it sounds like a lion's roar, It smells like honeysuckle and Jasmine. It tastes like honey, and it feels like warm velvet. If I were to describe the colour gold to a blind person, the above is how I would do it…

Painting emerged as a powerful way to access and unpack my emotions, and beyond its utility, it has become an immensely cathartic activity and a source of pride and self-esteem for me, as noted within 6.22 Vignette 27: A Man in the groves, this is not a circular, and it was noted that painting also activated a desire to share, as described within 6.25 vignette 30: Bees must be happy. Painting is perfect for my

sensory being and the way that sounds, smells, colours, and textures are decoded in my mind. They bleed together somehow. I smell colour, her it and feel it. I see sounds and feel them in texture, and this is why the medium is so powerful in terms of conceptualising and unpacking my feelings.

Utility was considered alongside necessity and noted within 6.13 Vignette 21: Operation noodle, hunger feels like anxiety, and 6.13 Vignette 22: Hunger feeds courage. This was unpacked within the context of a source of anxiety for me, namely going to the shops, or even going out at all, as described in 6.11 The Courage to leave the house, 6.12 Vignette 20: Death Walkers, and 6.15 Vignette 23: T-virus and the resident evil. The triggers for this anxiety were discussed in context.

Social communication emerged as a source of anxiety – requiring courage, and a feeling of being lost in the woods was depicted within 6.9 vignette 18: Some paths lead nowhere, all paths led somewhere, and the context of conversations, contradictions and misunderstandings emerged as being central. It was noted that clarity and context are courage-activators, or anxiety reducers.

Depression was depicted within 6.8 vignette 17: Mr. Blue. It was noted that having a way to identify and express my emotions – gave me the tools to sit with them, wait them out, invest in self-soothing and restorative measures, and perhaps honour my “oldest and most loyal friend”. Colour was also used as a medium to capture my anxiety towards change. This change was discussed in a variety of contexts, including rules, social conventions, conversational protocols, body language and

metaphors, and I noted that I sometimes feel like an alien, which was also described within 6.27.1 vignette 31.1: The man who was surrounded by aliens, and also described again within 6.30 vignette 33: Candyfloss Couds. The context within the latter related to verbal and non-verbal communication, and it also captured the thought-loops and intrusive thoughts that emerge in my mind, which has a mind of its own. Within the same vignette, I reflected upon the impact of sensory feed and processing on my anxiety and energy levels. The painting itself was noted to have arisen through the desire to escape anxiety.

Music has been discussed as a major courage domain for me, and recent research was discussed suggesting that music holds real power and meaning for autistic individuals, not least within the social space. Music was described as a way to escape, repair, understand, express, communicate and create. It has emerged as a truly powerful and efficacious courage inducer for me, and hiding within this thesis is a secret vignette which may surface within my Viva.

Chapter 7: Conclusion

7.0 Introduction

The purpose of this research was to explore the experience of both anxiety and courage through an autistic lens, and to do so in a deeply qualitative and introspective way. This level of depth has been missing from research, even though the research tells us that autistic individuals are predisposed to clinical anxiety (Kerns et al., 2014). It was noted within the anxiety literature review section that the mechanisms of this anxiety have not been deeply explored, and many of the questionnaires utilised in the identification of anxiety within autistic individuals assume high levels of self-awareness, advocacy, and access to one's emotions; yet the research tells us that these things are not always accessible to autistic individuals see (Sterling et al., 2015) and (White et al., 2012).

As noted above, autistic individuals have oft been described as anxious, and predisposed to clinical anxiety, which was explored within the anxiety chapter; and yet, this medical model, based on deficits, does little to align with the Neurodiversity paradigm. The Neurodiversity paradigm describes difference as opposed to disorder, disease, and deficit. Positive Psychology as a discipline considers strengths, values, virtues and that each individual possesses them, and yet autism is seen by many as a trope for incommunicability see (Pinchevski, 2005), and within this, autistics are seen as lonely loners masked by a cloud of social solitude according to Greenbaum (2010). I believe that life itself, in the form of the environment, whether built or social, presents barriers, and I believe that once removed, there is potential for autistic individuals to flourish.

With this in mind, in addition to exploring and unpacking anxiety, through an autistic lens, which has been missing from research thus far, as indicated above and within the anxiety chapter, I have considered that I may possess considerable reserves of courage, which is something considered to be a virtue. Courage was the other half of this PhD, yet when I started, I had considered that it was something of an ancillary gap. Through the exploration of courage literature, and my own experience of courage through the autoethnographical sections of the thesis, I have discovered that I have more courage than I previously suspected, considerable opportunities every day to use it, and the beginnings of a realisation that there may be a uniquely autistic presentation of courage, not dissimilar to the unique autistic experience of anxiety described within the limited research cited.

I feel that I have achieved the stated research aims, and that my experience of anxiety and courage have been explored to a great depth. Beyond this, I have grown considerably as an individual through the process. Much like many autistic individuals, my understanding of emotions at the beginning of this PhD was limited, as was my ability to unpack them in writing. Through the use of unconventional methods such as painting, poetry and music, my ability to unpack emotions, describe them, and to even create a narrative of my life has improved considerably. I consider that there is much potential for autistic individuals to build a higher sense of self, and potentially self-esteem in addition to understanding – through the use of strengths, and interest-based approaches such as artistic pursuits, journalling, music and exploring self through these methods. That I have been encouraged to

explore my experience of anxiety and courage in such an unconventional way within this thesis, speaks well of the University which has been my home for five years. I will also take this moment to remind the reader that I failed at school, and left education with no GCSE's. Reaching the level of PhD is an incredible accomplishment for me, and one that I am both proud of and grateful for.

Summary of thesis

Each main chapter within this thesis (listed below) has its own unique reflections & conclusions section, which draw out key themes, pertinent moments, and serve as a reminder of the deeply qualitative and analytical aspects of the chapter. This chapter is intended to serve as a signposting reminder of that which is contained within this thesis as a whole, and will not repeat previous reflections and conclusions in detail.

Chapter 1: Introduction

This chapter outlines the purpose of my research in depth, together with an overview of the pertinent literature, research, and gaps. It outlines my reasons for choosing anxiety and courage as a research subject, and the rationale behind autoethnography as a method and methodology. The chapter also provides important guidance and signposting, together with the context of autoethnography, which may not be familiar as a subject.

Chapter 2: Autoethnography

This chapter delves further into autoethnography as a method and methodology and discusses this in the context of the history and application of autoethnography within a comprehensive literature review, which begins with the introduction and moves into the context of participatory and emancipatory paradigms. This chapter finishes with reflections and conclusions which draw out key themes, pertinent points, and does so both reflectively and analytically.

Chapter 3: Autism & Anxiety

This chapter introduces the subject of anxiety, both generally, and within the context of autism, and contains a literature review on this subject. Discussions and critical analysis around the current diagnostic pathways for anxiety were considered, together with categorisation, and treatments. The chapter finishes with chapter reflections and conclusions. The first vignette is also introduced in a sly way in the form of Vignette 1: The sly fox, and the autoethnography begins in earnest.

Chapter 4: Autoethnographic Reflections on Anxiety

This chapter applies autoethnography and introspection in order to capture my own experience of anxiety, and it contains a wealth of vignettes comprised of paintings, poetry, reflections, marginalia, and even a self portrait carved in wood depicting my feeling as a prisoner to life, self, and my mind. Several key themes emerged within this chapter, including: My own conceptualisation of anxiety, identity and self-

esteem, shame, procrastination and autistic inertia, resistance to change, and where anxiety activates courage. Analytical writing clashed with reflective and abstract content in stark juxtaposition., and a symbiotic non-linear approach to research was applied in contrast with positivist thinking. Emancipatory and truly participatory research was embodied and brought to life.

Chapter 5: Courage

This chapter introduces courage as a concept and explores the literature in detail. Current theories regarding the composition of courage, together with its utility were discussed, and a gap within the research pertaining to the autistic experience of courage was identified, alongside gaps within courage research generally. Despite the gaps, considerable research was curated and explored, and this in itself is a contribution towards an understanding of the abstract concept of courage within the auspices of research. This chapter finished with reflections and conclusions.

Chapter 6: Autoethnographic Reflections on Courage

This chapter explored and unpacked my own experience of courage autoethnographically through a series of vignettes, reflections, and margin notes. In addition to the mixed methods of exploration, such as painting, and poetry as seen within the anxiety autoethnography section, music was introduced and described as a salve for anxiety, a source of courage and inspiration, method of expression and way to make sense of the social and emotional world. Justice was discovered to be a key courage activator, and this was discussed alongside

righteous anger as a key theme. Identity and friendships were explored in depth, together with self-identity and social identity specifically, and this was linked to current theories around autism within this context. The sensory domain, and my unique sensory experiences were unpacked within this chapter, which finished with chapter reflections and a conclusion.

7.1 Recommendation & Limitations

A key limitation of this study is that as an autoethnography, I am the sole researcher and participant, and my experience, whilst that of an autistic individual, might not be representative of other autistic individuals, and yet it may also resonate deeply. Dissemination to other autistic individuals may be a key part of addressing this limitation, and perhaps focus groups may be an apt way to embark upon this ahead of wider dissemination. One of my supervisors is an autistic individual, and it was noted that the choice and arrangement of words within this thesis, together with the descriptions, poems and pictures had a uniquely evocative impact, and at times a visceral experience for them. In part, this could relate to a deep autistic empathy within extremely relatable experiences as witnessed by another autistic individual, yet at this stage, I am hypothesising. A discourse analysis in the form of secondary research may also present an interesting opportunity within future research.

7.2 Impact on the Researcher and Participant (me)

Autoethnography presents an interesting conundrum, inasmuch that I am both the researcher and participant, yet this is also its great strength as a truly participatory and emancipatory approach towards research. My journey through the forgotten treasures and horrors of life has presented moments of catharsis, yet also holds potential to emulsify traumatic and unresolved experiences. Throughout this journey, there have been incredible moments of emotion of both positive and negative valence. I have taken care of myself, and also been taken care of throughout the journey, and the impact for good far outweighs the negative. This may seem to fit with a teleological view of ethics, yet strict adherence to ethical autoethnography, self-care, and anonymisation of others entering my space were also duly considered and applied within a deontological position. Whilst autoethnography holds tremendous power for good, it needs to be caveated with ethical pastoral care for the proponent. Whilst I considered this at the beginning of the journey, I could not and did not understand the full breadth and depth of the impact that going this deeply into myself would have on me.

7.3 Moving towards a Strengths-based Model of Autism

Many are familiar with the social model of disability juxtaposed with the medical model, and the neurodiversity paradigm. These approaches have been explored within this thesis. Strengths-based approaches within the auspices of Positive Psychology are less commonly understood. As an autistic individual, I believe that

my tendency to gravitate towards special interests in an immersive way, oft described as obsession and used as a derogatory remark, presents a unique form of strength in the form of hyperfocus, perseverance, and total immersion within the activity. Before this PhD, I couldn't paint, nor had I written a single poem, song, or piece of music. I have become a prolific and accomplished painter, a poet, keen fly fisherman, and even learned to play the guitar to a high level of proficiency – accompanied by the rapture of singing. None of this is "normal", "typical", nor "common". These are gifts that should be celebrated. I do not think that I am unique, but rather the anecdotal tendency for autistic individuals to develop deep passions and interests for a select number of interests, described as narrow, fixed and rigid within the medical model, are actually gifts, and a pathway towards uncommon mastery, when and where allowed, encouraged and cultivated. Shifting this lens away from deficit, I believe presents even more opportunity than even the social model of disability has to offer in terms of empowerment, and that it challenges the assumption that I am disabled at all. I believe that the locus of control resides within me, and that neither autism, nor my environment present barriers that I cannot break down.

7.4 Original Contribution to Knowledge

- A comprehensive literature review that has drawn together general anxiety research into the context of autism, which has been taken further within the analytical and autoethnographic sections of this thesis.

- The autoethnographic exploration of the autistic experience of anxiety through the lens of an autistic individual in a deeply qualitative way. Within this research, I have discovered a considerable number of anxiety activators, that I posit are unique to autism, together with a much deeper understanding of the existing knowledge-base within this area.
- A comprehensive literature review on the subject of courage generally, noting the lack of research into autism and courage.
- A deeply qualitative exploration of my own experience of moments of courage, together with the discovery of courage activators in a variety of forms. I have also recognised, cultivated, and built courage through the process of this PhD.
- Participatory and emancipatory research has been embodied throughout this research, and my voice has been fully captured and honoured in a way that is incredibly rare within research. Autoethnography as a method is rare within research, and in this case rarer still as an autie-ethnography.
- Autoethnography as noted above, whilst still rare within academia and research, has a developed following, yet there is little resolution on how to perform one. I consider that I have made a substantial contribution with an exemplar of many different approaches to autoethnography. Using creative writing, poetry, narrative enquiry, painting, music, wood carving, on-the-fly analysis, secondary analysis in the form of margin notes, reflexivity, deep introspection, and a truly non-linear approach that has embraced all other approaches as opposed to picking a side.

- Deep and meaningful self-understanding, growth and the building of self-esteem, self-advocacy and efficacy have been the building blocks of confidence within me as a fundamental part and result of this undertaking.
- A unique and novel approach towards doctoral study was shown within the methodology and method applied to the creation of this thesis. The shape of the thesis blends the conventional exploratory and analytical writing with qualitative writing, artifacts in the form of vignettes, reflections, marginalia. The stark juxtaposition of these seemingly contradictory approaches provide an exemplar of participatory and emancipatory research. The knowledge acquired within has made a very real impact on my life, and I believe has the potential to impact the lives of others, and to fuel further research into the autistic experience of anxiety and courage. Beyond this, I have experienced emotional and cognitive growth throughout the process.

7.5 Impact on the Reader

Each chapter has its own reflections and conclusions, which will not be repeated within this section, however, it has been noted within this research that courage exists in the presence of fear in one of its forms, including anxiety. Within the key chapters on courage and anxiety, the reader will find these subjects linked together within the narrative, and will encounter anxiety, whilst reading about courage, and courage whilst reading about anxiety. Perhaps the reader will also experience both of these things during the reading of this thesis. I hope that the reader will also experience joy, hope, laughter, and inspiration as much as they experience

anguish, despair, tears, and injustice. Some may remember experiences from their own lives in addition to being affected vicariously. Be courageous, take care of yourself, and hold space for others to take care of you. These things are the stuff of life, yours, and mine. They should be embraced and held as companions on the journey that unites all of us no matter what background, race, or operating system. Fellow life travellers, farewell!

A smile, a tear, another year. Four hath gone, another here. A work of life with more to live, a gift of hope, to you I give. This work I bind, with love and hate, my PhD, one whole year late!

Reece M Coker 2024

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