Threshold Concepts – A Multi-Modal Exploration of the Lived Experience

Susan Harrington

Department of Management Science
University of Strathclyde

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Previously Published Work

Harrington, S. and Dörfler, V. (2021) ‘Recognising Threshold Concept Experiences Through Network Analysis’. *BAM 2021*. Lancaster, United Kingdom.

Harrington, S., Dörfler, V. and Blair, S. (2021) ‘Combining Bayesianism and Reflexivity in Interpretivist Research’. *EURAM 2021 Conference*. Montreal, Canada.

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Abstract

This thesis expands upon the existing literature around threshold concepts, through discussing a multi-modal exploration into how these moments of transformational learning present themselves amongst a subset of late-diagnosed autistic adults. Moving away from the discipline-specific context in which threshold concepts have tended to be studied previously, this thesis details an exploration into a more personal transformation – that of reaching a place of self-acceptance following a late diagnosis of autism. In doing so, it discusses insights into this threshold concept specifically, and threshold concepts more broadly, alongside the further questions that have been raised by this new knowledge.

To provide background for this research, the thesis begins with an in-depth exploration of autism and neurodiversity, in which context the threshold concepts are then studied, and to a lesser degree, knowledge levels and the sensemaking which was used throughout. A brief literature review into communities of practice is also included, as the importance of communities and networks became evident once the empirical part of the study was underway. A synthesis of these separate areas is provided towards the end of the literature review, providing a brief overview of how they have been combined for a meaningful insight into the learning process in question.

The findings from this research, which can briefly be described as a striking similarity between the liminal journey of these autistic participants, and the liminal journey as discussed in existing threshold concept literature that, presumably, includes neurotypical participants. A potential further stage to the threshold concept framework is identified with potential relevance to threshold concepts generally. Furthermore, the role of communities and networks in this type of transformational learning has been established, and some important insights into neurodiversity have been achieved.

Seminal threshold concept literature states that experiencing a threshold concept enables membership of a community; this thesis shows that this community may not be the one which was expected, and recommends further research into the different roles of networks and communities while studying the phenomenon. Another question which has been raised by this research relates to the post-liminal phase of threshold concept acquisition, which does

not appear to be as final as existing literature suggests. With regards to neurodiversity, the thesis outlines how the main learning point on that front was that there was seemingly no apparent difference in the threshold concept experience while focusing on autistic adults, which is in itself valuable. Rather than finding further indications of a difference, this research has illustrated that autistic and otherwise neurodivergent people are, after all, still people, but people who think in a different way, thereby contributing to ongoing efforts to increase societal understanding and acceptance of neurodiversity.

In addition, this study is an example of how research indirection (Dörfler et al., 2018) and an emergent research design work to enable more meaningful exploration of a phenomenon – in this case, experiencing the threshold concept that is self-acceptance as an autistic adult. Rather than being limited to the methodological approach which is typical under a given philosophical framework, a combination of both qualitative and quantitative methods is used while engaging in phenomenal theorizing in a broadly interpretivist framework, alongside explanation of why the inclusion of quantitative methods does not make the research any less interpretivist. In fact, the thesis argues that good interpretivism involves embracing any and all methods which further understanding. In this case, a combination of autoethnography, unstructured interviews, and Twitter social network analysis are used to complement one another and develop a rich illustration of the phenomenon which was explored.

Future research into a potential addition of a further stage, beyond post-liminality, to the threshold concepts framework is proposed, as is further exploration of the role of identity and communities in transformational learning. It is proposed that future research continue the inclusion of quantitative methods in an interpretivist framework, a practice which is not entirely new, but remains an oddity despite apparent advantages.

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Glossary

Applied Behaviour Analysis (ABA) – This term covers a range of treatments developed to train autistic people to act more neurotypically. Due to the traumatic nature of these practices, this is strongly opposed by most autistic people and autism advocates, and is widely considered to be abusive rather than beneficial.

ASC – Autism Spectrum Condition

ASD – Autism Spectrum Disorder

High/Low Functioning – A term widely used to describe how well an autistic person can function in everyday life. In other words, how neurotypical they can appear. These terms are considered harmful by the autistic/neurodiversity communities, as functioning is not linear. See "spiky profile".

Hyper-/Hyposensitive – Being either overly sensitive to a particular stimulus, or under sensitive. Autistic people's sensory issues can take either or both forms, meaning a person may be sensory-avoidant, or sensory-seeking (or both).

Medical Model of Disability – This approach to disability seeks to cure or treat the underlying condition. For example, in the case of autism, this approach can involve Applied Behaviour Analysis (ABA) and similar attempts to "train" one to be "normal". This is in stark contrast to the social model of disability, which focuses on accommodation and adjustment. See "social disability".

Monotropism - The tendency for an autistic person to focus heavily on one task or topic, perhaps to the detriment of others. This can also be referred to as hyperfocus, or an atypical division of attention.

Neurodivergent – A person whose mind differs from that which is considered the "norm" e.g. an autistic person. Humans are neurodiverse, a person with a non-typical mind is neurodivergent

Neurodiversity – The natural diversity and variation amongst human minds. The Neurodiversity Movement is a separate entity, being a political movement to have this diversity recognized and accommodated by society

Neurotype – A type of mind, including how a person tends to respond to social cues, specific situations etc.

Neurotypical – A person who has a typically-developing mind, generally used to differentiate between those who have autism, for example, and those who do not. NB: neurotypical (NT) does not mean non-autistic.

Polysemous – A term which has multiple meanings or definitions

Social Disability – A condition or trait which is disabling only because of social norms and expectations, e.g. autistic people feeling they are only disabled when their needs are not accommodated. This approach to disability does not focus on cure or treatment, but on accommodations and adjustments, unlike the medical model (see "medical model of disability").

Socially Situated Difference – The neurodiversity approach to autism and other forms of neurodivergence does not quite fit with that of a social disability, although the premise is similar. Taking this perspective, it can be said that the differences and impairments experienced by autistic people do not exist when they are surrounded by similar people. Thus, the issues arise from the differences between people, rather than necessarily the traits in themselves.

Spiky Profile – A descriptive term for the realities of autistic life. For example, while one may appear "high functioning", they may struggle severely with sensory aspects of life, making seemingly mundane tasks near impossible. A non-verbal "low functioning" autistic person may find everyday life easier to navigate due to not having these sensory issues.

1. Introducing the Research

This chapter describes the origin of this research, and how it developed from both previous research and personal experience. The research journey, and a brief timeline of the various elements of the study is included, followed by an introduction to the aims and the approach which was used to achieve these. Later in the chapter, I explain why I have used a non-standard writing style throughout this thesis, before outlining the structure of the thesis.

1.1 Research Origins

This PhD research, rather than being a standalone project, is the culmination of several years of smaller studies into threshold concepts, personal experience, and interest in neurodiversity, which began with my son's autism diagnosis in 2013, and a lifelong penchant for always asking "why?"

To explain a little further, my interest in threshold concepts began with a research internship following my third year of undergraduate studies in 2017. This short research project, part of the Research Interns @ Strathclyde (RI@S) programme, involved first learning about what threshold concepts were, given it was a topic which I had never encountered before, and revisiting content from a Knowledge and Innovation Management class which I had recently completed, with a view to identifying potential threshold concepts within that curriculum. As this was a very short, eight-week internship, my interest in the topic was piqued, as was some element of frustration that much of these threshold concepts were studied and discussed from the researchers' perspective, despite the seminal literature (Meyer and Land, 2003: 13; Meyer and Land, 2005; Meyer and Land, 2006; Meyer et al., 2008) being very clear about it being an individual, personal experience.

At this point, it was becoming increasingly clear that understanding why and how people learn was incredibly fascinating to me and, following a further exploration into the topic of threshold concepts across knowledge levels as my undergraduate dissertation project, this became the foundations for my PhD research. Although this topic has evolved considerably since it began, the initial aim was to continue my research into threshold concepts which may occur during progression through knowledge levels (Dörfler et al., 2009), but with a focus on autistic people. As my eldest son is autistic, I had some knowledge of autism and, naturally, a keen interest in knowing more about how my son, and people like him, learned. To date, threshold concept research has not explicitly focused on the neurodivergent, and this felt like an interesting and important direction in which to expand it. In addition, it seemed sensible to expect that some aspects of learning, and specifically of threshold concepts, may be easier to observe in autistic people. The journey from here, to where this research has brought me – including how I became one of the subjects of the study will be discussed throughout this thesis.

1.2 Research Journey

As I have taken the roles of both researcher and participant throughout this study, I briefly outline that journey here, for the purposes of providing clarity for the reader. More detailed accounts, from both perspectives – although, there is no "both" really, as it all involves my own personal perspective and lived experience, with some deliberate steps back to look at the research from one perspective or the other when necessary – are provided in the relevant chapters of this thesis for example, Section 4.5.3 and my reflective account in Chapter 7.

This has by no means been a linear process, as the discoveries I made about myself along the way, and the insights I gained from reflecting upon participants' contributions as a peer, influenced the direction in which the research took me at various points. A very simplified overview is provided in Table 1.

Table 1 - Research journey

June 2018	Research into threshold concepts and autism begins with literature review. Currently researching from perspective of parent to autistic child, seeking new knowledge.
Summer 2018	Reviewing contemporary autism research prompts questioning of own now apparent traits. Perspective begins to shift. Autoethnographic book chapter submitted for publication.
2018 – 2019	Immersing myself in autistic community on Twitter, and strong focus on autism element of research. Understanding of shortcomings of diagnostic process and recognition of reality of autism cemented by own diagnosis experience.

Autumn 2019 – Spring 2020	Value of Twitter community is obvious by now, although nature of this value is not (yet). Learning R to conduct sentiment and keyword analysis to assist with threshold concept identification. Tentative exploration into potential threshold concepts ongoing.
Summer 2020	Ethics approval obtained. Interviews conducted fruitfully, but raised further questions. Due to relating strongly with the content of these interviews, more self-reflection, and reflection upon interview process begins.
Winter 2020	Network analysis into #ActuallyAutistic community conducted. Reflection on this analysis leads to further analysis on participants' own networks instead of network as a whole.
Spring 2021	Recognise the value in each of the research elements to date, but not how it all fits together. This comes with being interviewed as participant who has also been through the experience in question, with clarity achieved by stepping away from researcher role briefly. Sensemaking process begins, providing the "story" which underlies the entire research journey.

1.3 Research Approach and Aims

As the principle of research indirection (Dörfler et al., 2018) and an emergent research design were adopted from the start, there has been no set research question as such. The aim was to explore how threshold concepts presented in autistic adults and, while there have been several changes in direction over the course of the research, this has remained the core "question" which was to be answered.

In adopting this approach of research indirection, it was somewhat inevitable that the topic would evolve (my approach to emergent research has also evolved in the process, for example, emergent case studies (Lee and Saunders, 2017). While the core focus on threshold concepts in autistic adults has always been present, there have been changes in terms of this being a professional or personal threshold concept, whether the threshold concept and the liminal journey leading up to it were examined as a researcher or as an insider, and, indeed, how important the fact that the participants are autistic was to be.

The initial literature review involved the three areas which were originally intended to form the research – threshold concepts (Meyer and Land, 2003), autism, and knowledge levels (Dörfler et al., 2009). By the time this research began, I had a reasonable understanding of threshold concepts, thanks to my earlier research into the topic, so much of the literature review comprised knowledge levels and autism. This reflects the intention at the outset, which was to expand my earlier research into how threshold concepts present them as individual progresses across the levels of knowledge, with a focus on the progression of an autistic adult. While there was no definitive way in which this was planned, there was a tentative idea that this would be done through attempting to secure interviews with autistic savants, for example, Temple Grandin and Daniel Tammet, to discuss how their journeys towards their position as experts in their fields had unfolded.

Of course, with what I know now about autism and, more specifically, the way in which autistic people have both historically and currently been treated by researchers, I recognise just how problematic this approach would have been. However, it was a vague idea at the very beginning of the research, and was soon discarded as my foray into the world of autism research changed my perspective significantly.

Thus, the aim of the research changed just a few months in, from "*how do threshold concepts present as autistic adults progress across knowledge levels*", to a more general "*what is autism? And how do autistic people learn?*"

Given I had self-identified as autistic quite soon after embarking upon my review of existing autism literature, it became important for me to understand more about what autism actually is. I had believed I had a good understanding of autism due to my son being autistic, however, I soon learned just how mistaken some of my beliefs had been. As a result, I recognised that, while understanding autism itself was not a core part of the research aims, I could not feasibly understand threshold concepts in autistic people until I more clearly understood what it was to be an autistic person. I was now a participant as well as researcher, so it became essential to spend some time exploring my own journey to date, and approaching the research from an entirely different perspective.

From this point onwards, the research took a dramatically different approach, with my own autoethnography forming a core part of the earlier research. Shortly after I identified my own autism, I was presented with an opportunity to contribute a chapter to an upcoming book, which aimed to showcase lived experience and research from autistic and otherwise neurodivergent people, with a view to challenging some of the prevalent myths about neurodiversity which are entrenched in society and everyday life. This autoethnography has been included in Section 4.2.2, and is discussed throughout the thesis.

As I had now recognised that I was a participant as well as a researcher, the research approach became much more complex. At the same time as exploring the transformational learning in participants' lives, I was making these same discoveries about myself, which simultaneously added to the research and made it considerably more complex. Overall, this insider perspective is invaluable, and absolutely made it possible to gain insights which I would not otherwise have been able to recognise, let alone express adequately.

Following this learning about myself, the research has very much followed an iterative process. As I learned about myself, I could understand the participants and our surroundings more meaningfully, as my understanding increased, so too did my need to learn more about myself. As will be discussed throughout this thesis, the research approach involved a lot of reflecting upon what I knew, standing back and considering what I was learning from both researcher and participant perspectives, and working towards being able to explain all of this. As I discuss throughout, there was a long period where I knew that the components of the research had value in themselves, but could not express how they worked together to create the bigger picture. This clarity came only towards the end of the research where, having conducted the interviews, immersed myself in the community, and explored several aspects of the community, it was through being interviewed as a participant myself that it all came together.

A brief overview of the research design is provided in Figure 1 below, although it is impossible to capture just how intertwined and complex this was in reality.

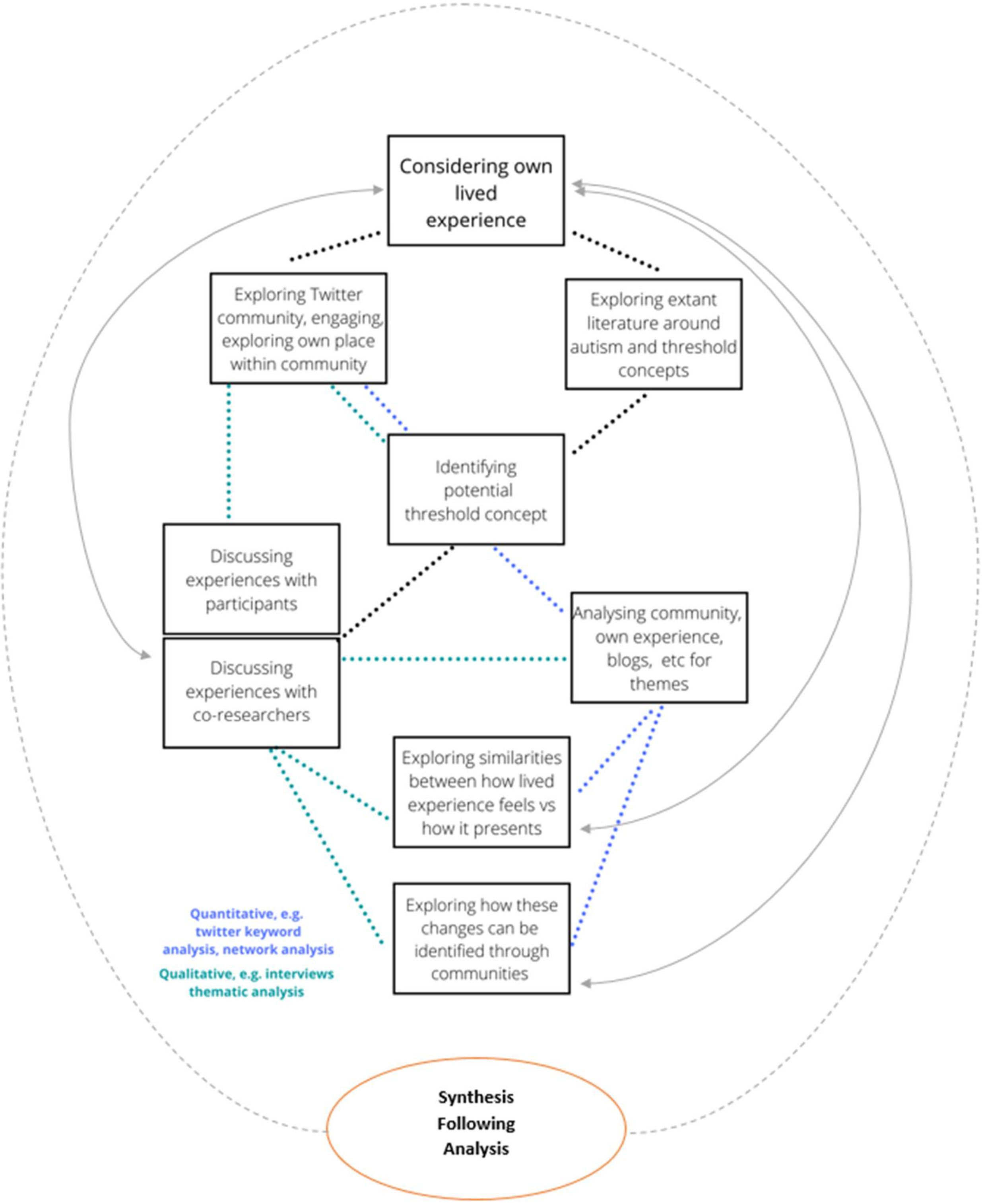


Figure 1 - Overview of research design

1.4 How the Writing Style Reflects the Research Approach

One aspect of this thesis which may stand out to the reader is the style of writing which I have used throughout, and the way in which the writing is structured. Writing in the first person, as I do, is not unusual in ethnography as it allows for a less awkward and more personable account (Gullion, 2016; Saldaña, 2011). However, the depth of my personal involvement in the research process means that a more narrative-like structure than may be expected has been used. I discuss how my autoethnography forms part of the research, and explicitly include two autoethnographic accounts, but my own immersion in the research goes deeper than this. To claim that only those accounts which I have labelled autoethnographic (Harrington, 2020) are reflective of my lived experience would be doing injustice to the research process, and also omitting some elements of how intertwined the various research methods, the stages in the research process, and my own progression through the phenomenon I studied actually were.

As an insider within the community where this research was situated, it is unavoidable that my own experiences, emotions, and learning play role in how the research unfolded. As I explore later in the thesis, this is not a limitation of the study, but undoubtedly a strength. Within the philosophical framing of this research, there is no objective truth to be had here, it is an exploration of very personal (and thus individual) lived experiences. Being able to understand and interpret these experiences can only be a good thing, really. Nonetheless, it does come with its own issues, which are no doubt also be evident throughout the thesis, as it is impossible to separate my researcher-self and my-personal self. All of the emotive, difficult experiences that I discuss during the thesis are what I experienced myself at the same time as studying them.

The purpose of this research was to explore a specific phenomenon within a certain population. The only way which I can see to present this adequately is to write it naturally, in a way which allows me to explore and discuss this phenomenon, with authenticity being more important and impactful than placing emphasis on fully adhering to more traditional academic writing conventions. The decision to do this was not an easy one, but one which I realised over time was the only way to do the research justice. I discuss in various chapters how my relationship to the research led to difficulties when I tried to use established research methods to explore and explain it, and how perhaps one of the most important realisations during the research journey was that I should stop trying, and instead allow myself to be led by intuition and emotion as I worked to make sense of what was happening.

Having said that, it is equally important to highlight that this is a thesis discussing research which has been conducted using tried and tested research methods, albeit in a less than commonplace combination. It was a great learning process for me in the realm of research methods, how far mixing methods and using multiple methods goes – rather than simply having a qualitative and a quantitative method within the same research project. It is not an autobiography, where my own experience is all that is important. I am one of a number of participants, and while my own experience is undoubtedly a core aspect of the research, I challenged my own assumptions and beliefs about myself as much as I did those around other participants, settings, and events.

The style of writing which I have used throughout the thesis is one which comes most naturally to me. I have at various stages of the research attempted to separate my researcher self from my lived experience, in order to apply research methods, and then write about them in a more standard way. This writing gets even more complicated in publications with various co-authors, when it is *my* experience based on which *we* draw conclusions… Following quite a bit of frustration when this did not work, and a realisation that my insider experience was an invaluable element of the research, and emotion is a form of tacit knowledge (Rivera, 2018), I have allowed this to be reflected in my writing, a decision which is intended to preserve the authenticity of the accounts of my own lived experience, and my interactions with the participants. In other words, I stopped trying, and I just "did". To use a rather famous quote – "you must unlearn what you have learned… Try not. Do. Or do not. There is no try" (Kershner, 1980).

1.5 Thesis Structure

In **Chapter 2: Knowledge Background**, after introducing a working vocabulary of necessary concepts, I conduct a review of the areas of research which overlap and combine to form the basis for this research, to varying degrees. Autism literature is reviewed in perhaps the greatest depth, primarily because this is where the biggest gap in my own knowledge was, and where I had to learn to understand myself and my lived experiences, as well as challenging previously held beliefs. Threshold concepts, knowledge levels, and sensemaking are also reviewed, with some commentary on their relevance to this research.

In **Chapter 3: Methodological Approach**, I discuss the combination of methods which was used while conducting this research, and the evolving philosophical framework behind my work. As this research involves autistic and otherwise neurodivergent people, some concerns were raised by the ethics committee prior to the empirical phase – these concerns are also outlined briefly, alongside the steps I took to ensure that appropriate ethical considerations have been upheld. The emergent research design meant that several methods were tried before the suitable combination was identified, and I also explain what was tried previously, and why it was deemed a less appropriate approach.

In **Chapter 4: Analysis,** the process through which the combination of methods discussed in Chapter 3 was used to draw rich and meaningful findings from the empirical data is outlined. I discuss how my autoethnography, both that account which was written early in the research and the later account which followed towards the end contributed to my understanding of what I was seeing elsewhere. The process through which I reflected upon the interview transcripts, and considered these in conjunction with social network analysis is also explored.

In **Chapter 5: Findings,** the key findings of this research are discussed. In this chapter, I identify the findings and how they relate to each of the subject areas which have been brought together in this research. I explain how these findings were obtained, how the methodological approach which I have taken made each of these possible where they might not have been otherwise, and briefly introduce the significance of each of these findings.

In **Chapter 6: Discussion**, the findings and insights from the interviews, my own lived experience, and network analysis are further explored. In this chapter, I explain how my initial assumptions about there being a difference in how threshold concepts are experienced by autistic people when compared to neurotypical people appeared to be inaccurate, and how this relates to the existing literature which formed the basis for my research.

In **Chapter 7: A Reflective and Reflexive Narrative**, I reflect upon the experience of conducting this research as both researcher and participant. As, unexpectedly, I was progressing through the very threshold concept which was explored, at the same time as conducting research into the phenomenon, this chapter provides a more detailed account of my participant experience. The discussion and reflections have been presented separately for ease of reading, and to emphasise the importance of my insider perspective and how this impacted on, and was impacted upon by, the research journey. My perspective as an insider takes two forms; that of being an insider as one who has experienced the phenomenon being studied, and that of being a trusted insider while talking to the interviewees.

In **Chapter 8: Conclusion**, I wrap up the discussion by summarising the findings from the research, looking at what has been and what has not been accomplished, leading to future research directions. Although the aims of this research have been met, in that I have explored how threshold concepts present in autistic adults, the findings from the social network analysis and the interviews have raised more questions relating to the role of communities and networks in this type of transformational learning. Some future research possibilities are also discussed, both in terms of transformational learning within communities and networks, and further development of quantitative approaches to Interpretivist research.

2. Knowledge Background

In this chapter, I discuss several areas which have been brought together while conducting this research; that is, autism, threshold concepts, knowledge levels, communities of practice, and sensemaking. The chapter begins with an initial description of core concepts. This is followed by an in-depth review of the history of autism research, from the early autism research which continues to form much of the research and practice today, to the contemporary participatory approach, and recognition of neurodiversity as an indicator of natural human diversity, rather than inherently deficit based. As I do not assume that the reader has any knowledge of autism in particular or neurodiversity in general, some definitions and a glossary of key phrases are provided.

A summary of threshold concepts literature is provided next, where the key characteristics of a threshold concept is discussed alongside the differences between important concepts and threshold concepts. Some criticisms of threshold concepts and the threshold concept framework are also included.

Next, I discuss four areas of knowledge background for which I review the literature specifically relevant for the current study in one way or another. The first one is the area of knowledge levels which, although not explicitly included in the final research, did inform my thinking while approaching the problem, particularly in terms of knowledge being personal. As communities have been found to play a significant role in the personal journeys framing the lived experience of threshold concepts, a short introduction of the communities of practice (CoPs) is also covered. Finally, a brief review of sensemaking literature has been included. Sensemaking became part of the research at a later stage, but contributed greatly to the analysis and findings.

At the end of this chapter, I provide a synthesis of these topics, which combine to inform my argument around how threshold concepts present in autistic adults, particularly in terms of the role of networks and communities in the liminal journey.

2.1 Introduction and Definitions

2.1.1 Autism Definitions and Key Phrases

To begin considering the research question, it is useful to try to define or, at least, describe each of the key terms, alongside some of the language that will be used throughout both the literature review and the thesis as a whole. Language can be an incredibly powerful tool and, when discussing a topic as emotive and as deeply personal as autism, it is essential to take care of and use appropriate language. For this reason, the language which I use while discussing autism has been deliberately chosen, as I will now explain.

Firstly, the decision to use the term "autistic person(s) or people" rather than "person(s) or people with autism" is deliberate, and based on preferences expressed by much of the autistic community (Kenny et al, 2016), including myself, as both researcher and research participant. This choice of language indicates that autism is a part of the person, and not a condition, illness, or disability, which can (or should) be removed or cured. Without the autism, you would not have that person. There is not a neurotypical person hiding inside each autistic shell, waiting to be uncovered or rescued by whatever means may be necessary (Sinclair, 2012). Autism is intrinsic to the individual. For similar reasons, the term "autism" will be used, rather than "ASD" (autism spectrum disorder) or "ASC" (autism spectrum condition) or related terminology. This language is an important part of the identity of autistic people, and I firmly believe it to be disrespectful to ignore this preference, whilst claiming to be conducting inclusive research. Making this effort serves as an illustration of a move away from the "othering" of autistic people, through being respectful of those preferences which have been expressed. Having said that, I do, of course, recognise that not all autistic people share this preference, and their right to do so will be respected at all times. I also understand that some of the earlier research that I have used, particularly that which formed the seminal autism research, may now be seen as problematic, however, some aspects have been included as important precursors to current research and belief.

Where the term "autism" is used in this research, I am using it broadly as per the definition of monotropism, an atypical division of attention, a trait which is commonly illustrated by the presence of special interests, or those which can be, somewhat undesirably, referred to as autistic obsessions. This monotropism (Murray et al., 2005) is what enables autistic people to learn a lot about a topic in which they have developed a special interest – stereotypically something inanimate like trains, but this can also involve a special interest in a person, such as a celebrity, or perhaps a hobby – in my case, reading. Where there is a finite amount of attention available to be distributed across tasks, an atypically strong focus on a special interest, for example, may leave less than is considered desirable for everyday tasks (Milton, 2012b), a spread of attention which may account for some of what is listed as "deficits" by traditional autism models (Kanner, 1943; Frith, 1991; Baron-Cohen, 1995; Baron-Cohen, 2002; Baron-Cohen, 2004; Baron-Cohen, 2009; Baron-Cohen and Hammer, 1997; Baron-Cohen et al., 2001a; Baron-Cohen et al., 1997; Baron-Cohen et al., 2002; Wing and Gould, 1979). Monotropism can also account for some of the sensory aspects of autism, which will be discussed in more detail later.

Even following three years of research into autism, sixteen years of parenting an autistic son and, indeed, almost four decades of being autistic myself, it is impossible to pinpoint exactly what autism is. It is absolutely not a set of deficits, or an indication that a person is somehow lesser than another, but it is *something* which does undoubtedly come with a number of challenges. These challenges vary from person to person, and often even in the same person depending on the situation they are currently in. Perhaps the most relevant, in my experience, way to think of autism is as a form of neurodivergence (Singer, 2017). It is not something which is "wrong" with a person, but a divergence from what society thinks of as the average person. It is a neurotype, not a flaw.

As autism is a neurotype that is, at this point, understood to be different from the average human neurotype, the terms "neurotypical", "neurodivergence" and "neurodiverse" will be used. In this context, a neurotypical person is one who is not affected by any neurological difference, such as autism, ADHD, or similar. Neurodivergence relates to people whose neurotype deviates from this norm in some way, of which there are numerous potentials. We, as people, are all neurodiverse. Neurodiverse is not the opposite of neurotypical, instead it is a term which encompasses people of all neurotypes, which was first introduced by Judy Singer in her 1997 thesis (Singer, 2017), although first appeared in a publication by Harvey Blume (1998). Singer is given due credit for coining the term, as it is evident that, although she did not publish first, having used the term in a thesis, she is responsible for creating the word and its definition.

Nowadays, autism is widely understood and accepted to involve a spectrum – or indeed a constellation (Happé et al., 2006) – rather than being a concrete and tangible set of symptoms and characteristics, so it is impossible to conduct research which applies fully to all of those who identify as autistic. As this research initially related to deep and transformative learning in autistic people who can be expected to have progressed through at least one knowledge level as defined by Dörfler et al (2009), there is a focus on those autistic people who have achieved a successful career, or mastered a particular skill. From the outset, my intention has been to involve autistic academics and professionals due to the reasonably visible increase in expected knowledge as one progresses through education, and this remained a criterion when the focus of the research shifted to those who have reached self-acceptance following a diagnosis in adulthood. The reasons for choosing each of the criteria are outlined in Section 3.7.

Again, this selection of participants makes it necessary to define some further use of certain language. The terms "high functioning" and "low functioning" have been deliberately avoided, in so much as is possible without changing the words used by a person who chooses to apply them to themselves. These terms have been reported to be highly problematic within the autistic community and by autism researchers (Alvares et al., 2019), mainly due to misunderstandings by neurotypical persons and even health professionals about what exactly is meant by "functioning". While it is not relevant to explore this in much depth, suffice to say that an autistic person may appear to be high functioning in that he or she has achieved a successful career, or can apparently navigate life without much support, however, that same person may require significant support in certain areas. In short, the terms are believed to add to the stereotype that autism is a condition, and that there are degrees of autism. In reality, one is either autistic or not, and there is no sliding scale of functioning. More discussion will follow as to the implications of using the metaphor of a spectrum (Wing and Gould, 1979), constellation, or other image in relation to autism.

To add a final definition to my autism discussions, autism can be referred to as a social disability (Oliver, 2013), as opposed to a medical disability, which is how the word “disability” is generally understood. In terms of the difference between the two uses of “disability”, a social disability is only disabling due to social norms, conventions, and constructs which make life difficult for those who do not fit the mould of what is considered to be normal, a category which currently includes autistic people, and other neurodivergent people. As stated by one autistic participant in earlier research “if I socialise with other Aspergians of pretty much my own functionality, then all of the so-called social impairments simply don’t exist […] we share the same operating systems, so there are no impairments” (Cornish, 2008: 157).

This perspective on autism, whereby the impairments do not exist when surrounded by others with similar traits and characteristics, is perhaps more fittingly described as a socially situated difference (see Glossary). As mentioned above, the social model of disability does not quite fit with the perspective taken throughout this research, although there is absolutely a social element to the disabling characteristics of being autistic. For the purposes of this research, I have taken a perspective which primarily fits with that of the neurodiversity paradigm, with acknowledgement of the view of autism as a social disability. As I am not seeking to define what autism is, but rather to explore a specific experience amongst autistic people, it seems most appropriate in this instance to adopt that viewpoint which is taken in much of the existing participatory autism research.

I recognise that adopting this perspective may be open to criticism, particularly as some autistic people absolutely do consider themselves to be disabled beyond what could be described as a socially situated difference (see Glossary), however, it is the most fitting for this research. In addition to my own views on the matter as a neurodivergent person, this also serves as recognition of the perspectives of the participants who shared their experiences with me, and also those which tend to be expressed by members of the community which is being explored here. As autistic researchers and advocates work towards greater societal acceptance and understanding of autism, any stance which is taken on the definition is unavoidably political. As such, in adopting the stance which I have, I am effectively declaring myself on the side of differences, rather than deficits, although am in no way denying that being neurodivergent can be problematic in a multitude of ways.

Although there is really no such thing as "normal", there remains a strong belief within society, conscious or otherwise, that we should all conform to the norms, and any deviation from this is somehow wrong. Similarly, the distinction between social and medical models of disability is too binary to truly reflect reality, but is an acceptable available option at present. Again, I should state that not every autistic person will have the same perspective on whether or not they consider themselves to be disabled, so this usage is my preference, and not a generally accepted one.

2.1.2 Threshold Concepts Definitions

Moving away from autism and into the other two main topics encompassed by this research, the term "threshold concept(s)" relate to those as described by Meyer and Land (2003) and subsequent publications as learning which is transformational on a very deep level. Rather than simply learning by rote, or memorising information for an exam, for example, a threshold concept can only occur when the learner is fully invested in the learning process. This is also where threshold concepts can be linked to communities of practice, where there is no community of practice without identity investment (cf. Wenger, 1998; Pyrko et al., 2017). Generally following an, often extended, period of turmoil and difficulty, the threshold concept tends to materialise as a kind of portal through which the learner passes, leading to a transformation of the self on some level, as well as in their understanding of the concept in question. Such a shift in belief can be incredibly unsettling for the learner, who may find that their fundamental beliefs and faith are being called into question as they come to terms with their new learning, and they are required to become almost a new version of themselves in order to embrace it.

This will be explored in greater detail in Section 2.3, however, for illustration purposes, some commonly used examples of a threshold concept include learning that the world is a globe rather than being flat (although one would hope that this is now the default belief, it would have been troubling when first discovered), and transforming from a child into an adult through puberty. Puberty, in this example, demonstrates the liminal space, or liminal tunnel, through which the learner must pass and, once through, cannot reverse the effects. The liminal space, or space between boundaries, is used while discussing threshold concepts to describe the time spent processing and mastering the new knowledge which becomes the threshold concept As every individual, autistic or neurotypical, will experience different threshold concepts, no limitations have been placed on what may constitute a threshold concept for the purposes of this research, other than the characteristics laid out by the seminal work of Meyer and Land (2003) being fulfilled. Indeed, it is perhaps irrelevant what the threshold concept experience by an individual actually is, so long as at least one has occurred.

For the purposes of considering and discussing threshold concepts, the term "transformational learning" is used as defined and developed by Mezirow (2009; Mezirow and Taylor, 2009) across a number of papers as how adult learners use critical thinking and their previous life experiences and perspectives to process new knowledge.

The transformational learning, in both Mezirow's models and in the threshold concept literature, occurs when the learner changes at least one aspect of their worldview as a result of this new learning. To use Mezirow's own words: "transformative learning may be defined as learning that transforms problematic frames of reference to make them more inclusive, discriminating, reflective, open, and emotionally able to change" (Mezirow, 2009: 22). Essentially, what will be explored in this research will be how such a transformation can present in an autistic adult, and how identifying these threshold concepts or moments of transformational learning can be used to enable people, both autistic and non-autistic, to achieve their potential.

2.1.3 Knowledge Levels Definitions

Where the term "knowledge levels" is used, it refers to the model developed by Dörfler et al (2009), which illustrates the journey one may follow from novice to grandmaster. Again, this will be explored in more detail in the relevant section of the thesis but, in brief, there are five levels of knowledge which may be attained - novice, advanced beginner, expert, master, and grandmaster. Everyone will begin on novice level, and few will ever attain grandmaster level knowledge in any discipline, with none achieving it in more than one. Due to the limits on cognitive schemata which can be retained within the long-term memory, it is not possible to become a grandmaster in a second discipline without compromising on the first. Each knowledge level is reached once a certain number of cognitive schemata have been created, with each level requiring ten times more schemata than that which precedes it. It has been tentatively suggested in earlier work completed for my undergraduate dissertation that a threshold concept is the final schema required to progress from one knowledge level to the next (Harrington, 2018), and the intention at the outset of this research was to explore this suggestion further, with particular emphasis on the autistic mind.

In this section of the thesis, I have outlined the key points and definitions required for the reader to gain some understanding of the main components in this research. In the follow section, I will provide a review of the literature in each field, beginning with autism.

2.2 Autism and the Neurodiversity Literature

"…Right from the start, from the time someone came up with the word "autism" [it] has been judged from the outside by its appearances, and not from the inside according to how it is experienced."

(Williams, 1996: 14)

The quote above from Donna Williams (1996) explains briefly why it is important to me to conduct inclusive and participatory autism research. Lived experience should be valued highly in this type of social research, with the prominent voices being those belonging to the community in question, in this case, autistic people. Contemporary autism research, such as that discussed briefly earlier, has made significant progress in terms of encouraging participatory autism research (cf. Milton, 2014; Milton et al., 2019), however, there is still much room for improvement. In order to facilitate that improvement, we must first debunk some of the common myths and stereotypes around autism, introducing a more accurate picture of how an autistic mind actually works.

Since the term was first coined by German psychiatrist, Eugen Bleuler, in 1911 as he attempted to describe some of the most severe cases of childhood schizophrenia he had encountered (Bleuler, 1911, cited in Milton, 2012), understanding of autism has undergone several significant transformations. Despite the dramatic shifts in what autism is understood to be, there remains no universally accepted definition. Indeed, we are yet to reach a consensus on how to describe autism – is it a disorder, a neurological condition, or something else entirely? For the purposes of this research, I have taken the decision to use the definition of autism as an atypical attention to detail (Milton, 2012a; Murray et al., 2005) whereby an autistic person is not considered to have a disability or disorder, but a somewhat different way of attending to the world, which impacts the viewing and interacting with this world. Where we each have only a certain amount of focus to use, this model of monotropism posits that autistic people focus much of their attention on their special interest at any given time, leaving less for executive function and other tasks (Milton, 2012a; Murray et al., 2005).

It follows, therefore, that a social model of disability (Oliver, 2013) is used when conducting this research, whereby it is considered that the disabling factor is society, and societal norms, rather than the fact that a person is autistic. Although an autistic person may be disabled by co-occurring conditions, autism itself, when considered as a different neurotype, is not inherently disabling. Of course, this is not a claim that nobody finds their autistic traits disabling, rather a distinction between the ways in which a person might be disabled or impaired by external factors.

In order to arrive at this definition, and understand why it is important to not only autistic people, but the world as a whole, to stop treating autism as an inherent disability, one must consider the history of the term "autism", the magnitude of the advancements that have been made in autism research over the past century and, perhaps most pertinently, the significant benefits associated with embracing cognitive differences, rather than othering those who do not fit into a socially-constructed box. In the words of Temple Grandin, herself a prominent autistic academic, (Grandin, 2008), without autistic people, we would still have people standing around in caves, socialising but not making great discoveries.

My own beliefs, as both researcher and participant in this study lie along the lines of autism as a different way of thinking, or a neurotype, rather than a disability, condition, or otherwise in need of treatment or management. If we adopt this definition of autism, more traditional theories of autism as something which needed to be cured, medically managed, or potentially eradicated can be largely disregarded as irrelevant. That said, some of this more traditional approach will be referred to in so much as it is useful for explaining the current state of autism research. It is essential to have some understanding of how autism is currently understood, and misunderstood, in order to appreciate the importance of participatory autism research, and the need for significant change.

Since DSM-V (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) (American Psychiatric Association, 2013) was introduced, the triad of impairments (Wing and Gould, 1979) previously required before a diagnosis of autism could be made, has, officially at least, been reduced to a dyad of impairments. While atypical language development was traditionally required before an autism diagnosis could be made, it is now considered to be a co-occurring condition, rather than an essential criterion. As such, an autism diagnosis is now made based on the presence of social difficulties and special interests.

As neither of these is, in its own right, a medical issue or a disability, it appears to stand that autism is not a disorder, condition, or disability. Instead, it is a case that society should be changed to allow for people who do not conform to what is, after all, a socially constructed norm in terms of communication and distribution of attention or focus. A societal norm is not infallible and, certainly in the case of autism, was constructed prior to developments in research, awareness, and knowledge.

Since Bleuler's early 20th century research led him to utter the words "The schizophrenics who have no more contact with the outside world live in a world of their own. They have encased themselves with their desires and wishes... they have cut themselves off as much as possible from any contact with the external world. This detachment from reality with the relative and absolute predominance of the inner life, we term autism" (Bleuler, 1911, cited in Milton, 2012: 1), autism research has come a long way.

While this association with schizophrenia is worlds away from what we now understand about autism, there can be little doubt that this is what Bleuler was describing. In spite of this, much credit for early autism research is attributed to Austrian psychologist Hans Asperger, who made his first recorded mention of autism during a seminar in 1938 (Frith, 1991), and his Austrian-Hungarian counterpart Leo Kanner, who first used the word "autism" in 1943 (Kanner, 1943). Kanner's work, which was published later than Asperger's, remained the cornerstone of autism research and practice for several decades, as Asperger's contribution languished unrecognised, for the most part. Why and how this happened remains in dispute – while Kanner remained adamant that he was unaware of Asperger's work, two of the former's core colleagues were involved in Kanner's "discovery" (Silberman, 2015). Any mutual awareness of each other will not be examined here, as I am interested in the merits of the research, not the politics behind it, in so much as the politics can ever be disregarded, considering the role which the researcher's perspective plays.

Leo Kanner is first noted to have used the word autism in 1943 (Kanner, 1943), after noticing that a number of his young patients appeared to live in their own world – autism is derived from the Greek word "autos", meaning self. As Kanner saw it, these children were at their happiest when left to their own devices as such, or in isolation. Around the same time, Austrian psychologist Hans Asperger was making the same discoveries about some of the children under his care, adding that, although these children were clearly most comfortable on their own, they spoke in surprisingly complex and formal language. Using much more complimentary language than was typical of the time, where autism was thought to be a form of childhood psychopathy or schizophrenia, Asperger referred to these children as his "little professors". Rather than considering the autistic patients at his clinic as being disabled, Asperger saw them as essential allies in developing methods of teaching which worked with the ways in which the autistic mind can learn. Coining the term "autistic intelligence", Asperger saw the great value in teaching these children how to harness their intense interests in somewhat niche subjects, and learn from them, stating that the fact that these children simply could not accept something as truth purely on fact alone was an advantage, rather than an impairment.

This seemingly instinctive understanding and acceptance of his autistic charges can, interestingly, perhaps be explained when one becomes familiar with the characteristics of Hans Asperger, the person. Described by Silberman (2015) as a gifted, eccentric, aloof child who often lost himself completely in a book, and exasperated his peers with his lack of understanding of social norms, it is possible that Asperger understood his little professors, and invested himself so deeply in improving their learning and life experiences, due to being one of them himself. Indeed, this short description alone builds an image of one who is monotropic (Milton, 2012a) and prone to hyperfocus – two of the characteristics of autism as it is understood in 2021.

Unfortunately for those who perhaps may have benefited from such an understanding of autism, the University of Vienna was bombed by allied forces in 1944 and, while Asperger himself survived World War II, his work and his case notes did not – more precisely, until recently were believed not to have. When the Children's Clinic and the Heilpadagogik Station were reduced to ashes by incendiary devices, so to was Hans Asperger's relatively sympathetic work on autism, and his ideas relating to a spectrum or continuum which was not at all rare, but could be seen everywhere once one knew what they were looking for (Silberman, 2015). Instead, Kanner's model of autism became the basis for the following decades of autism research and treatment.

Kanner's work focused on children, meaning that teenagers and adults were not considered in autism research until much later. The two main characteristics attributed to the condition by Kanner were a desire to be alone ("extreme autistic aloneness") and a severe fear and dislike of change ("anxiously obsessive desire for the maintenance of sameness"). It should be noted that Kanner did not give a name to a condition at this point – although he referred to the behaviours themselves as autistic, he first used the term early infantile autism in 1943. The differences between Kanner and Asperger's work became evident around this point too as, rather than recognise and acknowledge the spectrum or continuum as Asperger did, Kanner evidently overlooked some major discrepancies in the behaviours exhibited by his young patients, in order to define autism as a strictly rigid condition, going so far as to make the assertion that there was little difference visible between his verbal and non-verbal patients, despite the obvious fact that some could communicate through speech, while others could not. This insistence on Kanner's part perhaps led to the conception of the extreme male brain perception of autism which continues to cause harm to the numbers of undiagnosed females and, to a lesser degree, males, who do not fit exactly into this mould of what autism should look like.

It would not be prudent to fully lay the blame for this on Kanner, however, it is indisputable that his work marked the beginning not only of the recognition of autism, but of the inaccurate portrayal of a neurotype that reaches far beyond the Kanner-imposed limits of young males. In fact, the work of Kanner was further limited by the way in which he ran his clinic, ensuring that only the most severely affected children of well-connected American families ever saw him. Those who could not afford to pursue diagnosis or treatment from Kanner, or those whose impairment was less severe, would not have come to his attention at all. Given what we know about the breadth of the autism spectrum now, it is clear that this practice did a great disservice to developments in the field of autism, and understanding of autistic persons.

This issue was brought to Kanner's attention, and that of child psychiatry in general, by Louise Despert (1938), who wrote alerting him to the similarities between his work on early infantile autism, and work she had previously published. Indeed, Despert saw Kanner's work as being a way of composing new terms to describe what was already know. Similarly, Asperger's spectrum model of autism was somewhat mirrored by that of Loretta Bender (Faretra, 1979), although Bender was treating children for what was known as early-onset schizophrenia, but is now recognised as autism. In the 1950s, childhood schizophrenia was as overly broad as autism was overly narrow, as both fields were explored for the first time.

While it may be a great coincidence that two psychiatrists made the "discovery" of autism at the same time, what is not so great is the version which became accepted as 'truth' for quite some time afterwards. Leo Kanner published his "Autistic Disturbances of Affective Contact" (Kanner, 1943) a year before Asperger published his postdoctoral thesis "Die Autistischen Psychopathen in Kindesalter" (Autistic Psychopathy in Children)(Frith, 1991), however, the latter work became somewhat of a footnote in the shadows of what was accepted for half a century or so as the authority in the field, to the point where autism was, for some time, commonly referred to as Kanner's Syndrome. Kanner is said (Silberman, 2015) to have deliberately omitted his knowledge of Asperger's work when writing, speaking or teaching about autism, an omission which not only served as an obstacle in the progression of autism research, but also set in motion a number of serious consequences for both autistic people and their families (Silberman, 2015).

Any possibility, however slight, of Kanner being unaware of his Austrian counterpart's work is quickly discarded when one learns that Asperger's diagnostician, Georg Frankl, travelled to Baltimore to work in Kanner's clinic around the same time as the latter made his key discovery (Silberman, 2015). So, too, did Anni Weiss, who was also previously a colleague of Asperger's. The inaccuracies in Kanner's work and resulting perception of autism are at the root of much of the misconception and harmful "treatment" of autism which still exists today, for example, Applied Behaviour Analysis (ABA) (Lynch, 2019a).

At the time, autism was believed to present as an aloof awkwardness, combined with some kind of abnormal ability in a particular skill - maths and other technical subjects being the standard assumption. This stereotypical perception of autistic people remains prevalent some seven decades later, as those who are not familiar with autism tend to picture a *Rainman*-type savant. As an aside, apart from this stereotype being potentially damaging for many autistic people – as discussed later – the man on whom the *Rainman* character was based was not actually autistic in reality, his traits were related to Rett Syndrome instead (Silberman, 2015). This has meant that people, in general, do not only have a very skewed perception of autism, but that skewed perception is, in fact, not even related to autism.

Rather than considering autism to be a condition or an impairment, this thesis focuses on the currently accepted view of autism as a social disability (Woods, 2017). That is, any disability associated with autism is not, in fact, a result of being autistic, it is as a result of living in a world which is tailored to cater for the neurotypical, ignoring the range of ways in which people can be neurodiverse. Of course, this is not to say that autistic people cannot also be impaired by a co-existing condition or medical disability. The term "co-morbidities" has also deliberately not been used, to further strengthen this disconnect between autism and medical diagnoses.

While Kanner's term of autism, relating to the self, is still somewhat relevant and appropriate, it is perhaps more helpful to think about this concept of the "self" as implied by the Māori term for autism, which means "in his/her own time and space", with needing one's own space, or some additional time, to process an instruction, question, or new concept, being entirely different to being one who craves, and indeed thrives in, isolation.

Asperger's Autistic Psychopathy in Childhood was translated into English by Uta Frith (1991), making it more accessible to a larger audience. Some of what Asperger wrote in this thesis in the early 1940s remains relevant, including the following excerpt from his introduction, which highlights just how widespread and damaging misunderstandings about autism still are:

"[…] we can demonstrate the truth of the claim that exceptional human beings must be given exceptional educational treatment, treatment which takes account of their special difficulties. Further, we can show that despite abnormality human beings can fulfil their social role within the community, especially if they find understanding, love and guidance"(Asperger, 1994, cited in Frith, 1991: 37).

Admittedly, the language used does not match that which is currently considered acceptable but, if the majority shared this view, there would not be a need for autistic academics and autism researchers to continue to battle myths and stereotypes in 2021, as countless parents invest infinite amounts of time, energy, and money into securing the education and support their autistic children need, and deserve. This is not to say that Asperger's view of autism was anything even approaching perfect; he also described autistic behaviours as malicious, calculated and intentionally spiteful (Frith, 1991).

Early research on autism by Hans Asperger described it as an extreme form of male intelligence (Silberman, 2015: 107) and, some seven decades later, this myth is still prevalent, and echoed by the work of Simon Baron-Cohen (Baron-Cohen, 1995; Baron-Cohen and Hammer, 1997; Baron-Cohen et al., 1997; Baron-Cohen et al., 1999; Baron-Cohen et al., 2001b; Baron-Cohen et al., 2001a; Baron-Cohen, 2002; Baron-Cohen et al., 2002; Baron-Cohen, 2004; Baron-Cohen, 2009). However, it is essential to recognise that autism is also widely present in females, many of whom struggle to be diagnosed and access the support they require, due to this "extreme male brain" preconception (Baron-Cohen and Hammer, 1997). Indeed, although Kanner and Asperger are credited with being the first autism researchers, similar work had previously been published by a female psychologist in Moscow, Grunya Sukhareva (Posar and Visconti, 2017).

Sukhareva first produced work relating to what she referred to as a type of schizoid personality disorder in 1926, some twenty years before the "seminal" works of Kanner and

Asperger. In fact, in this paper, which was translated into English in the mid-1990s (Wolff, 1996), Sukhareva, or Ssucharewa as she is referred to in the translation, makes reference to shared characteristics of the six boys who formed her group of participants, which are remarkably similar to those which are now associated with autism. Each of these boys, who were aged between 2 and 14, was an in-patient at Moscow's Psychoneurological Department for Children for an average of 2 years between 1923 and 1926. The six all received a diagnosis of personality disorder, schizoid (eccentric), and reportedly shared the following characteristics:

- A tendency towards an "odd type of thinking", generally involving a preference for systemising and organising
- An "autistic attitude", described as a tendency to prefer their own company, avoiding other children where possible, and behaving differently when in the company of other children
- Flatness or superficiality of emotion, with some exceptions towards people to whom they were particularly close
- Inflexibility and preference towards repetitive tasks
- Impulsive and odd behaviour in three out of the 6 cases

Some of these traits are still regarded to be autistic traits, particularly where one is using the stereotypical definition of autism. However, there were a few parts of Sukhareva's paper which were interesting and, in fact, more in line with modern autism research than that which happened in the decades between her observations in the 1920s and current work in 2021. For one, Sukhareva reports loving relationships between the boys and their mothers – in a way casting doubt on the refrigerator mother and toxic parenting theories before they were ever suggested; and a quote from a 13 year old patient who appears to refer to his hyperfocus and tendency to enter a state of flow (Csikszentmihaly, 1997) while engaged in a task - "it is difficult for me to start anything. I have to make lengthy preparations, and afterwards it is hard for me to stop" (Sukhareva, 1926, translated in Wolff, 1996: 122). Sukhareva also made references to giftedness within music and arts, which was also pointed out by Hans Asperger in his seminal work on autism.

Leo Kanner's work also paved the way for the prevalent view of the mid-20th century, which attributed autism to the behaviour of the child's parents. Over-stimulation, under-stimulation, and so-called refrigerator mothers have all been blamed for the onset of autism in a young person, alongside the infamous and wholly false claim by Wakefield that autism was caused by the MMR vaccination (1998, now retracted).

For reasons which are still disputed, Hans Asperger's work was not widely known outside of certain parts of Europe for quite some time, although his spectrum model of autism did eventually come back into focus. Somewhat ironically, the spectrum model was reinforced by a psychologist with an autistic son, who had himself initially supported Kanner's view of autism. Bernard Rimland's 1964 book, Infantile Autism (Rimland, 2014), was one of the early moves towards the current acceptance of autism as being cognitive, rather than the consequences of refrigerator or otherwise toxic and harmful parenting. Rimland taught himself about autism due to being curious about his son's experiences, and went on to become the founder of the National Society of Autistic Children, and an activist who successfully lobbied United States government for legislation entitled all differently wired children to an education (Silberman, 2015: 282-283). However, it should be noted that Rimland used terminology such as conditioning and training, rather than teaching and education, which was common in the psychology literature of the time.

Rimland made a valuable contribution to autism research, and to support for autistic people and their families, however, he still believed that autism was a condition that was treatable. A partnership with Ole Ivor Lovaas with the objective of training autistic children to become "virtually indistinguishable from their peers" marked the birth of applied behaviour analysis, or ABA (Rekers and Lovaas, 1974) a practice which has more recently been discovered to result in post-traumatic stress disorder (PTSD) and Complex Post-Traumatic Stress Disorder (cPTSD) in those autistic persons who have been subjected to it (Kupferstein, 2018). Rimland was also responsible for the mistaken belief that autism could be cured through special diet, massive doses of vitamins (Rimland et al, 1978, cited in Cornish and Mehl-Madrona, 2008), and various supplements. Well-meaning as the intention may have been, forcing one to become something they are not is neither treatment nor cure, but rather mistreatment and abuse. Further issues were also present in Rimland's work, for example, a theory that autistic children had a certain look and colouring, while psychotic children had another. Despite the controversial nature of some of his research and work, it cannot be disputed that Rimland's dedication to the spectrum model of autism, at least, has contributed to how we understand autism now.

During the 1960s, academic and clinical thinking regarding autism was, in effect, turned on its head, as experts such as Victor Lotter and Michael Rutter defined autism as almost the opposite of what had originally been believed. Rather than being used as it had been by Piaget (1923, cited in Evans, 2013), Bender, Kanner and others to describe a fantasy life lived by children with schizophrenia, autism was now becoming understood as significantly different to schizophrenia or any of its characteristics. Rutter (1972, cited in Evans, 2013) following his completion of the first genetic study of autism, stated that an autistic child, in fact, had a complete lack of imagination or ability to fantasise, essentially the polar opposite to what had come before. In the 1970s, Rimland's idea that the more intelligent an infant was, the greater their risk of autism, was disproven by Rutter and similar autism researchers, who quite clearly found that autism does not discriminate by intellectual ability, and can be found in children (and adults) of all levels of intelligence and social standing (Fletcher-Watson and Happé, 2019).

2.2.1 The Extreme Male Brain Theory of Autism

Perhaps one of the most renowned autism academics at present, for differing reasons depending on your perspective on autism and autism research and practice, is Simon Baron-Cohen. As may be unsurprising given the seemingly endless contradictions and disagreements about what autism is, what causes autism, and whether or not it is a condition which should be treated, Baron-Cohen's work is divisive.

Baron-Cohen is originator of the Extreme Male Brain hypothesis, which, as the name suggests, defines autism as an extreme version of the male brain, programmed to operate in a more systematic way than the female brain, which tends more towards empathy. As Baron-Cohen himself explains it "the female brain is predominantly hard-wired for empathy. The male brain is predominately hard-wired for understanding and building systems" (Baron-Cohen, 2004: 1). Despite the fact that he recognises that there is an issue with defining brains by gender, Baron-Cohen remains adamant that this extreme version of the male brain is at play in autistic people. If one considers the traditional stereotype of an autist as one who behaves in a repetitive manner, perhaps as a child lining up toy cars rather than playing with them in a more socially accepted fashion, and is somewhat devoid of empathy, this particular theory can appear to make sense.

Conversely, as discussed in more detail later, Damien Milton, an autism academic who is himself autistic, explains – the problem is not that autistic people lack empathy; the problem is that autistic and non-autistic people alike struggle to understand each other. It is, therefore, a double empathy problem (Milton, 2012b), rather than an absence of empathy. In fact, autistic people, particularly women, can tend towards being overly-empathic, adopting others' stress and negative emotions as their own (James, 2017).

To return to the works of Baron-Cohen, his exploration into the male vs female brain aspect of autism began in the late 1990s, when he first set about testing the model originally outlined by Asperger (Baron-Cohen and Hammer, 1997). Although Asperger published his postdoctoral thesis "Die Autistischen Psychopathen in Kindesalter" in 1944, it was written and therefore published in German, and was not particularly accessible nor available to those English-speaking autism researchers until it was translated by Uta Frith almost five decades later (Frith, 1991).

Separating the population in those who fell into the categories of Type E (empathising) and Type S (systemising), Baron-Cohen made the claim that autistic people were those with a strong predilection for Type S behaviours, or what he referred to as an extreme male brain (Baron-Cohen, 2004). Baron-Cohen does go to the trouble of explaining that he is talking about averages – that is, the average male will tend more towards systemising, while the average female will tend to be more along the Type E end of the scale – and is not suggesting that this applies to all males and all females. He also clarifies that the male vs female brain does not necessarily match with a person's biological gender, rather it is perfectly plausible for a man to have what he calls a female brain, and vice versa. This does not appear to be how the concept of male and female brains is used in diagnostic practice, however, exploring this further is beyond the scope of this research.

In his book, The Essential Difference, Baron-Cohen (Baron-Cohen, 2004) goes into detail on what he means by the extreme male brain hypothesis, which he states is based on a model first put forward, albeit informally, by Hans Asperger when he wrote “the autistic personality is an extreme variant of male intelligence. Even within the normal variation, we find typical sex differences in intelligence… In the autistic individual, the male pattern is exaggerated to the extreme” (Asperger, 1944, cited in Baron-Cohen, 2004: 149).

This extreme male brain theory is strongly disputed by autistic people nowadays, particularly though autistic academics who are striving for recognition of neurodivergence and its value, however, it does appear to have been demonstrated and supported by extensive research, carried out by various researchers seeking clarity on the prevalence of extreme Type S personalities in autistic persons. According to published findings, participants who had been diagnosed with an autism spectrum disorder, to use the wording as per the research, did indeed predominantly fall into this category (Baron-Cohen, 1995; Baron-Cohen and Hammer, 1997; Baron-Cohen et al., 1997; Baron-Cohen et al., 1999; Baron-Cohen et al., 2001b; Baron-Cohen, 2002; Baron-Cohen et al., 2002; Baron-Cohen, 2004; Baron-Cohen, 2009). However, although various researchers were involved in proving this theory, it is notable that Baron-Cohen himself was involved in each of the papers cited here. That is not to say that the findings were not accurate, but rather that one needs to look at the bigger picture.

When multiple scenarios prove that the extreme male brain is prevalent in autistic people, it may not be proof that autistic people in general are Type S personalities, but that the diagnostic criteria are failing many autistic people who do not fit this stereotype. For evidence of this, one simply needs to do a little research into the large numbers of late diagnosed autistic people, many of whom are women and/or do not fit with the image of the solitary male who lives by rigid routines and repetitive behaviour. It is not just that autism cannot be reduced to scoring a certain way on a multiple-choice test, it is that humans in general are far more complex than this.

Simon Baron-Cohen is also renowned in the field of autism for his work on mindblindness. Much like his work on the extreme male brain hypothesis of autism, this theory takes a rather positivist view of autism. To put it very simply, if you are not autistic, you can read other people's emotions through facial expressions and body language, whereas, if you are autistic, you cannot. Of course, the mindblindness model is significantly more complex than this, but the previous sentence gives a reasonable brief overview of what is at the root. Where a non-autistic person is referred to by Baron-Cohen as a mind-reader, or one who can read emotions, mindblindness refers to the alleged inability of an autistic person to detect the mood or emotions of another (Baron-Cohen, 1995), and forms part of his model of "theory of mind".

As previously stated, there remains no single definition on what autism actually *is*. Some consider it to be primarily a social deficit of some form, while others suggest that it may be an umbrella term used to encompass an array of slightly different neurological conditions. At present, the autistic community, as well as preferring to be referred to as autistic rather than persons with autism, is widely embracing neurodiversity. Neurodivergence encompasses all those who are not neurotypical, and tends to be used as an umbrella term covering autism, dyslexia, ADHD, and similar. Perhaps interestingly, although the movement towards using this term can be found more frequently in recent works and conversations, Hans Asperger alluded to it in his first public lecture back in 1938 (Frith, 1991). In this same lecture, he also spoke about what is now the spectrum model of autism, indicating that although he was a very early researcher in the field of autism; having been one of two separate practitioners who coined the term coincidentally and almost simultaneously, at least some of his thinking was infinitely ahead of the "refrigerator mother"-type perceptions which were more widespread in the mid-20th century.

Although Asperger Syndrome was, until recently, a diagnostic term used for those autistic persons who were deemed to be high functioning, it was not used as early as Asperger himself was studying autism. In fact, Asperger Syndrome first came into use in 1994, when it was added to the Diagnostic and Statistical Manual of Mental Disorders (DSM). It was then removed from official use with the publication of DSM-V. (American Psychiatric Association, 2013) Asperger believed that autism, dyslexia and similar are not merely checklists of deficiency (Silberman, 2015), but are naturally-occurring cognitive variants, essential contributors in the development of much of the technology and various other aspects of the society in which we now live. The same society that still, in 2021, does not fully accept any cognitive differences.

2.2.2 Behavioural Therapy and How to Become Less Autistic

As soon as autism, using the various names it was given over the course of early research, was identified, those psychiatrists and professionals working with autistic children became focused on finding a cure, and treating their young patients. Given that autism is not a medical condition and, as such, cannot be treated or cured – indeed, neither should there be any attempt to “cure” or “treat” autistic persons – these were in reality a battery of humiliating, painful, and downright barbaric practice. There may have been good intentions at the root of some of these treatments, but they were far from being beneficial or pleasant for those subjected to the testing of hypotheses, treatments, and tortures mooted as cures. From concentration camps to bleach enemas, via the unnecessary exposure to potentially deadly mumps, measles and Rubella viruses, the lives of autistic children were and, to some extent, still are considered secondary to the need to eradicate this deviation from what is accepted to be normal. It is, perhaps, prudent at this point to state that normal does not exist. There is no such thing as the perfect human being.

An example of this comes in the form of Bruno Bettelheim, or Dr B, whose doctorate in arts apparently became a PhD in psychology, and whose history was significantly changed when he decided to begin work as an autism expert after being released from a concentration camp. It has been surmised that Bettelheim actively proclaimed that his doctorate had been in psychology, and claimed to have completed the required training to work as a psychologist at the time – neither of which were true. Despite painting himself as a benevolent saviour of those on the autism spectrum, life in Dr B’s institution involved beatings, harmful so-called treatment, and endless fear of what was to come next, according to former patients (Bernstein, 1990). Indeed, the life to which autistic people incarcerated in Bettelheim’s Orthogenic School were subjected does not appear to be too far removed from the Nazi concentration camp in which Dr B himself was imprisoned, despite him having described the setting as being similar to a concentration camp in reverse.

Founded in a belief that the only way in which to remedy these young people was to remove them from their home environment, Bettelheim created in the Orthogenic School a milieu enabling the children to move around freely, so long as they remained within the confines of the school, where they were forced to undergo psychoanalysis and treatment designed to undo the damage they had sustained from their unloving parents and dysfunctional homes. The Orthogenic School specialised in training these young people to become "normal", functioning members of society, which may appear to be a positive goal on first consideration, but essentially involved turning autistic children into Bettelheim's equivalent of Pavlov's dogs. Whatever the intention of the measures Bettelheim and his staff employed in the Orthogenic School, the punitive treatments did not involve the child's parents whatsoever, believing as he did that poor parenting, particularly on the part of the mother, was a root cause of autism.

Bettelheim was far from being the only proponent of ABA and similar practices, however, this has been included to provide an insight into some of the more harmful autism approach and practise which has, and still does, exist, and it is not relevant to explore in further detail here. The ongoing harm which is caused by these treatments (Lynch, 2019a) is, albeit primarily indirectly, referred to throughout the thesis, as the autistic participants discuss their own experiences, and the impact of various traumas.

2.2.3 Neurodiversity: The Value of This New Paradigm

Much of this research is based on the value of neurodiversity and neurodivergence, or the acceptance and embracing of those minds that work differently from what is generally considered to be "normal". This does not only apply to autism, but also encompasses other neurological conditions such as attention deficit and hyperactivity disorder (ADHD/ADD) and pathological demand avoidance (PDA).

Although some debate has taken place over who is to be credited with the conception of the neurodiversity movement, given that the word first appeared in print when Harvey Blume (1998) said "Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favour a somewhat autistic cast of mind", the actual first mention of neurodiversity was in Judy Singer's dissertation in 1988. As

Singer herself has stated that her determination in being credited is a deliberate act against the tendency in history for women not to receive recognition (Singer, 2017), it is important to ensure that this trend is not continued here.

As it currently stands, the neurodiversity paradigm is supported and advocated for by many autistic autism academics, and non-autistic autism academics who are also investigating autism from a similar point of view to me, where focus is placed on strengths rather than deficits. The idea was first proposed by Judy Singer in her 1988 thesis, but has become more popular and gained more traction over the past few years (Singer, 2017). This view does not fully accept the idea of autism as a social disability, acknowledging the advantages of using this model over the medical model of disability, but also referring to the fact that “like all movements that try to provide a Grand Theory of Everything, the social model had its cultish, fundamentalist tendencies” (Singer, 2017: 13).

Singer also refers to her belief that the social model appears to attempt to banish all notion of suffering – autistic people, perhaps particularly those with co-occurring conditions, do suffer. And so do parents, particularly mothers, of autistic children; on the one side as they do not fully understand their children who do not fully understand them, and on the other side, as they are often accused of bad parenting and their children of being social misfits. While society may be at the root of some of this suffering, the very real pain, physical and psychological, that goes along with it should not be discounted. I do not believe that the social model does discount this suffering, but this is a valid point, nonetheless.

The Neurodiversity Movement is a current civil rights movement, where autistic and otherwise neurodivergent people are fighting for their right be accepted for who they are, which is more than some type of “other” (Reynold Lewis, 2020). Singer herself attempts to explain why this movement has gained momentum now, rather than at some other point in history, stating that, in her opinion, “thanks to the success of feminism and identity politics, the decline in the authority of medical practitioners due to the consumer ethos, the failures of psychotherapy, the successes of neurology, and the democratising effect of the internet” this has become the time for autistic people to come forward (Singer, 2020). The point about the role of the internet in this movement seems particularly valid, given the richness of autistic interaction on Twitter, where the removal of the need to conform to social protocol to some extent – for example, there is no need to make eye contact while conversing online – has enabled autistic people to build a strong community, where they can self-advocate, advocate for others, and make evident to those outside of the autistic community just how unjustly and, often, cruelly (both intentionally and unintentionally) those who are neurodivergent in any way have been, and continue to be, treated.

There is also the neurodiversity paradigm, which mainly centres on the fact that there is no such thing as "normal", using the three principles that:

1. Neurodiversity is, in itself, a normal variation of human nature, which offers as much value as being neurotypical.

2. There is no one type of healthy or normal mind or cognition. This is a fallacy, constructed by society, and is as inaccurate and harmful as other stereotypes such as there being a normal or best race, religious belief, sexual identity, and so on.

3. Neurodiversity, and the acceptance of neurodivergent individuals involves shifting social power and dynamics, again similar to how they have been, or must be, shifted to embrace other minorities or divergence from what is considered to be the norm (Walker, 2014).

To clarify, when working with the neurodiversity paradigm and/or movement, it is not correct to say that one has neurodiversity, but that one is neurodivergent. This applies for similar reasons as those which have led much of the autistic population to prefer the term "autistic person" to "person with autism", as the former acknowledges and positively includes diversity, whilst the latter frames it as an undesirable addition to a person's self.

Another interesting point made by Singer relates to misconceptions about autism in girls and women. It is widely acknowledged that the stereotypical view of autistic people as having impaired empathy is not accurate. Instead, many autistic people are "extreme empaths" meaning that they feel others' pain too strongly, if anything, and, in general, the issue is that autistic and neurotypical people have difficulties understanding each other's perspectives, as illustrated by the idea of a double-empathy problem (Milton, 2012b). The extreme empathy side of autism tends to be acknowledged more by autistic people recounting their own experiences, for example Leary (2017), and not by academic publications, which still largely tend towards adhering to stereotypes. Singer points out that, amongst the autistic women she has come into contact with, there is a definite tendency towards both extreme empathy and exceptional levels of intuition. It is not the case that significantly fewer women are autistic, or have Asperger's Syndrome as it used to be known before the publication of DSM-V, it is merely that those researchers and practitioners were looking for the wrong traits (Singer, 2017).

The value in taking a neurodiversity-based perspective lies in what is quite clearly indicated by the name – diversity. Whether autistic or not, we are all individuals, and there is natural diversity inherent in the population. The Neurodiversity Paradigm recognises this diversity, and seeks to have it recognised, and celebrated, rather than automatically derided. This is not to diminish any obstacles and issues which individuals may encounter, but simply to accept that we are all different, and being different is not necessarily wrong, or lesser.

2.2.4 The Social Model of Disability, Monotropism, and Flow

While there have been numerous models and descriptions of autism mooted by various practitioners and professionals over the past few decades, the autism-focused element of this research is aligned with the current terminology favoured by the Participatory Autism Research Collective (Milton et al., 2019), autistic academics, and similar groups. The current model, which is the most accepted those autistic academics who can offer a unique, personal perspective on what it is actually like living as an autistic person in a neurotypical world, is that of autism being a normal variation of the human condition, and not a disorder or medical condition which is inherently "wrong" and, as such, requires prevention or cure. Indeed, there are some qualms around using the word normal at all in this context as, after all, what is normal, other than a socially constructed ideal which does not exist?

The main reason why the terms autism spectrum disorder and autism spectrum condition are used minimally here, and even then, only when necessary to refer to a particular piece of work, is the connotations with the medical model of disability. Autism, in itself, is not a disability. Some autistic people may also have medical conditions, disabilities, and impairments which affect them greatly, and autistic people may be affected more severely by some impairments, etc. than neurotypical people. However, when we purely focus on autism, the social model of disability is infinitely more appropriate and relevant.

The social model of disability can be related to autism (Woods, 2017) as, were the world constructed in a way which accommodated autistic people, there would be no impairment or disability to consider. Social disability can be explained quite succinctly with the phrase, often wrongly attributed to Albert Einstein, that "if you judge a fish by its ability to climb a tree, it will live its whole life believing it is stupid". With that said, there are, of course, autistic people who do consider themselves to be disabled, arguing instead that the stigma around the word disability is the issue. In the words of David Gray-Hammond, a prominent autistic advocate, it is perfectly feasible that one can be both disabled and happy – the two are not mutually exclusive (Gray-Hammond, 2021).

To enable the world to fully accept and embrace autistic people (the time for autism awareness events has well and truly past – there are surely very few people who are unaware that autism exists; the problem lies with the existence of social norms which make everyday occurrences and tasks nigh on impossible for those who think even a little differently), it is necessary to make the somewhat sizeable shift from seeing autistic traits as deficits and impairments, to seeing them as strengths. For example, take the weak central coherence model of autism (Frith, 1991; Frith, 2003; Frith and Happé, 1994; Shah and Frith, 1983; Shah and Frith, 1993; Jolliffe and Baron-Cohen, 1999), which relates to the tendency for autistic people to see the constituent parts of a gestalt image, rather than the whole. Where a neurotypical person will tend to form a recognisable, familiar image from a cluster of smaller shapes, lines, numbers, or similar, one who is autistic will tend towards seeing the smaller details more clearly. That is not to say that an autistic person cannot see the familiar object, merely that the default will be to spot the tiny details. The whole being greater than the sum of its parts is, therefore, not always wholly accurate.

The term "weak central coherence" appears to imply that this is a deficit on the part of the autistic mind, however, should one decide to consider the same phenomenon as "enhanced perceptual functioning" as first proposed by Mottron et al (2006), the same tendency can be viewed as a strength, rather than a weakness.

Temple Grandin, an autistic woman who, unusually for one born in the mid-20th century, was diagnosed with autism at a young age and enabled to fulfil her potential by a very understanding, tenacious, and encouraging mother, was the person who first coined the phrase "different, not less" (Grandin, 2012), which is widely used by the autistic community, and organisations supporting them and their families, as an express of how autism is not a disability, but a different ability. One example of this different ability is illustrated in the gestalt example above, but the advantages of seeing the world in such a way was not explained fully. Grandin, now a professor of animal sciences, and renowned speaker about autism and the abilities of autistic people, points out that a world without autistic people would be very different, and not necessarily in a good way (Grandin, 2006; Grandin, 2008; Grandin, 2012; Grandin, 2014).

Those amongst us who can see the smaller details have an advantage in certain scenarios. Those who are not motivated by social expectations and a desire to surround themselves with people may, instead, focus their energies on solving problems, inventing, and using that eye for detail for the greater good. As Grandin herself put it, if we all stood around the cave chatting, we would all still be living in caves (Grandin, 2006). It is those who go against the norm that make the difference. I must highlight here that Grandin herself is now considered problematic amongst certain elements of the autistic population, due to her views on therapies and treatments for autism. Regardless, her work, and her views on autism, undoubtedly laid the groundwork for much of the contemporary autism research, and its value as such should be recognised.

Another description of autism, and perhaps that which has the most significant impact on this research, is that of monotropism (Murray et al., 2005), or an atypical way of dividing focus and attention. Relating in part to the tendency to see the finer details rather than the whole, monotropism offers some explanation of why autistic people tend to have special interests, or those which may be seen by neurotypical persons as obsessions. This monotropic super drive has been linked to the state of flow (Csikszentmihalyi, 2002), and it is currently believed that this is where the link between the three research areas of autism, threshold concepts, and knowledge levels lies. When one thinks of the stereotypical autistic person, one of the first associations that tends to be made, based on personal experience and a not-insignificant amount of time reading about other autistic people's encounters as relayed to the autistic Twitter community, is that of the special interest (Grove et al., 2016; Grove et al., 2018).

Except, in laypeople's terms, it is not referred to a special interest. The conversation will typically tend to involve questions such as "so what's your/their superpower?", "oh, you mean like *Rainman*?", or some mention of obsessions, and the stereotypical comments on eye contact, or lack thereof, social skills, and perhaps an element of surprise that the autistic person is able to hold a "normal" conversation. Well-intentioned as these queries and comments may be, they serve mostly to continue the "othering" of autistic persons, which is the polar opposite of what autistic researchers, advocates, and the autistic community in general, are trying to achieve.

2.2.5 The Various Models of Autism

At the time of writing, a literature search for the term "autism" on the University of Strathclyde library returns 350,000 results, making it impossible to read everything that has ever been published on the topic. With thousands of new papers being published each year, this is continually becoming even more unrealistic a task. Additionally, a concerning proportion of these papers continue to focus on curing, treating, and preventing autism.

I deliberately do not discuss the early models which were based on impairments and deficits, focusing instead on the monotropism model (Murray et al., 2005), the link between monotropism and flow (Milton, 2012a), and neurodiversity in general. The causes of autism are not, in my opinion, relevant, and there are obvious reasons why preventing a neurotype is problematic, to say the least. The spectrum model of autism is far from perfect, however, it can be used in a way which helps to explain neurodiversity, so will be included in this context.

When thinking about autism, it is important that we move away from the traditional view of an impaired individual, whose level of functioning can be labelled permanently. While there are autistic people with varying learning disabilities and other forms of neurodivergence that impact upon their daily lives, the difficulties in living as an autistic person, particularly one who has been misdiagnosed or diagnosed as an adult, lies in the lack of understanding. As outlined by Milton (2017), the misunderstanding between autistic and non-autistic people is what creates much of the difficulty, due to the tendency to believe that there is a right and wrong way of being. Rather than being inherently averse to social interactions, or unable to function, autistic people are impacted by what Milton calls the double empathy problem (Milton, 2012b; Chown, 2014; Mitchell et al., 2019), whereby autistic and non-autistic people encounter mutual misunderstandings due to the differences in their perception.

It is not that autistic people do not have empathy; it is that both sides struggle to see the other's perspective. Indeed, autistic people often report that this communication issue is minimal, or even non-existent, when communication with other autistic people (Crompton et al., 2020; Davis and Crompton, 2021). The advantages offered by communicating with a shared language and experiences (Williams, 2021) will be discussed in detail throughout this thesis.

Taking this approach to autism involves understanding neurodiversity (Singer, 2017), and the concept that there are different ways of thinking, not lesser ways of thinking. The evolution of models of autism, from spectrums to neurodiversity, is discussed next.

2.2.6 Spectrums, Constellations, and Spiky Profiles

One of the most common misconceptions about autism, aside from the stereotypical image of a young non-verbal male, relates to the concept of the autism spectrum. Although most likely intended to portray autism as having numerous aspects to it, when first introduced by Lorna Wing (1979) this image of a spectrum seems to have led to a widespread belief that autism is linear, and that one can be a little bit autistic, or very autistic. This is not true; a person is either autistic or they are not, but there is not a concrete profile which can accurately describe every autistic person, just as there is no profile which fits all people who are not autistic. An autistic person is not either at one end or the other in terms of severity (another word which I am using only as there does not seem to be a more appropriate alternative), as I will now outline.

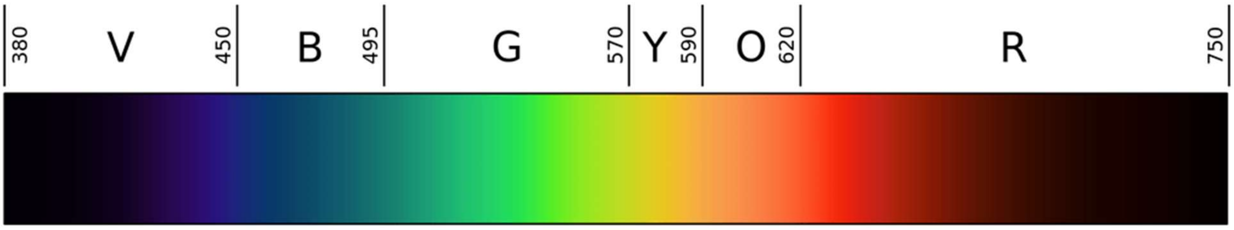
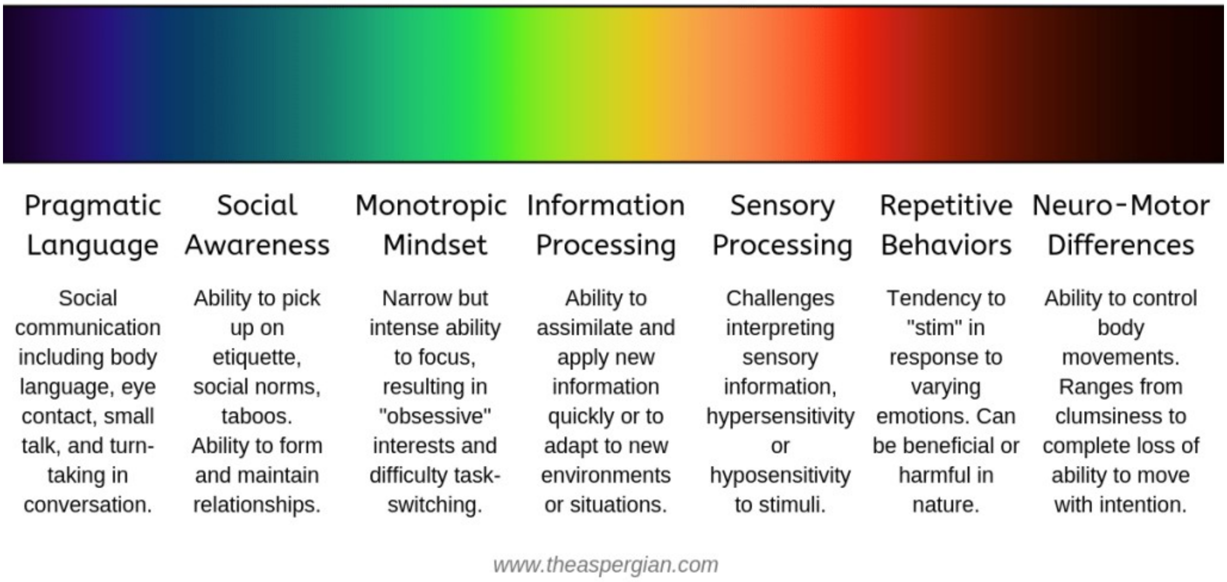


Figure 2 - Colour Spectrum

Looking at the spectrum above, we do not say that blue is a little bit red, or that red is very green. All of the colours are on the spectrum, but are not degrees of each other; neither do we say that blue is on the low end of the spectrum, and red is on the high end (Lynch, 2019). Of course, this analogy would not hold if we were to consider the colour spectrum as, for example, a physicist would, but serves a purpose as a metaphor for explaining a complex phenomenon. According to this updated spectrum model, people tend to misunderstand the difference between a spectrum and a gradient. The autism spectrum can be viewed similarly as a range of neurological conditions which may co-occur, but are also equally valid in their own right. Sticking with this analogy, the gradient, in turn, would be the level of presence of each individual condition. Where a person experiences one of these neurological conditions, it will be diagnosed as a standalone condition, perhaps communication disorder, or dyspraxia. Where more than one of these conditions is present, it tends to get diagnosed under the umbrella term of autism.

If we consider each of the skills which are associated with autism, we will find that some autistic people are excellent at some, but very poor at the others, such as being able to communicate fantastically, but unable to manage many everyday tasks due to poor executive functioning. Lynch (2019b) uses the following image (see Figure 3) to represent the autism spectrum in the same format as the visible spectrum above.



Pragmatic Language	Social Awareness	Monotropic Mindset	Information Processing	Sensory Processing	Repetitive Behaviors	Neuro-Motor Differences
Social communication including body language, eye contact, small talk, and turn-taking in conversation.	Ability to pick up on etiquette, social norms, taboos. Ability to form and maintain relationships.	Narrow but intense ability to focus, resulting in "obsessive" interests and difficulty task-switching.	Ability to assimilate and apply new information quickly or to adapt to new environments or situations.	Challenges interpreting sensory information, hypersensitivity or hyposensitivity to stimuli.	Tendency to "stim" in response to varying emotions. Can be beneficial or harmful in nature.	Ability to control body movements. Ranges from clumsiness to complete loss of ability to move with intention.

www.theaspergian.com

Figure 3 – Reimagined autism spectrum (Lynch, 2019b)

The misconception of the spectrum as linear means that many autistic people do not get the support they need in daily life because they have been labelled high functioning. This basically just means that an autistic person is verbal. So, the deep blue pragmatic language may be excellent, but what about the other six colours? What about the differences caused by tiredness, situation, stress-levels, and a myriad of other factors that may be in play at any point in time? Conversely, a so-called low-functioning autistic may be unable to communicate verbally, but have superior skills in several other areas. As is a neurotype, and not an illness, autism does not need to be, nor should be, graded in terms of severity. This does raise the question of how support could be obtained without this type of grading. This is a valid concern, and one which there does not appear to be an answer for as yet, beyond a societal shift to a perspective where differences are embraced and, therefore, inherently supported. For example, we can buy left-handed scissors without it being seen as a massive deficit to be left-handed. Being left-handed is only an issue if you are forced to act right-handed, and it has not at all been an issue for me to grow up left-handed now that society has generally moved on from feeling the need to correct this.

In an attempt to move away from this often misunderstood spectrum model, the constellation model was proposed in order to better illustrate the differing levels of ability in different skills (Fletcher-Watson and Happé, 2019). The lines which serve as supports to each of the autistic people represented on the constellation can also be used to show just how things could change should that support be removed. Any autistic person may find themselves at any point within the 3-dimensional space created by plotting spoken language, auditory hypersensitivity, and IQ score alongside one another.

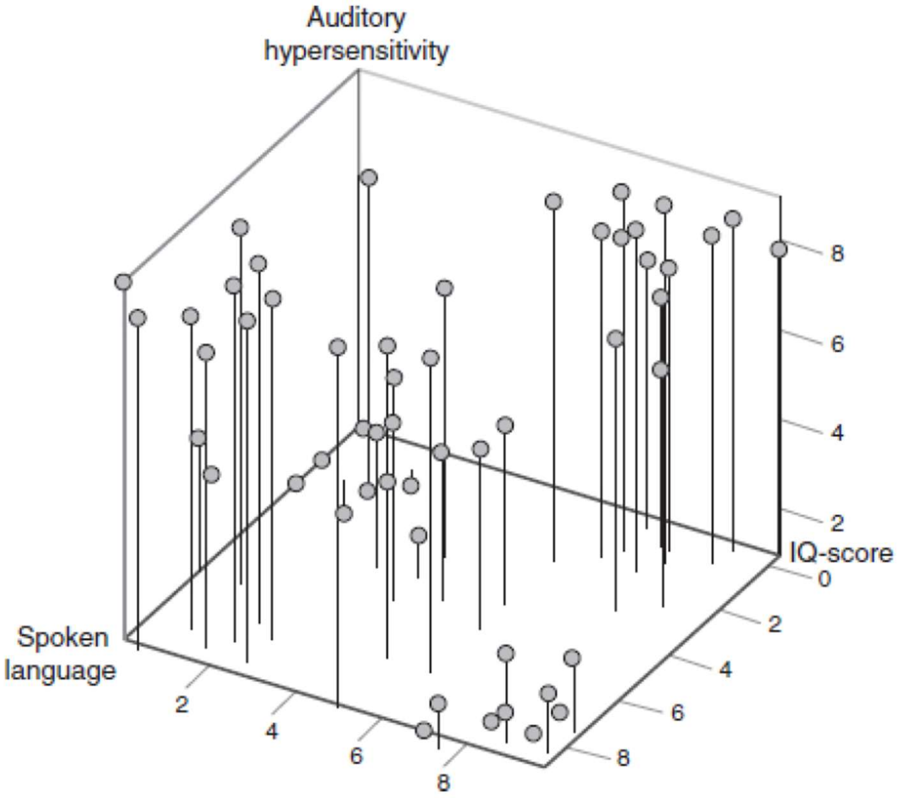
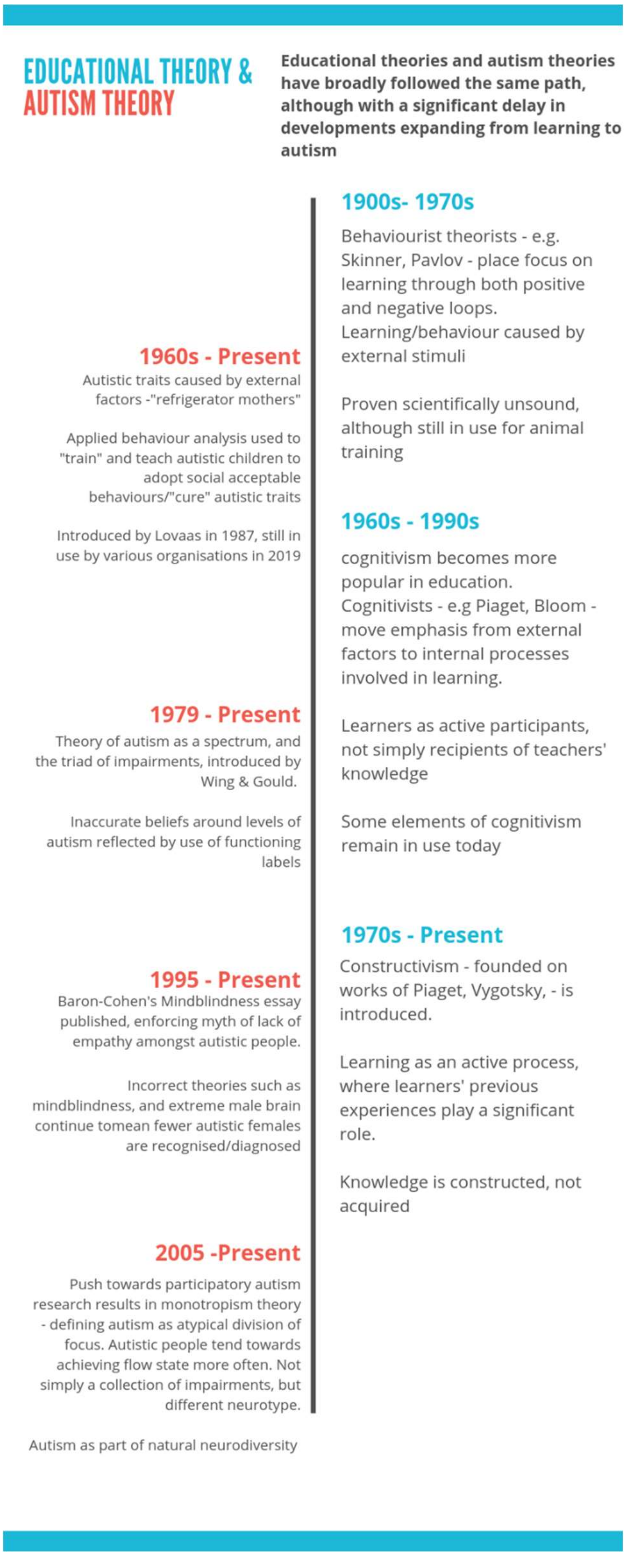


Figure 4 - Autism Constellation (Fletcher-Watson and Happé, 2019)

The constellation also makes it easier to understand the spiky profile (Milton, 2012a), and consider autism away from the linear view of the spectrum. It is important to remember that autistic people do not only experience hypersensitivities to factors such as noise or other sensory experiences, but can also experience hyposensitivity, for example, in feeling pain. Both of these can be equally problematic, in so much as too much of something can be as bad as too little, depending on the skill or ability in question, and the scenario which is faced.

2.2.7 Exploring Threshold Concepts in Autistic People

This study into exploring threshold concepts in autistic people has evolved significantly since it was started. Autism research and practice has historically lagged behind educational research and practice, as is briefly illustrated in Figure 5 below. While not the main aim of this research, one of the objectives in studying threshold concepts in autistic people is to expand this particular branch of educational models to the neurodivergent. As it is exploratory in nature, this research does not focus on an educational or discipline-specific threshold concept, but seeks to illustrate any differences in how transformational learning of this kind presents in those who think differently.



EDUCATIONAL THEORY & AUTISM THEORY

Educational theories and autism theories have broadly followed the same path, although with a significant delay in developments expanding from learning to autism

1900s- 1970s

Behaviourist theorists - e.g. Skinner, Pavlov - place focus on learning through both positive and negative loops. Learning/behaviour caused by external stimuli

Proven scientifically unsound, although still in use for animal training

1960s - 1990s

cognitivism becomes more popular in education. Cognitivists - e.g Piaget, Bloom - move emphasis from external factors to internal processes involved in learning.

Learners as active participants, not simply recipients of teachers' knowledge

Some elements of cognitivism remain in use today

1970s - Present

Constructivism - founded on works of Piaget, Vygotsky, - is introduced.

Learning as an active process, where learners' previous experiences play a significant role.

Knowledge is constructed, not acquired

1960s - Present

Autistic traits caused by external factors -"refrigerator mothers"

Applied behaviour analysis used to "train" and teach autistic children to adopt social acceptable behaviours/"cure" autistic traits

Introduced by Lovaas in 1987, still in use by various organisations in 2019

1979 - Present

Theory of autism as a spectrum, and the triad of impairments, introduced by Wing & Gould.

Inaccurate beliefs around levels of autism reflected by use of functioning labels

1995 - Present

Baron-Cohen's Mindblindness essay published, enforcing myth of lack of empathy amongst autistic people.

Incorrect theories such as mindblindness, and extreme male brain continue tomean fewer autistic females are recognised/diagnosed

2005 -Present

Push towards participatory autism research results in monotropism theory - defining autism as atypical division of focus. Autistic people tend towards achieving flow state more often. Not simply a collection of impairments, but different neurotype.

Autism as part of natural neurodiversity

Figure 5 - Educational models and Autism models

2.3 Threshold Concepts Literature Review

Threshold concepts are a relatively new addition to education literature, having first been introduced by Meyer and Land (2003). In their seminal work, the authors describe threshold concepts as being similar to a portal, through which a learner must pass in order to truly master a discipline. The passage through this "portal" will not be a simple one, rather, it is almost inevitable that the path to mastery will be fraught with obstacles, turmoil, and significant doubt in one's own ability to succeed. Whilst a learner navigates this troublesome phase, or liminal space, there may be times where they feel as though they are regressing, rather than travelling ever closer to mastery, as this is not a simple case of learning by rote and committing information to memory. In fact, a threshold concept can be described as being the antithesis to rote learning (Cousin, 2006a), requiring much personal investment on the part of the learner, in an embodiment of the phrase "you get out what you put in".

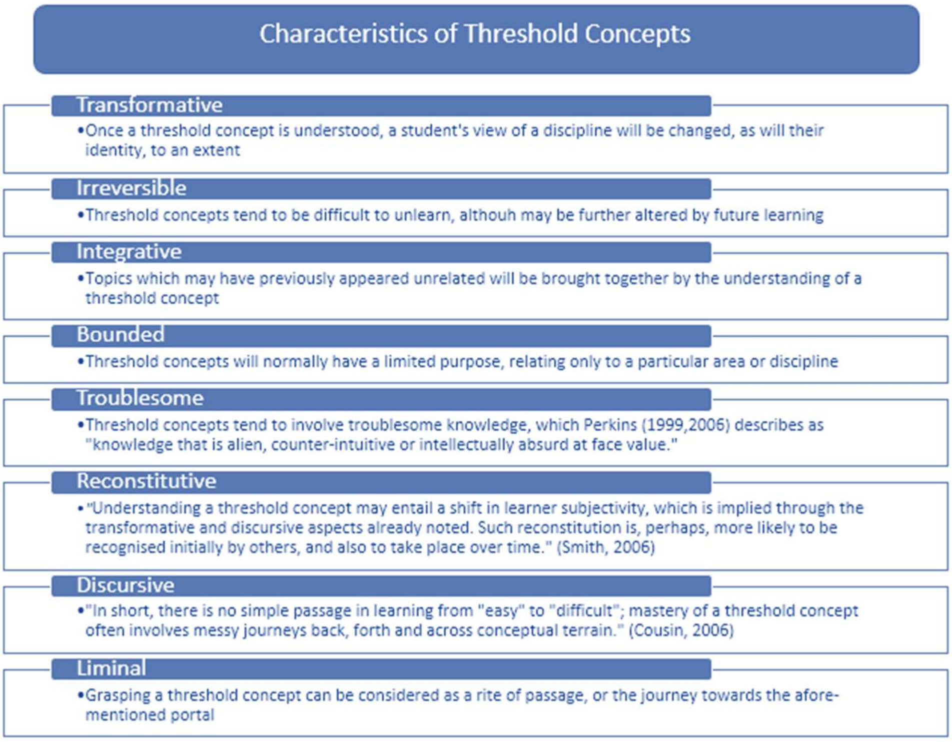
As such, one cannot be taught to experience a threshold concept, but merely guided towards adopting the required mindset and attitude to learning that can make such an experience possible. As part of this exploratory research, I intended to investigate the implicit learning which is an essential component of transformational learning, and those learners who are either diagnosed, or self-identifying, as autistic. While it may be less complex to disqualify self-identification from the process, the inadequacy of the current autism diagnosis process, and, indeed, the breadth of commonly held misinformation about what constitutes autism, would render this an ineffective, and inaccurate, method of selection.

To use the original authors' own definition of a threshold concept, it can be described as

> *"akin to a portal, opening up a new and previously inaccessible way of thinking about something. It represents a transformed way of understanding, or interpreting, or viewing something without which the learner cannot progress. As a consequence of comprehending a threshold concept there may thus be a transformed internal view of subject matter, subject landscape, or even world view. This transformation may be sudden, or it may be protracted over a considerable period of time, with the transition to understanding proving troublesome. Such a transformed view or landscape may represent how people 'think' in a particular discipline, or how they perceive,*

apprehend, or experience particular phenomena within that discipline (or more generally)” (Meyer and Land, 2003: 1).

While there remains no set definition of what a threshold concept actually is, the following characteristics (see Figure 6) must normally be present in order for a particular concept to be considered threshold (Meyer and Land, 2003):



Characteristics of Threshold Concepts

Transformative
- Once a threshold concept is understood, a student's view of a discipline will be changed, as will their identity, to an extent

Irreversible
- Threshold concepts tend to be difficult to unlearn, althouh may be further altered by future learning

Integrative
- Topics which may have previously appeared unrelated will be brought together by the understanding of a threshold concept

Bounded
- Threshold concepts will normally have a limited purpose, relating only to a particular area or discipline

Troublesome
- Threshold concepts tend to involve troublesome knowledge, which Perkins (1999,2006) describes as "knowledge that is alien, counter-intuitive or intellectually absurd at face value."

Reconstitutive
- "Understanding a threshold concept may entail a shift in learner subjectivity, which is implied through the transformative and discursive aspects already noted. Such reconstitution is, perhaps, more likely to be recognised initially by others, and also to take place over time." (Smith, 2006)

Discursive
- "In short, there is no simple passage in learning from "easy" to "difficult"; mastery of a threshold concept often involves messy journeys back, forth and across conceptual terrain." (Cousin, 2006)

Liminal
- Grasping a threshold concept can be considered as a rite of passage, or the journey towards the afore-mentioned portal

Figure 6 - Characteristics of Threshold Concepts (Meyer and Land, 2003)

Since their conception in 2003, various attempts have been made to propose and identify threshold concepts within specific disciplines, and to pin down exactly what constitutes a threshold concept. Why is one concept “threshold” while another is not? The original authors were clear that a threshold concept is considerably more than simply a key concept in a particular topic, and most definitely involves some level of personal growth or change, as opposed to demonstrating the learner’s ability to memorise what they have been taught.

While there is increasingly more literature published in this relatively new field, Timmermans’ (2010) work on the developmental potential of threshold concepts strikes the researcher as being particularly astute and relevant to this research. One point which resonated particularly strongly was that “it appears it takes a little time for the guts to catch up with such leaps of the mind” (Perry, 1981, cited in Timmermans, 2010: 7). Although the presentation of threshold concepts in autistic people will be explored more fully later, this focus on the development aspect of threshold concept, a feeling of being “torn apart” (Magen et al, 2002, cited in Timmermans, 2010: 6), and a sense of generally being unbalanced seem notably poignant when considered in this context.

Amongst the other issues and disconcerting aspects of being one who is neurodivergent, to find oneself in a position of having even your already precariously holding norms challenged greatly is surely comparable to being “torn apart”.

Of course, traversing this liminal space may not feel the same for everyone - Timmermans (2010) likens it to standing on the edge of cliff. Some people are incredibly unsettled and terrified, others actively enjoy the adrenaline rush and fear. There is no doubt that the liminal phase will involve some uncertainty, but it is also uncertain that every learner will experience that uncertainty in the same way. It may not be troublesome, as such, in the eyes of everyone. Gaining the understanding of what one was previously fundamentally unable to understand will feel differently to different people, just as any other emotion will tend to. A threshold concept, therefore, may not necessarily have to involve some learning which appears significant to anyone outside the self, but rather something which enables a new perspective from within. As people, as a whole, are strongly resistant to change, embracing something as unknown and uncertain as an entire shift in world view, is quite an achievement. Before achieving greatly, one is required to allow oneself to become vulnerable, a state which, again, tends to be resisted.

Humans have boundaries they do not want to break down or cross, consciously or otherwise, and accepting a shift in perspective as major as a threshold concept will necessitate the destruction of these boundaries and barriers.

Kegan (1994, cited in Timmermans, 2010: 11) states “transforming our epistemologies, liberating ourselves from that in which we were embedded, making what was subject into object so we can “have it” rather than “be had” by it - this is the most powerful way I know to conceptualise the growth of the mind”. Transformative learning encompasses this shift in epistemology and a radical change in identity and the concept of one's self. Referring to differences in experiencing the "cliff edge" of the liminal space discussed briefly above, the fact that some learners can embrace this shift, while others determinedly resist it, may indicate that it is not within the learner's control. A threshold concept lies far beyond what one can be taught, as one can only alter one's own self. A learner must be willing to accept this change before a threshold concept, or transformation learning, can occur.

Studying threshold concepts and how they present in autistic people, in the way in which I am doing it, could be considered a form of emancipatory research, whereby the research is done in order to give a voice to a marginalised community and address an imbalance of power, and to increase understanding about what autism actually is, placing more emphasis on abilities rather than continuing down the traditional route of exploring deficits, such as the triad of impairments (Wing and Gould, 1979). Mezirow, whose work on transformational learning is strongly interwoven with much of the extant threshold concept literature, has in fact explicitly cited this type of learning or research as "[…] often transformative. In emancipatory learning, the learner is presented with an alternative way of interpreting feelings and patterns of action; the old meaning scheme or perspective is negated and is either replaced or reorganised to incorporate new insights. In emancipatory learning we come to see our reality more inclusively, to understand it more clearly, and to integrate our experience better" (Mezirow, 1991, cited in Hodge, 2018: 135). As such, I am tentatively considering that there may be a threshold concept involved in carrying out this exploratory study in itself.

While there is little doubt that learning, whether threshold or not, can be difficult, there are a myriad of reasons why this acquisition of knowledge may be troublesome – from challenging the beliefs currently held by the learner or their culture, to being tacit, rather than explicit. New knowledge may also appear counter-intuitive to the learner who is encountering it for the first, or near to the first, time, or it may require some understanding of a seemingly separate topic in order to be fully understood. Whatever the reasons behind the knowledge being difficult to accept and assimilate, the value of it appears to lie specifically in this difficulty (Shulman, 2005).

Through carrying out this review of extant threshold concepts literature, and considering the theory in relation to autism in particular, an additional interpretation of what a threshold concept actually is has been developed. This proposed addition to the literature is that there may be different levels of threshold concept, just as there are different levels of knowledge. Given the link which has been tentatively made with the knowledge levels model (Dörfler et al., 2009) during this, it appears to stand to reason that the conceptual knowledge which facilitates progression from novice level to advanced beginner, is not equivalent to that which must occur for one to progress from master to grandmaster, or even from expert to master, for example. Even if one chooses not to use the knowledge levels model, it is not beyond the realms of possibility to assume that what is threshold may be more or less complex given the learner's prior knowledge of the topic in question, the discipline itself, and potentially various other factors. I will be exploring this in more depth as my research progresses.

To this end, while the basic characteristics of threshold concepts, as outlined by Meyer and Land (Land et al., 2008; Meyer and Land, 2003; Meyer and Land, 2006) have been adhered to, this research has been undertaken with the view of a threshold concept potentially taking more than one form, either as a transformational increase in knowledge within a specific discipline, or as a more general threshold experience, strongly influencing one's sense of self and identity. No rigid parameters have been imposed on what may or may not constitute threshold concepts, rather, an open mind regarding what may be considered threshold in the experiences of each of the participants, and others, has been maintained. The first point which must be considered when identifying what may be threshold is the difference between a threshold concept, a key concept, and a basic concept. Each of these are important in their own right, but have a different level of impact upon the learner.

2.3.1 Threshold Concepts, Key Concepts, and Basic Concepts

One of the difficulties reported by researchers investigating threshold concepts, and attempting to identify them across various disciplines, is the subjectivity of the word "concept". What is a concept? And what makes one threshold? Land's (2006) description of threshold concepts as "the jewels in the curriculum" gives some level of insight into the expected richness and depth of a threshold concept, yet it is still open to much interpretation.

On one hand, this has formed the basis of some of the literature criticising and contesting the validity of threshold concept theory, for example O'Donnell (2010) and Barradell (Barradell, 2012; Barradell and Fortune, 2019; Barradell and Kennedy-Jones, 2013; Barradell and Peseta, 2014) while on the other, and the one which best matches the view of neurodiversity which is embraced in this research project, it can conceivably be argued that there is no need for homogeneity in defining what is conceptually threshold. If each person learns and, indeed, exists, as an individual, why should it be necessary to tightly restrict what can be considered threshold or transformative. Perhaps threshold is in the mind of the learner, just as beauty is in the eye of the beholder.

Regardless of which view is to be taken on that particular topic, it is necessary to distinguish between several different uses of the word "concept" which can be found scattered throughout educational literature. Several authors have done so previously, with Davies and Mangan (2005: 39) defining basic concepts as an "understanding of everyday experiences transformed through integration of personal experiences with ideas from a discipline", in contrast with their take on threshold concepts as "understanding of other subject discipline areas integrated and transformed through acquisition of theoretical perspective" (Davies and Mangan, 2005: 39).

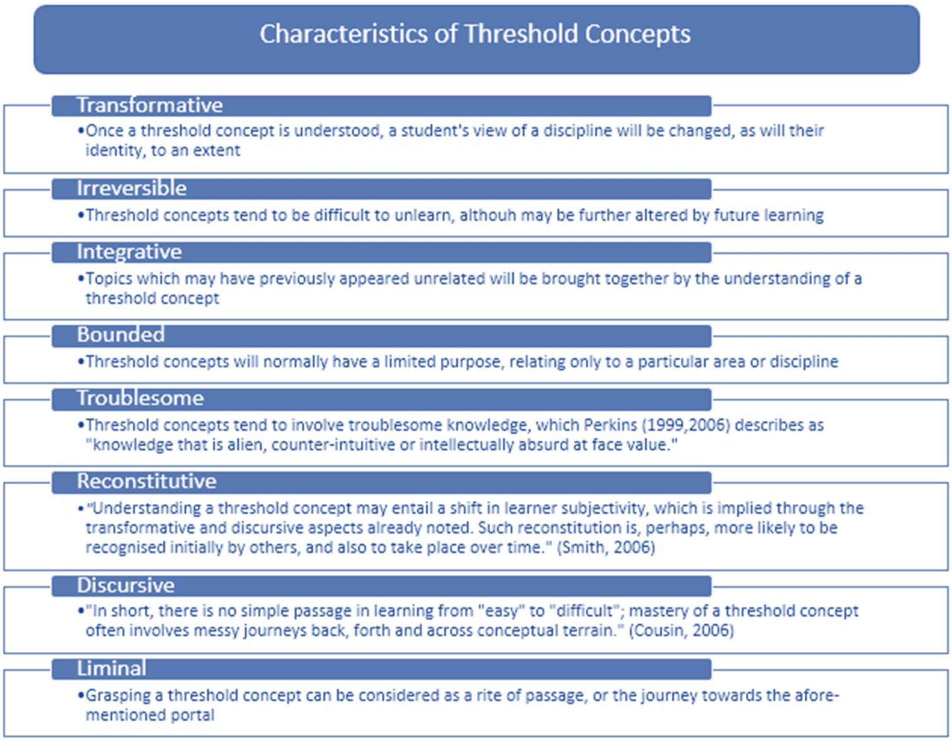
It can be seen from these definitions that the learner's personal experience will have an effect on how they acquire both basic and threshold concepts, with threshold concepts relying on a more in-depth integration of experience, discipline-specific knowledge, and theory. Key concepts, on the other hand, are essential concepts, without which a learner cannot master a discipline, but which can be fully grasped and understood without having any transformational effect on the learner, or requiring any integration on the level of a conceptual threshold. Barradell and Peseta (2014) illustrate this difference using examples from physiotherapy. Learning to take a client-centred approach to care is a key concept in this field, while understanding that patients and their families are going through a life-changing event, could be considered threshold (Barradell and Peseta, 2014). Again, this demonstrates the difference in depth and understanding - knowing to put a patient's needs first is one thing, fully understanding why this is essential, and the potential impact of one's actions as a medical practitioner, is quite another.

Another educational theory which can cause confusion amongst those initially learning about threshold concepts is what is described by Cope (Cope and Staehr, 2008; Cope and Byrne, 2006) as educationally critical aspects. Just as with a threshold concept, a learner cannot progress towards mastery of a discipline without gaining a deeper understanding of these aspects (Cope and Prosser, 2005) however, no shift in identity or overall transformation is involved. For example, one cannot learn to add 4 and 8 without first realising that 8 is made up of 6 and 2 (Marton and Booth, 1997), illustrating that even a concept which may seem so simple to anyone who has taken a basic mathematics class can prove educationally critical. The difference, and interrelation, between threshold concepts and educationally critical aspects is explained by Cope (2008: 354) as "if we consider the knowledge associated with a particular discipline, then threshold concepts are at a macro level and educationally critical aspects are at a micro level… each threshold concept is likely to have educationally critical aspects. Unless [these] are understood by students, progression in understanding a threshold concept is likely to be limited". Despite this, however, it is essential to be aware that an educationally critical aspect is not the same as a threshold concept.

Without experiencing a relevant threshold concept, one cannot learn how to think as a practitioner within their chosen discipline. This involves, for example, learning to think and act as an accountant (van Mourik and Wilkin, 2019), rather than simply memorise how to complete a set of accounts. This change in thinking will be accompanied by a change in the language used by the learner while speaking about their area of expertise, as the adoption of more expert language goes hand-in-hand with the transformation in identity and thought that constitutes a threshold concept (Meyer and Land, 2003). This language, and the underlying identity, will vary depending on the field in which the threshold concept in question belongs, as will now be demonstrated through providing some examples of threshold concepts.

2.3.2 Examples of Threshold Concepts

According to early work on threshold concepts (Meyer and Land, 2003), these otherwise undefined concepts can be recognised by the presence of some required characteristics (see Figure 7).



Characteristics of Threshold Concepts

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Liminal
- Grasping a threshold concept can be considered as a rite of passage, or the journey towards the afore-mentioned portal

Figure 7 - Characteristics of Threshold Concepts

While it would make the identification of a threshold concept significantly easier were all of these characteristics required to be present, there is no requirement for this to happen. In fact, the only prerequisites of a threshold concept, according to Meyer and Land (2003), is that significant learning, and a transformational effect on the learner, are involved. To paraphrase Land (2016), a threshold concept occurs where there is a shift in subjectivity in a time of significant uncertainty.

As such, a threshold concept can be expected to present at a point of extreme discomfort, if not explicit difficulty, for a learner. This difficulty can generally be attributed to the newly found doubt in previously unshakeable beliefs, and the forced requirement to suddenly question the legitimacy of what one has known before. For example, the discovery that the world is not flat is likely to have been a time of significant learning with a transformational effect on those who were now expected to switch their perspective, however obvious it may seem to most of us nowadays.

Threshold concept literature names a number of concepts which are believed to be threshold in their respective disciplines, although I would tend to disagree with some of them, particularly the mention of opportunity cost being a threshold concept in economics. Although it is important for an economics student to understand this concept, I would argue for its classification as a key concept, rather than threshold, as it does not involve any significant transformation of the self, or the learner's world view. Puberty, on the other hand, I would argue is a threshold concept, as the transformation is undeniable, and may serve as evidence that threshold concepts are not restricted to formal education. One key point which is shared by all threshold concepts is the requirement for the learner to be emotionally involved and invested in their learning, and willing to embrace the uncertainty which is essential for entering and traversing the liminal space.

2.3.3 Uncertainty and Learning

Although difficulty and anxiety may tend to be seen as negatives or, at least, fairly undesirable aspects of life in general, they are essential for the mastery of a threshold concept. It is impossible for a threshold concept to occur and, therefore, for a learner to master a topic, without this phase of sometimes extreme discomfort. Shulman (2005: 18) phrases this as "one must have something at stake. No emotional investment, no intellectual or formational yield" while Albert Einstein is reported to have said, as part of his three rules of work, that "in the middle of difficulty lies opportunity". The difference between those who experience a threshold concept, and those who do not is, perhaps, a willingness or ability to embrace rather than avoid this difficulty. Just as a child learning to ride a bicycle for the first time must power through the nerve-wracking wobbling when the stabilisers are first removed, one looking to master any discipline must recognise the value in the less enjoyable, troublesome, aspects of their journey.

As briefly explained above, uncertainty is an essential component in learning. Memorising information or learning by rote, as was encouraged by behavioural learning theories, can, perhaps, be achieved without much uncertainty on the part of the learner but, for a deeper level of learning to occur, to the extent where it can have a transformative effect on the learner, this, sometimes considerable, uncertainty is unavoidable (Land, 2016). While threshold concepts are not limited to classroom learning or other official education-based environments, an understanding of this theory makes it clear that educators should be encouraging their students to explore deeper levels of inquiry, going beyond what is simply necessary, or required by a set curriculum (Nicola-Richmond et al., 2017). A rigid curriculum, as can often be found in schools, tends to encourage students to learn purely for the purpose of passing exams and achieving high grades. A pedagogy of uncertainty, that necessity for experiencing a threshold concept should, therefore, have the ultimate aim of transforming the learner in some form, rather than reducing a subject to bare facts which can be committed to memory or mimicry (Meyer and Land, 2005).

According to extant literature, a threshold concept must be introduced neither too early to be understood by the learner, nor too late to be effective (Land et al., 2006). However, the aforementioned element of essential uncertainty means there is no concrete best time at which to introduce potential threshold concepts. Additionally, there is, as yet no definitive evidence that timing plays a significant role in mastery of a threshold concept and, as such, it may not be as significant as currently believed. The learner's investment in their own learning and development could feasibly be proposed as being of greater significance. This is somewhat consistent with what Etienne Wenger writes about identity investment in learning in the context of communities of practise (Wenger-Trayner, 2010), a concept which could possibly be applied to the autistic community – this link will be explored in more detail later in my research. In order to traverse the period of liminality and uncertainty, the learner must be willing to fully immerse themselves in their learning, regardless of how uncomfortable it becomes, and how challenging the questions it raises may be.

Should there be too much certainty regarding what will be included in exams, or otherwise tested as a means of measuring learning, students will, naturally, tend towards memorising and repeating the content which has been presented by their teachers. This mimicry (Cousin, 2006b) does not allow for anything more significant than surface learning to take place.

Perhaps interestingly, the uncertainty necessary for transformational learning is also required of the teacher. For a teacher to encourage their students to embrace uncertainty, and learn from it, they must be willing to take this approach themselves (Blackie et al., 2010). The teacher’s uncertainty can be expected to be different from that felt by the learner - perhaps relating to their own research, or another part of their career - but it is their attitude to this uncertainty which holds importance. Imposter syndrome, whereby one may feel like they do not deserve, or are not qualified for, a certain role (Clance and O'Toole, 1987) may be triggered by this academic uncertainty, forcing, as it does, the teacher to consider what they do not yet know, alongside what they do know. Vulnerability, therefore, is a necessary evil for all involved in this learning process.

The recent trend towards treating education as a commodity which can be bought and sold, and focusing heavily on student experience, may actually be detrimental to students’ learning. While it is undoubtedly correct to ensure that students have an overall good experience during education, one must remember just how important uncertainty is. Where anxiety is a prerequisite for transformational learning, a shift from a student as one who much engage and invest in their education, to one who is simply a consumer of a service, may not be conducive to exceptional education (Bunce et al., 2016; Nixon et al., 2018; Woodall et al., 2014). Land (2016: 15) corroborates this viewpoint with the statement that “when education is presented as personal transformation, it becomes more difficult, indeed probably impossible, to commodify. Transformation is not consumed, it is undergone”. Oversimplification of facts with a view to making it easier for students to learn may, in reality, have the opposite effect, making it more difficult for a student to grasp the complexity at a later stage. When one understands that troublesome knowledge (Perkins, 1999) is not only desirable, but essential, it becomes evident that this simplification is a poor pedagogy (Baillie et al., 2012).

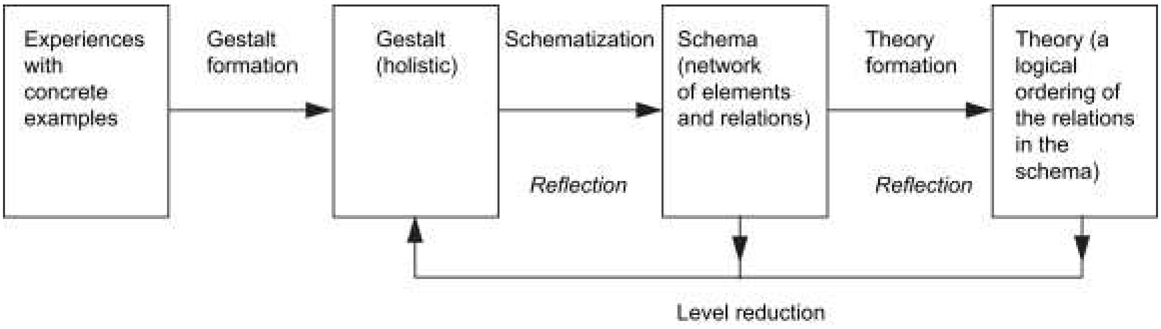


Figure 8 - 3 Level Model of Situated Learning

This 3 level model of situational learning (Korthagen, 2010) illustrates how important it is to have full understanding of a basic concept in place before further learning can occur. This could be used to emphasise the importance of threshold concepts, but also to back up the theory that existing knowledge, and the resulting perspective, plays a key role in learning. After all, we cannot build on what isn't there. In other words, knowledge is not fixed, but reconstituted as required in the context of experiencing a certain phenomenon (Marton and Booth, 1997, cited in Cope, 2008) .

With regards to learning in general, a change of perception can make the difference between *elementitis*, *aboutitis* or playing the whole game, as outlined by Perkins (2010). According to Perkins, elementitis refers to approaching a discipline or topic while focusing only on individual elements, with no end game in sight. While this can be a useful starting strategy, elementitis becomes an issue when it is continued into the longer term. Aboutitis, representing almost the exact opposite of elementitis, involves endlessly learning about a topic, and never putting it into practice. In other words, perception can help us move away from simply memorising facts or learning without doing, to achieving a broader, deeper understanding of a discipline as a whole. Perkins (2010: 6) describes this as moving from "an informational backdrop" to "an empowering and enlightening body of understanding." The junior version, according to Perkins (2010), is a basic manifestation of a discipline or field, and tends to be where threshold concepts occur.

While much of the extant threshold concept literature focuses on the uncertainty element of learning, this has been challenged by Stopford's work on troublesomeness and uncertainty, where the author posits that the key to threshold concepts may lie in a form of

Wittgensteinian existential certainty, rather than uncertainty (Stopford, 2021). This existential certainty provides the basis on which knowing and learning can occur, even if that certainty is later revealed to be ill-placed. There has also been some suggestion that explicitly teaching students what the threshold concept(s) in a particular module is can increase critical thinking and, subsequently, improve grades, in exams. For example, students mentioning a threshold concept in questions where it had not been explicitly requested, or obviously related (Peter et al., 2014) although, whether or not a student is aware of what the threshold concepts in a class are, the level of active participation in the class appears to have a significant impact on learning.

Teacher awareness of threshold concepts within their discipline improves teaching, perhaps more so than student awareness affects learning. Students do not have to be aware that a threshold concept is a threshold concept to benefit from it, and there is no evidence that awareness of threshold concepts reduces their impact, despite threshold concepts being described as an educational tool for engaging people in educational thinking without them realising (Baillie et al., 2011). However, the troublesome aspect of the liminal space means that the learner will be aware that they have reached a particularly challenging point.

Teaching a threshold concept requires a teacher to identify ways of assisting learners to recognise explicitly what is currently left tacit (Meyer and Land, 2006: 82) . While it may be impossible for a teacher to return to the pre-liminal state, by listening to, and understanding, their students as they express their uncertainties, a teacher can cultivate “a third ear that listens not for what a student knows… but for the terms that shape a student’s knowledge” (Ellsworth, 1997, cited in Meyer and Land, 2005: 378). Teachers must also be willing to engage in certain behaviours, such as listening to understand, and demonstrating that they can support their students through liminal phases (Cousin, 2006).

Perhaps one of the most important points about threshold concepts, particularly with regards to this specific project, is that an individual may never experience the phenomenon, adding an additional level of difficulty to studying the complexities of the term.

Blackie et al (2010) serves as one example of threshold concept literature which places emphasis on the notion of “being”. Transformational learning is at the core of threshold concept theory, as is the learner's fundamental growth as a person as a result of experiencing whatever the threshold concept in question may be. Given that one of the characteristics of a threshold concept is the irreversible change in the learner (Meyer and Land, 2003), the "being" of the learner cannot be separated from their learning, and the knowledge they already possess. This combination is what enables the learner, who has experienced a threshold concept, to become a member of a community, or to think in a certain way within a discipline (Meyer and Land, 2003).

2.3.4 Product Vs Process Views of Threshold Concepts

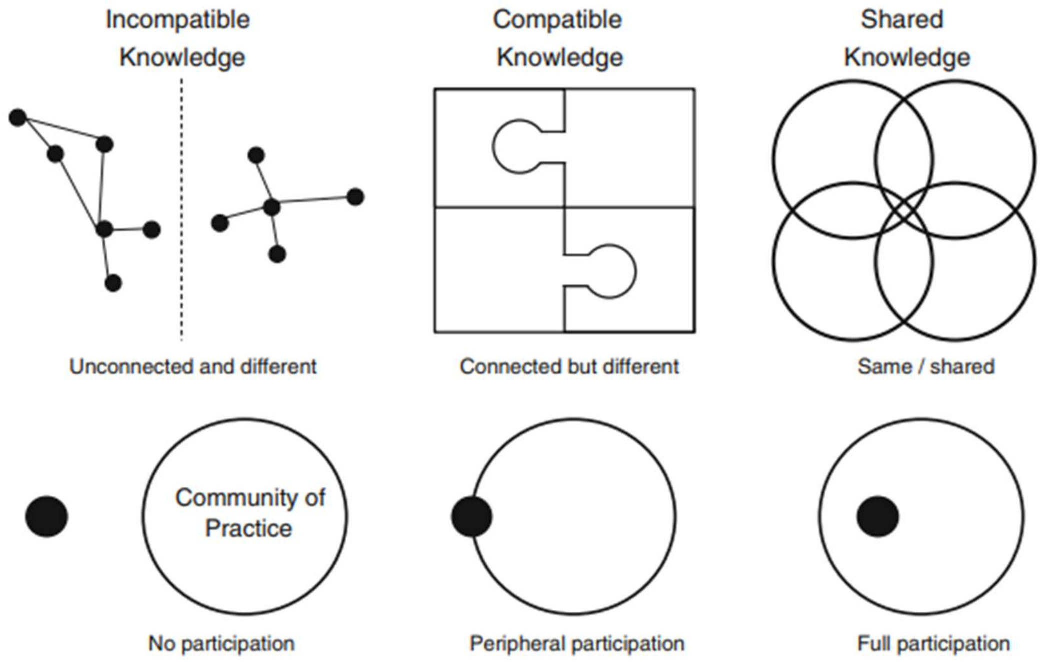


Figure 9 - Product V Process Views of Threshold Concepts (Walker, 2012)

An alternative perspective on threshold concepts, and how they exist within the mind of the learner, is offered by Walker (2012) and the product and process views of threshold concepts. As illustrated by the graphic above, taking a product view involves considering a threshold concept as being constructed and developed within the learner's mind, invoking "ideas of deep learning, being able to view the world in a different way, operating in a more effortful, conscious and knowledge-based manner" (Walker, 2012: 249). Meyer and Land's seminal work on threshold concepts, on the other hand, takes a more process-based view (cf. Meyer and Land, 2003). From this perspective, the focus is less on the concept itself and how it is formed, and more on the transformative journey where a learner progress through distinct stages, towards the threshold concept as expert knowledge. It is this process-based perspective on threshold concepts which will be adopted during this research into self-acceptance as a threshold concept amongst late-diagnosed autistic adults, although the two perspectives are not necessarily mutually exclusive.

2.3.5 The Emotional Element of Learning

It has already been acknowledged that threshold concepts are the antithesis of rote learning and memorising information in order to achieve specific tasks or pass an exam (Cousin, 2006a), involving instead the learner's arrival at a point where they can see and understand how different aspects of their knowledge are not separate entities, but work together. The existing knowledge held by a learner will mean that future learning is shaped by this perspective (Hay, 2010), rather than each topic being learned in isolation, regardless of whether a conceptual threshold is passed or not.

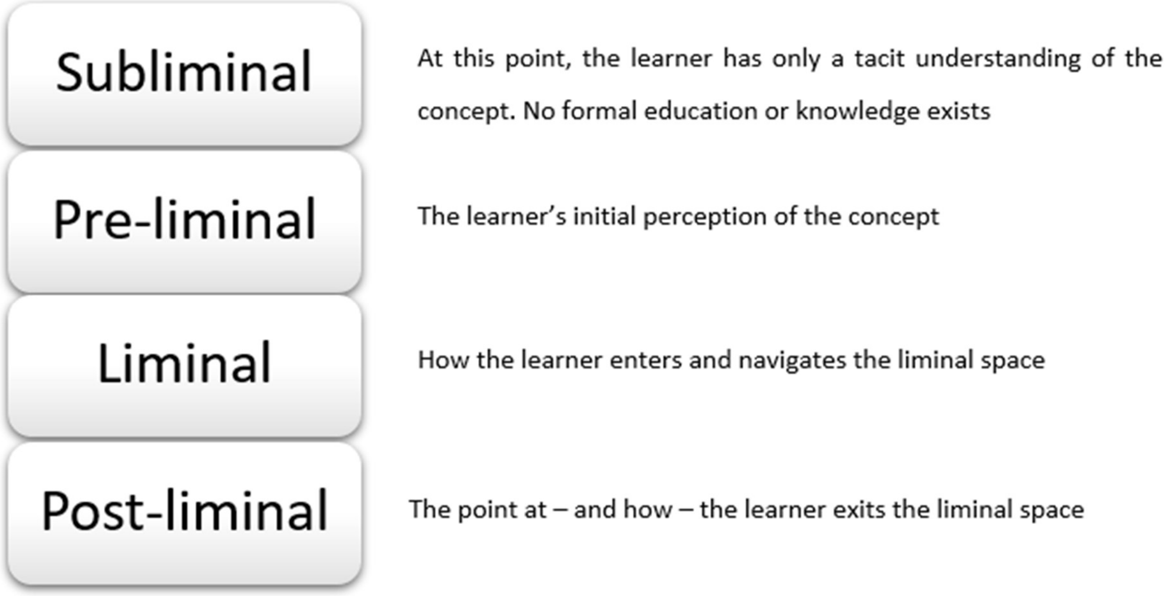
While accepting that every learner will have a different perspective on what is currently being taught is, to some extent, a positive - particularly when one starts to consider the learning potential of various neurotypes - it is important not to specifically try to teach a threshold concept as a threshold concept. In doing so, a new type of certainty is introduced, removing that uncertainty which is needed in order to successful navigate the liminal space (Land, 2016).

As a threshold concept, and the associated shift in perspective, will almost undoubtedly have a significant effect on a learner, it is also essential for the emotional aspect of this process to be taken into consideration. Not all troublesome knowledge will involve a particularly emotionally-charged subject matter - for example, opportunity cost is cited as a threshold concept in economics (Shanahan et al., 2006), and is not a topic which immediately appears overly-emotional - the learner's interaction with the new knowledge is what is likely to involve some level of emotional turmoil (Cousin, 2006b; Blackie et al., 2010). When new knowledge requires one to question beliefs they may have held for as long as they can remember, whilst combining this same new knowledge with that which is already known, distress cannot be entirely unexpected. This serves as further confirmation that acquiring knowledge and crossing a conceptual threshold cannot ever be fully separated from the learner themselves, as “functional fixedness, deriving from Gestalt psychology, corresponds well with the need to “reformulate one’s meaning frame” or experience a “rupture in knowing” as reported in Schwartzman (2010)” (Land, 2016: 22).

Of course, emotions can be positive as well as negative, and the term “emotionally-charged” can be used to refer to the sense of immense achievement, joy, and fulfilment which can be expected when one has finally mastered a previously troublesome concept. Indeed, Barnett (2008, cited in Blackie et al, 2010: 641) refers to this as a “durable ecstasy”, an experience which would not be possible without the less pleasant emotions which tend to come as the learner traverses the liminal space.

2.3.6 The Four Stages of Threshold Concept Acquisition

Extant threshold concept literature states that there are four distinct stages of threshold concept acquisition (Meyer et al., 2008). It should be noted at this point that the word “acquisition” is used as it was by the original authors, although it does not fully fit with my own beliefs about what a threshold concept actually is. Acquisition implies that a threshold concept is something which can be “gotten” and, while this fits with descriptions of threshold concept mastery as being akin to a Eureka moment (Baillie, 2011), it does not match the view of a threshold concept as the process of combining knowledge and discarding certain beliefs, rather than necessarily requiring the learner to get or acquire something entirely new. This perspective notwithstanding, the four stages can be considered a tool for illustrating and better understanding the process.



Subliminal	At this point, the learner has only a tacit understanding of the concept. No formal education or knowledge exists
Pre-liminal	The learner's initial perception of the concept
Liminal	How the learner enters and navigates the liminal space
Post-liminal	The point at – and how – the learner exits the liminal space

Figure 10 - 4 Stages of Threshold Concept Acquisition (Meyer et al., 2008)

Although a brief overview of each stage is included in Figure 10 above, it should be noted that the liminal phase, which has earlier been alluded to several times, is perhaps the most important stage in threshold concept acquisition and, thus, the most challenging. Much of the uncertainty associated with mastering a threshold concept occurs whilst the learner is traversing the liminal space, and it is not unusual for one in this phase to begin to doubt whether this learning is worth pursuing after all, such is the difficulty involved in navigating this phase.

This journey from preliminal to postliminal was also illustrated by Meyer et al. (2010), albeit in a much simplified form, as shown in Figure 11. It is these three stages, rather than four, that will be referred to throughout this thesis.

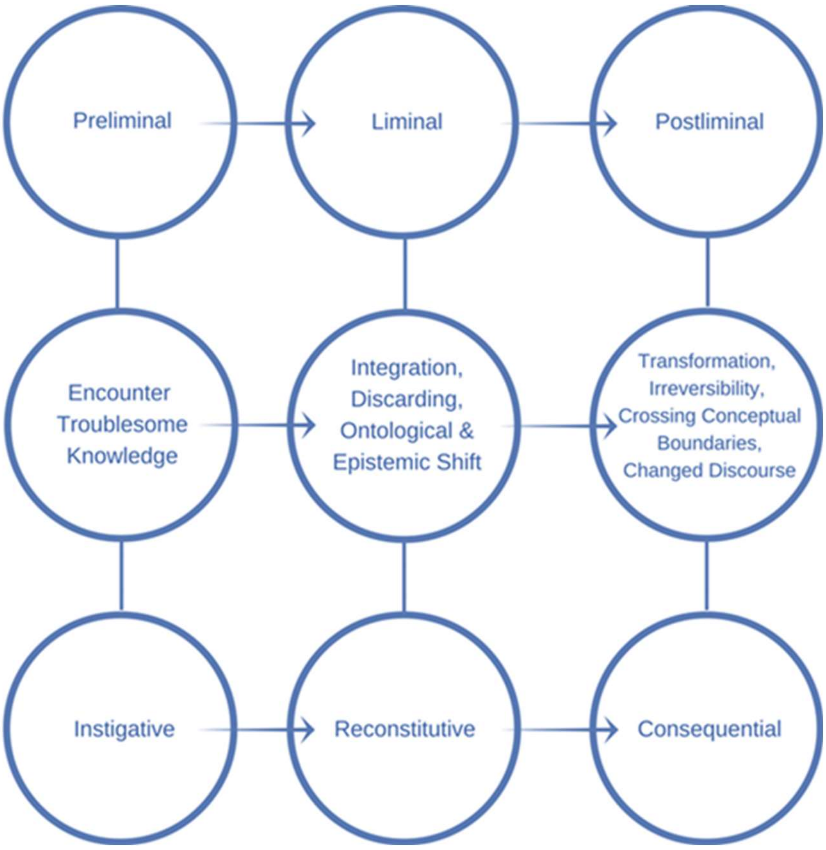


Figure 11 - The Liminal Journey

The journey across the liminal space is, as already mentioned, not as straightforward as it may appear from the illustration above, useful as it may be for general understanding purposes. Cousin (2006a) explains that there is no linear or simple way of passing from easy to difficult, and there are often numerous journeys back and forth before the learner finally masters the threshold concept and exits the liminal space. As such, the liminal space may be more accurately portrayed in all its complexity as per Figure 12 below:

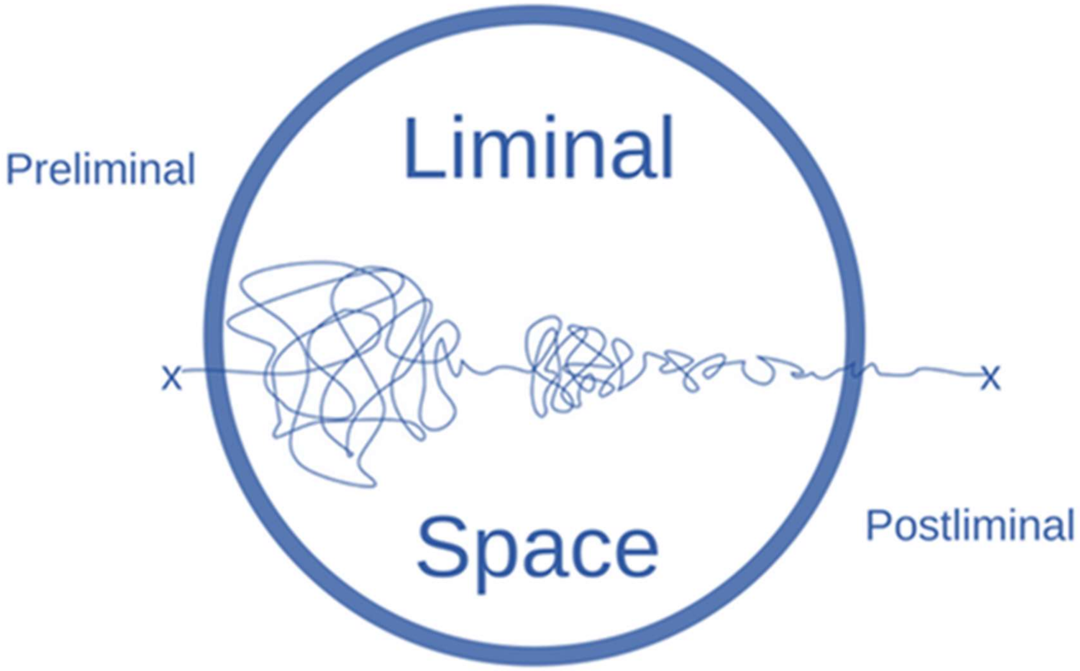


Figure 12 - Liminal Space (Adapted from Meyer et al., 2010)

As one who has undergone transformative learning in the past, and perhaps even as one who has not, the line drawn through the liminal space makes the discomfort, and sheer frustration, involved in understanding such troublesome knowledge, immediately apparent. When one is working towards a goal, feeling as though no progress is being made, let alone a sense of outright regression, can be nothing short of trying, and significantly discouraging. Perhaps this is where the monotropism theory of autism (Murray et al., 2005) presents as a strength of the neurodivergent mind, given that it enables the individual in question to focus intently on one particular topic or aspect of learning, at times to the exclusion of everything else.

A further illustration and explanation of the journey across the liminal space is offered by Land, Rattray and Vivian (2014) in the form of the liminal tunnel. This paper states that the learner’s emotional resilience and other aspects of their psychological state may contribute to how they progress through this troublesome period and, eventually, master the threshold concept in question. The different reactions of different people to daunting scenarios has already been briefly discussed, and Rattray adds to this the suggestion that resilience, optimism, and hope may also affect just how troublesome the liminal space proves to a particular learner. The liminal tunnel serves well as an illustration of an obstacle to be navigated before a threshold concept can be fully mastered, or acquired.

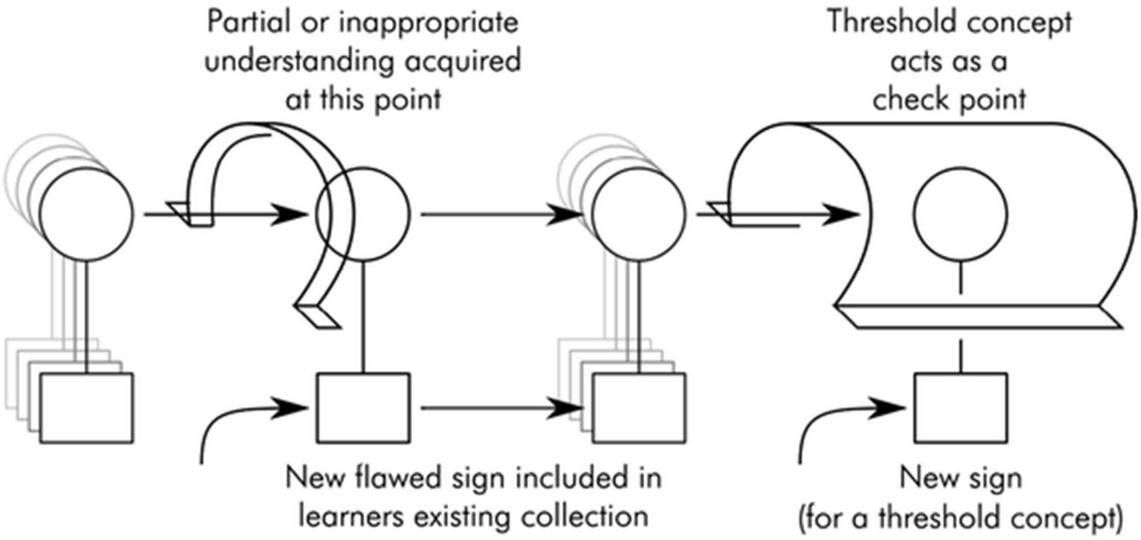


Figure 13: Liminal Tunnel (Land et al., 2014)

2.3.7 Addressing Criticisms of the Threshold Concept Framework

While the fluid nature of the threshold concepts theory is generally explained by the fact that the differing existing knowledge and experiences held by various individuals can mean that conceptual thresholds also vary, it forms the basis of much of the criticism levelled by Rowbottom (2007) and O'Donnell (2010). Drawing on the statement that a threshold concept will usually, probably, or likely display either some or all of the characteristics listed earlier, these papers imply that this elasticity is not concrete enough to prove that threshold concepts ever occur.

This criticism of threshold concepts, disputing the legitimacy and usefulness of a framework which does not have a concrete definition is expanded upon quite forcefully by Salwén's critique (Salwén, 2021). In this paper, an argument is put forward about the lack of definition of what constitutes a threshold concept and, indeed, what is considered to be a concept in itself. While the fluidity of threshold concepts has been brought into question in earlier papers, for example (Rowbottom, 2007; O'Donnell, 2010), this is perhaps the most vehement opposition to date, to the best of my knowledge. Salwen argues that, without set definitions, it is impossible to generalise what a threshold concept is, and what characteristics confirm that a concept is threshold, therefore rendering the framework redundant to the point where “academics who use the threshold concept framework are thus laboring under a delusion” (Salwén, 2021: 36). To make threshold concepts a legitimate tool for academic research, according to the author, it is necessary to make some fundamental changes, namely adequately defending the use of the word “concept”, and providing methodological detail that makes the studies into threshold concepts replicable, with the latter of these two arguments also made by Nicola-Richmond et al. (2017). However, assuming that good research must be replicable, and that any study into human behaviour and learning can be reduced to what amounts to a checklist is strongly suggestive of the authors having taken a particular philosophical standpoint, which does not allow for the individuality of both humans in general, and how we all learn.

As I have approached this research from an interpretivist viewpoint, this fluidity and lack of requirement for rigid definitions and an ability to replicate human behaviour is exactly what is valuable about the threshold concepts framework. When we consider that knowledge is personal (Polanyi, 2002), and each of us thereby begins from a different starting point when introduced to a discipline, there will be no concrete model which will fit in each case. Any attempt to categorise and classify learning in this manner surely misses the nuances which will be expressed by any research participants, and the inherent individuality of learning. When we must all forge our own path when learning, this acknowledgement that threshold concepts can differ is not a weakness, rather a means of encompassing the individuality of each learning process and, consequently, each journey across the liminal space. The concept of liminality has been employed in management research to better understand the context and lived experience of those in situations which are flexible and evolving (Irving et al., 2019; Bamber et al., 2017; Borg and Söderlund, 2014) , and it is that fluidity which enables this to happen, through appreciating the non-permanence of liminality (Söderlund and Borg, 2018).

Another criticism of threshold concepts is that made by Davis and Green (2020) around the apparent failure to account for the backgrounds and previous experiences of marginalised students, as the author posits that naming a concept threshold within a discipline assumes that the learners each have comparable backgrounds and previous experiences, which may not be the case if a class is comprised of different socioeconomic groups. In this case, it could perhaps be countered that the discipline-specific threshold concept may be the same across those from varying backgrounds, however, there may be additional threshold concepts involved in shifting from the perspective nurtured by a certain background. This particular weakness is largely in line with my own assertion that there is no threshold concept research which explicitly acknowledges, never mind focuses on, the neurodivergent. This would appear to be a criticism of previous threshold concept literature, however, and not an inherent flaw with the threshold concept framework itself. Indeed, in conducting the research which informed this publication that authors have contributed to addressing this issue through the explicit inclusion of marginalised students.

Nonetheless, although Rowbottom's (2007) point that all concepts are transformative in a way is overly simplistic, it may be considered accurate to a degree, particularly when one adopts the perspective that threshold concepts may present in different levels, or that a transformation of the self may occur due to the cumulative effect of a number of smaller threshold concepts. This will be discussed in more detail throughout this thesis, most notably in terms of my reflection upon the research process, and the autoethnographic elements.

In summary, while I acknowledge these criticisms of the threshold concept framework, and the very notion of threshold concepts, each of them appears to be embedded in a similar perspective of needing certainty and rigidity in research. From my understanding of threshold concepts, this is almost entirely missing the point. The fluidity in the threshold concept framework and definitions appears to be deliberate. When observing something as individual as learning, to be overly prescriptive would be to lose the essence and the nuance which form the most valuable aspects of understanding humans as individuals.

In this section of the literature review, I have summarised and discussed extant literature on threshold concepts, some contexts in which the framework has been put into practice, and the criticisms that have been levied against it. I will now move on to discuss the next area of research which has been incorporated into this study, knowledge levels and personal knowledge.

2.4 Knowledge Levels Literature Review

The third topic which was originally intended to form part of this research, knowledge levels, has not featured significantly due to the changes triggered by the reflexive, emergent research design, however, it has been included here as an area of research which informed my thinking at the outset.

Knowledge levels are as introduced by Dörfler et al (2009), as an illustration of how the increase of knowledge requires the acquisition of additional cognitive schemata, otherwise known as the building blocks of the mind. While a cognitive schema, in this regard, can be considered to be anything that is known and forms a single whole, it relates back to Méro's definition: *"Cognitive schemata are units meaningful in themselves with independent meanings. They direct perception and thinking actively, while also being modified themselves, depending on the discovered information. Cognitive schemata have very complex inner structures, various pieces of information are organized in them by different relations. The various schemata are organized in a complex way in our brains; in the course of their activities they pass on information to each other and also modify each other continuously"* (Méro, 1990: 84).

To provide some examples, any single letter of the alphabet, a word, or an entire poem can each be regarded as a cognitive schema, despite the obvious disparity in levels of complexity (Dörfler et al., 2009). On a more extreme level, one particular chess grandmaster, Garry Kasparov, could recall a game of chess in its entirety as a single schema. As cognitive schemata are stored in the long-term memory, they are understandably difficult to measure and, in fact, can only be measured through informed assumptions based on what is evident while these schemata are in use in the short-term memory (Dörfler et al., 2009).

The afore-mentioned knowledge levels model makes use of cognitive schemata, and chunking (Simon, 1974), with a specific number of schemata required for a learner to progress from one level to the next. As posited by Méro, each level contains ten times the cognitive schemata as that which precedes it. As such, one who is a complete novice in a specific area will have no cognitive schemata relating to the topic in question. This will then increase to ten schemata at advanced beginner level, 100 at expert level, and so on, until eventually the maximum number is reached when grandmaster level is attained. It should be noted that schemata at novice level will not be equivalent to one at grandmaster level, as briefly alluded to earlier.

When knowledge is acquired, the related cognitive schemata are organised into related units, or chunks, which can become larger and comprise more complex information as one progresses. There are a finite number of chunks or schemata which can be stored by the long-term memory, and this added complexity allows the learner to increase the knowledge they can store within these chunks. Of course, as grandmaster level involves the full potential number of schemata, this also means that no one person can achieve this level in more than one discipline, as space will need to be made to increase the knowledge in any subsequent attempts to attain grandmaster status.

As a greater understanding about how knowledge is acquired and developed was reached, Dreyfus and Dreyfus (1987) outlined a knowledge levels model to illustrate how one begins with nothing before acquiring ever increasing numbers of cognitive schemata while progressing through the model, until the maximum capacity is reached and, with it, grandmaster level. This model was expanded upon by Dörfler et al (2009), to include a starting point of novice, followed by advanced beginner, expert, master and grandmaster levels. This model, and the language which is used to describe it, gives the impression of a hierarchy, and does not always sit easily with the currently accepted social norms in the West. As such, it can be more palatable to remove the terms “master” and “grandmaster”, and replace the levels with dimensions, numbered from one to five. As a learner reaches each new dimension, they gain with it the ability to view their discipline or chosen field from an additional perspective.

2.4.1 Knowledge Levels in 3D

Whether one chooses to use the knowledge levels or knowledge dimensions terminology, each of the five stages affords its own capabilities and perspectives to the learner.

At novice level, a learner will only be capable of acquiring simple facts and basic features. This will then become familiarity with the rules associated with the discipline in question, which a novice will be able to use in conjunction with the facts and features provided. Any instructions given to the novice must be extremely clear and very well-defined, for example, showing a gear stick to a learner, explaining how to use it, and specifying at which speed they should shift up to the next gear, or back down to the previous.

Competence or proficiency in a task is achieving partly through gaining the ability to organise related information, and assigning levels of importance to the simple facts and features provided at novice level. Once advanced beginner level is attained, more than one set of these facts and features can be recognised and remembered, and importance can now be understood. To continue with the driving example, a driver who is at advanced beginner level can choose the best driving route based on traffic, for example. In other words, the learner driver is now able to figure out what they should do (Dreyfus, 1987)

At the next knowledge level, expert, the learner first becomes able to use intuition when taking a decision. For example, an expert driver can refer back to a previous similar scenario, and use this experience to determine their current actions. However, although this does mark the beginning of intuitive decision-making, it will, at this stage, be swiftly followed by a more analytical approach.

This progression will continue gradually until the learner reaches grandmaster level, at which point all decisions related to their chosen field will be made entirely intuitively, with absolutely no active thinking or analysis involved in the process. As such, the journey from novice to expert can be described that from making highly analytic decisions about a subject from which the learner is completely detached, to making unconscious, intuitive decisions based on previous experience (Dreyfus et al., 1986).

If one was to consider these knowledge levels from the less hierarchal perspective of dimensions, it becomes easier to illustrate and understand the complexity of such learning. Progressing from one level to the next can appear linear and straightforward, however, entering a new dimension can conjure imagery of a much bigger leap. Learning involves certain shades of grey, rather than being black and white, and, as such, may be better represented by the five knowledge dimensions, using another framework provided by Dörfler et al (2009). The intuitive aspect of becoming a grandmaster in any discipline is also better represented by this framework, acknowledging, as it does, the quintessence of fully mastering a subject, rather than reducing the progression from master to grandmaster to simple acquisition of new knowledge.

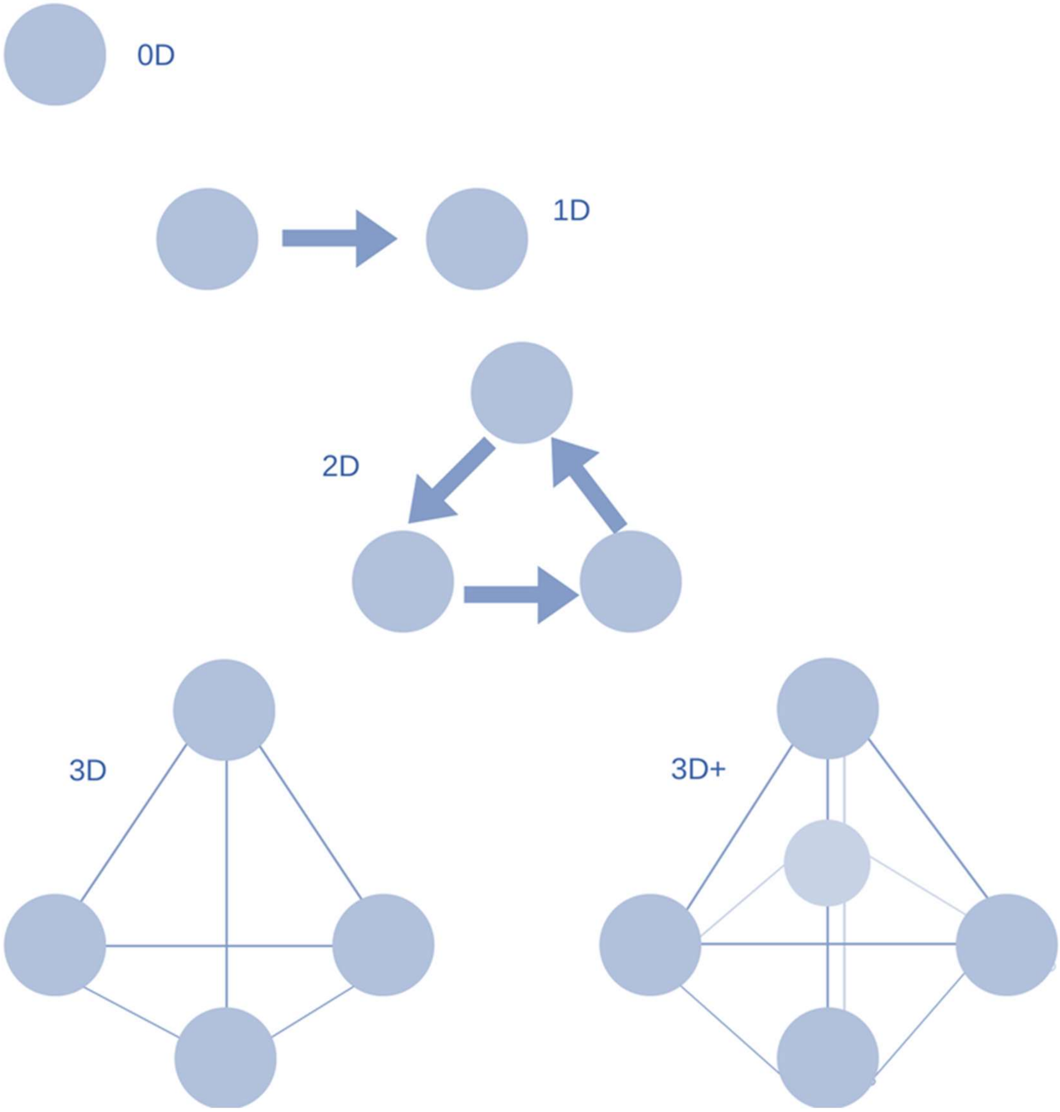


Figure 14 - Knowledge levels in 3D

Removing the hierarchal connotations from the knowledge levels model not only makes the complexity of knowledge acquisition on this scale more evident, but arguably also forms a better fit with cultural beliefs in the U.K, and the West in general, where using terms such as “master” can prove problematic, and may detract from the value of the framework.

When using knowledge dimensions, rather than moving from one level to the next, a learner will gain the ability to approach a scenario from a new perspective. In this model, "novice" is replaced with zero-dimensional knowledge, progressing to 1D, 2D, 3D, and finally, 3D with the ability to see the quintessence. Considering the acquisition in knowledge in this way offers increased flexibility, as it can be appreciated that a learner with 1D perspective can, as seen in the image above, apply this perspective to more than one scenario. There may be numerous points, or pieces of knowledge, linked to the first using a straight line, but the ability to connect these points will not yet be present (Dörfler et al., 2009). This approach also allows for the understanding that, while two people may be on the same knowledge level, their actual perspective, and the knowledge they hold, may be very different. That is, knowledge is personal (Polanyi, 2002), and so too is the learning journey.

Moving on from the hierarchal view is also useful for acknowledging that learning does not always follow a linear path. As previously discussed in terms of threshold concepts, the road to mastering a subject is not a simple one, and may involve various steps backwards as well as forwards. For example, one who is at expert level may briefly spike at grandmaster level, which can be more meaningfully represented by the less prescriptive knowledge dimensions. If the knowledge levels model were to be adhered to, these spikes in knowledge would not be possible, but they do conform to the underlying theory of the dimensions model. Similarly, autistic people, and their spiky profiles, where one area may be extremely well-developed, while another is under-developed, can be better represented by dimensions, which have greater scope for encompassing different neurotypes. As such, it is proposed that, while the knowledge levels model is valid, it is best considered as the basis for the knowledge dimensions model, rather than on a standalone basis.

This view is also expressed by Cope and Byrne (2006), where they discuss dimensions of variation (Marton and Booth, 1997), in terms of the number of dimensions of variation that need to be in focus for a certain topic to make sense. In other words, the novice, with zero-dimensional knowledge is less equipped to make sense of a point than a grandmaster, who can experience it from three dimensions, plus the quintessence. These dimensions of variation are considered to be a key aspect of phenomenographic research which, again, focuses on how an individual experiences a concept (Cope and Byrne, 2006). Using the model of achieving competence through learning and experiencing, outlined by Dörfler, Baracskai and Velencei (2015), it could be said that, rather than requiring a specific background of knowledge, a threshold concept may occur through meta-level concepts being applied to a new domain. For the purposes of this thesis, this approach to the development of knowledge and learning will not be explored further, however, has been included here as it featured in the early stages of this research, and as acknowledgement of other models of learning and understanding existing alongside that which has been adopted throughout my research. As this has limited relevance to this particular research, this is the extent to which this approach will be explored.

2.5 Communities of Practice Literature Review

Although communities of practice were not originally intended to form part of the research, it quickly became evident while talking to the participants that networks and communities were incredibly important while discussing self-acceptance. The value of communities of practice in autism-related education has been discussed previously by Guldberg et al. (2019) while advocating for a more participatory approach to autism research and practice. As I am an autistic researcher, a participatory approach has been adopted from the outset of this research, however, the extent to which networks and communities were significant while considering threshold concepts and transformational learning in autistic adults did not become clear until later.

Throughout this thesis, communities of practice, amongst other aspects, will be discussed in terms of autistic people and neurodivergence. This has been done for context, rather than with the intention of placing primary focus upon the neurodivergence itself. As will become clearer as the discussion unfolds, the intention is to demonstrate not how threshold concepts or communities of practice are different when they involve the neurodivergent, but how they are the same.

Communities of practice, where the term is used throughout this thesis, refers to the explanation of communities of practice as a social learning system (cf. Wenger, 1998; McDermott, 1999; McDermott, 2000; Brown and Duguid, 1991; Wenger-Trayner, 2010;

Wenger-Trayner and Wenger-Trayner, 2015; Wenger et al., 2002; Wenger-Trayner et al., 2014; Pyrko et al., 2017; Pyrko et al., 2019; Lave and Wenger, 1991; Nicolini et al., 2022) . Building upon the definition of communities of practice as "groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly" (Wenger-Trayner and Wenger-Trayner, 2015), this explanation of communities of practice as social learning systems recognises the role of identity, social standing within a group, and shared ideas and goals. The community which was explored during this research fulfils these criteria on several levels, acting as a place where members can connect with similar people, obtain information on autism, and engage in sharing information with the objective of increasing societal understanding and acceptance.

These seemingly casual, informal interactions between members can have great value in terms of learning (Brown and Duguid, 1991), and is enabled by the ease of access to digital social networks currently available; although communicating virtually is not without its drawbacks and restrictions (Brown and Duguid, 2002). For the purposes of this research, the focus is primarily on if or how the specific community in question featured in the participants' liminal journeys. This involves some initial exploration around whether what is referred to as the Twitter autistic community is, indeed, a community in the sense of communities of practice, or a network.

Where the term "communities of practice" is used in this thesis, it is used in relation to social learning, rather than specifically in an organisational context. The use of communities of practice here stems from the concept's inclusion in research relating to the two primary topics which are brought together here, namely autism, where communities of practice in autism education and practice have been discussed by Guldberg et al. (2019), and threshold concepts, where communities of practice are mentioned and discussed often, for example as an illustration of the process view of threshold concept acquisition (Walker, 2012) and (O'Mahony et al., 2014).

The four premises of learning and knowledge which are outlined by Wenger (1998) are also at the core of this research, founded as it is on a basis that knowledge and learning are personal, but also developed through our interactions. These four premises are as follows:

1. We are social beings. Far from being trivially true, this fact is a central aspect of learning
2. Knowledge is a matter of competence with respect to valued enterprises – such as singing in tune, discovering scientific facts, fixing machines, writing poetry, being convivial, growing up as a boy or a girl, and so forth
3. Knowing is a matter of participating in the pursuit of such enterprises, that is, of active engagement in the world
4. Meaning – our ability to experience the world and our engagement with it as meaningful – is ultimately what learning is to produce (Wenger, 1998 : 4)

No judgement is made as yet as to whether or not a community of practice was at play amongst the group which is studied during this research, but the presence of elements of a potential community of practice is tentatively explored throughout.

2.6 Sensemaking Literature Review

Sensemaking (Weick, 1995; Weick, 1979) is another area which was not originally intended to be included in this research, but became essential while reflecting upon the interview data. Much of the social network analysis which has been conducted to date has also been carried out with sensemaking in mind – the intention was not to simply see how the Twitter networks in question were constructed, but to understand why, and how this related to the liminal journey which had been undertaken by each participant (see Section 4.4.3).

As forms a strong theme throughout this thesis, my positioning as an insider within the autistic community (see Harrington et al., 2020) which served as the context for this research afforded me a level of insight into the conversations and interactions I had with other autistic people in a way which could not have been achieved otherwise. That is, as one who had come to the realisation about my own neurodivergence as an adult, I could make sense of their stories in a way which was only possible with that specific experience. While this in itself had been clear since earlier in the research, sensemaking appeared to offer a way in which I could explain to others, who do not have the same experiences, how I could relate and interpret what I did from what was *not* said, as much as I could from what was said.

It is essential to be clear that, while autistic people and their communities are what I studied in this instance, this is simply the context for the research. The autistic community (or lack of, as will be explained later), does not serve as confirmation that autistic, or otherwise neurodivergent people are different to those who are neurotypical, but rather as an illustration that we are the same. This is where sensemaking became important, it is easy to say that the autistic participants were similar, or even to say that they were different from one another, but it is quite another to effectively explain that neurodivergent people are still just people.

Through considering the stories of these participants, and myself, in terms of sensemaking, my intention is to provide a relatable account of how much impairment and othering is a result of social construction, and a general reluctance to accept that what is different is not inherently wrong or bad. While this statement possibly does not appear particularly controversial or outlandish on the face of it, the more time I spend exploring and embracing my own neurodivergence, the clearer it becomes that greater understanding is needed on both sides.

2.6.1 Sensemaking and Neurodiversity

Sensemaking is a process people engage in when their experience is different to what was expected (Maitlis and Christianson, 2014). As this research has been based upon the lived experiences of late-diagnosed autistic adults, it is fair to say that reality differing wildly from expectations has been a recurring theme throughout, as has the need to make sense of this new reality which has been uncovered. Although the research started out with studying autistic people as a community, where members engaged in a form of sensemaking together, the primary focus is on the journey towards self-acceptance that was taken by each participant as an individual. That said, as may be expected when studying human behaviour in any context, the communities, networks, and individual actors within this are both intertwined and independent, and impossible to fully separate, given that the action within the communities will impact upon the behaviour and perspective of the individual going forward, and vice versa.

As has been discussed earlier in this literature review (see Section 2.2.4) contemporary autism research has already touched upon some overlap between how autistic people as a group work and learn together towards improving societal understanding and awareness of autism and neurodivergence, and concepts which are used in organisational and management studies, such as communities of practice. I have introduced this in the relevant section of this literature review, and here will outline how there is also an overlap between autism and neurodiversity literature and activism, and sensemaking.

Within organisational and management literature, there is much said about how sensemaking is used as people work to understand events which are confusing or otherwise unexpected through attempting to make sense of what has happened, and what is continuing to unfold around them (Weick, 1995; Weick, 1979; Weick et al., 2005). While engaged in sensemaking, individuals will extract cues from their environment and surroundings, interpreting these stimuli, and constructing a plausible explanation of what is going on (Weick, 1995). The key word here is "plausible" – sensemaking does not involve an absolute truth about a certain reality, but is a way of understanding events in a way which is plausible to those involved. Sensemaking also goes far beyond this interpretation, into taking action and constructing the environment (Weick, 1995).

Much emphasis in extant sensemaking literature is place upon engaging in sensemaking in an organisational context (Cornelissen et al., 2012; Monin et al., 2013; Hernes and Maitlis, 2010; Navis and Glynn, 2011; Rudolph et al., 2009; Whiteman and Cooper, 2011), particularly in terms of strategic change and decision making (Gioia and Thomas, 1996; Rerup and Feldman, 2011), creativity and innovation, and organisational learning, for example (Drazin et al., 1999; Hill and Levenhagen, 1995; Catino and Patriotta, 2013; Gephart, 1993; Weick, 1988; Weick, 1990; Weick, 1993). This organisational approach, particularly with regards to learning, applies here while discussing the autistic community(-ies) (see Table 6) and their role in the journey towards self-acceptance, which is undoubtedly an important one, and will be touched upon throughout this thesis. However, my primary interest is in the individual learning which took place, both within this community or otherwise. As such, in this context, the term "sensemaking" is used more to mean that which is engaged with individually and socially

(Klein et al., 2006; Louis, 1980; Starbuck and Milliken, 1988; Maitlis, 2005; Weick, 1995; Weick et al., 2005).

2.6.2 Sensemaking and Identity

Identity is at the core of this research, and it is fair to say that most, if not all, of the sensemaking from all perspectives has been centred on discovering and forging identities. Identity has been a key feature in sensemaking literature, forming a core concern of sensemaking as outlined by Weick (1995), and it can be seen throughout this research in terms of:

- My sensemaking around my own neurodivergence, as is described in the autoethnographic component, and again as I reflect upon the process at a later stage
- The participants' sensemaking around their own selves, and how they worked towards establishing their own identities and senses of self, either following late diagnosis or the realisation of neurodivergence which prompted them to seek the diagnoses to begin with
- The role of the autistic community in enabling and encouraging autistic people to forge their identities based in their new knowledge about themselves. More will be discussed about this point later, particularly how it is not necessarily a good or helpful aspect

Obtaining a diagnosis of autism or other form of neurodivergence in adult life can be considered a traumatic experience, triggering sensemaking as the negative emotion experienced by an individual leads them to questioning themselves (Pals and McAdams, 2004; Maitlis, 2009). This is not to suggest that it is an entirely negative experience on the whole, but it is undoubtedly distressing. As stated by, for example, Maitlis (2009), Neimeyer et al (2002), and Ainsworth and Hardy (2004) an emotional event of this magnitude can threaten the sense of self, prompting sensemaking, which is inextricably linked with emotions.

While pursuing a "new" identity armed with this newfound knowledge, individuals can connect with others in a similar position, using these new social connections to construct their renewed sense of self. As identity is always socially constructed, the journey towards embracing this identity can be seen in the language used by the individuals concerned (Ainsworth and Hardy, 2004; Karreman and Alvesson, 2001), the way in which each individual tells their story, and the narrative they adopt while recounting their experiences to others (Lieblich et al., 1998; McAdams, 1993).

Each of these elements are fundamental to sensemaking, as the individual strives to maintain "continuity with who they have been, while also integrating reality of a changed world into their conception of who they must now be" (Neimeyer et al., 2002: 236). Finally, the assertion made by Maitlis (2009) that identity is dynamic, and continually developed, legitimised and modified through our interactions with others, can be seen as the role of the autistic community as a member works towards self-acceptance. This identity exists both within and outside of the community.

In summary, the seven properties of sensemaking (Weick, 1995), that is:

- Grounded in identity construction
- Retrospection
- Enactive of sensible environments
- Social
- Ongoing
- Focused on and by extracted cues
- Driven by plausibility rather than accuracy

are each embedded throughout this thesis, and the research which was conducted prior to it, as will become evident as the discussion unfolds.

For clarity, the definition of sensemaking offered by Maitlis and Christianson (2014) is what I consider closest to how it has been enacted throughout this study, where sensemaking has been engaged with as "a process, prompted by violated expectations, that involves attending to and bracketing cues in the environment, creating intersubjective meaning through cycles of interpretation and action, and thereby enacting a more ordered environment from which further cues can be drawn" (Maitlis and Christianson, 2014: 67). In this regard, sensemaking has been engaged with as both a way of analysing and reflecting upon the data collected during the empirical phases of this research, to facilitate the articulation and expression of my autoethnography, and in understanding how each of these worked in conjunction with the other.

2.6.3 Sensemaking and Social Network Analysis

Although the majority of existing sensemaking literature appears to predominantly use qualitative methods, it is not unheard of for sensemaking research to involve mixed methods, particularly earlier works such as Gioia and Thomas (1996), and Putnam and Sorenson (1982). Making use of newer methods, such as social network analysis, can help to facilitate the construction of a fuller representation of the process which is being studied, where the ability to make sense of a phenomenon is only improved by the addition of a broader perspective and range of information. Social network analysis has previously been used by Oliver and Montgomery (2008) and Vardaman (2009) whilst studying sensemaking amongst lawyers and public policy-makers respectively, and by others such as Stieglitz et al. (2018) while exploring sensemaking on social media during extreme events. Moving more extremely towards the quantitative, Rudolph et al. (2009) used mathematical modelling to explore the relationship between the various parameters at play during sensemaking, such as initial cues, developing plausible explanations, acting upon these explanations and testing the outcome. The methodological approach which has been adopted in this particular study will be explained in more detail later in this thesis.

2.7 Synthesising the Literature

In this chapter, I have reviewed several areas of literature: namely autism, threshold concepts, knowledge levels, communities of practice, and sensemaking. Some of these areas are perhaps more obviously linked than others, however, each has played an essential role in informing and developing this research. In this final section of the chapter, I provide a synthesis of the literature, through presenting a conceptual framework for the arguments I put forward throughout this thesis. One of the key ways in which I do this is by outlining how, in several of these areas, recognition is given to the importance of community and social environments in learning. Threshold concept literature consistently emphasises that it is mastery of the requisite threshold concept which enables membership of a particular community, however, this does not appear to necessarily be where the transformational learning stops. In fact, this research strongly suggests that this community (or network) is where the transformation is enabled. In this synthesis, I will outline how each of these areas can be combined to obtain a more in-depth illustration of how this transformational learning has occurred with regards to this particular phenomenon.

2.7.1 Learning to Join the Community, and Again to Leave

If we are to take threshold concept literature at face value, the end result of mastering a threshold concept is becoming a member of a community, profession, or other group (Meyer and Land, 2003). Strong emphasis is placed upon the effect to an individual's identity while progressing through the liminal phase, and while finally reaching the post-liminal, where the new identity is in situ. Conversely, communities of practice literature focuses on the learning which happens within a community, and how it is the ability to think together, with each individual contributing their own expertise, which facilitates significant learning (Lave and Wenger, 1991; Wenger, 2010; Wenger, 1998; Wenger-Trayner et al., 2014) , while that which informed the development of knowledge levels (Dörfler et al., 2009) posits knowledge as inherently personal. There is little, if any, dispute that knowledge and learning are personal, but there is some contradiction between these areas in terms of the role of the community in the learning process.

As I began this research with some background of threshold concepts, and very little of communities of practice, my initial assumption (once I had reached the point of identifying self-acceptance following a late diagnosis as a potential threshold concept) was that achieving this acceptance, and thereby gaining membership to the autistic community would essentially illustrate the liminal journey. Speaking to autistic adults about their experiences soon revealed that, while the autistic community is invaluable and there are huge benefits to be had from interacting with other autistic people, it was not everything. Yes, they had learned a lot about themselves, and shifted their perspective significantly in order to find their place within this community, but there was still more learning and growing to be done from there. This is considered in more detail in Sections 4.3.6 and 5.3, but it is what prompted me to think that there was more than just acceptance of neurodivergence involved with self-acceptance, and that the further learning and development done amongst other autistic people was equally as important a step in this particular liminal journey.

Perhaps the threshold concept explored by this research is, therefore, better described as “yes, I am autistic, but autistic is not all I am”. It is this constantly evolving identity and sense of self which is at the heart of self-acceptance. Indeed, self-acceptance itself is not static, and will continue to change and evolve even once achieved. This evolving sense of self and identity is illustrated in Figure 15 below.

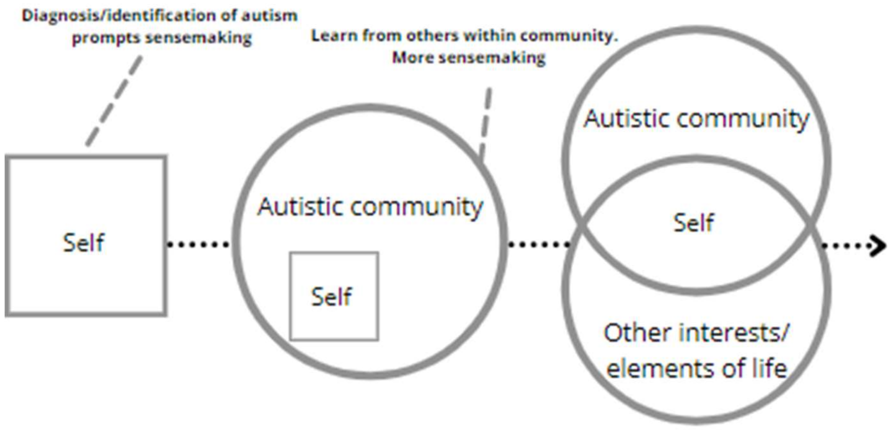


Figure 15 - Evolving sense of self and identity

3. Methodological Approach

The reasons behind why I have chosen to study this topic, and the underlying research problem (as a broad concept, in contrast with the more specific research question) have been discussed in earlier chapters. Although the research problem has broadly remained the same since the outset, the research itself (including the more specific research question) has evolved over time, and the methodological approach along with it. As the motivation for researching an autism-related topic stemmed from personal experience rather than a specific gap in the literature – although there was a gap in that threshold concepts had not been studied with explicit focus on neurodivergence of any kind – it has evolved over time. While this chapter will outline the methods initially proposed alongside those that are being used, this introduction will serve as an overview of this evolution and how my research has been affected. I will also discuss my philosophical stance, again in relation to how it has evolved and influenced the methodological approach taken.

3.1 Initial Direction of Research

The initial intention for my research involved building on that which I had done during a research internship, and subsequently my undergraduate dissertation, on threshold concepts (Meyer and Land, 2003) and how they may occur as one progresses through the various knowledge levels outlined by Dörfler et al (2009). As neither of these had been explored in terms of the autistic mind, this appeared to be a logical path to take, particularly as my eldest son is autistic.

The initial methodological approach proposed at this early stage of the research involved observing how my son learned, and speaking to autistic people to gain some first-hand insight into how they had experienced threshold concepts. As the majority of the population are (at least currently believed to be) neurotypical, most of the research done into learning, and threshold concepts to be more specific, is focused on the neurotypical mind as seen by neurotypical people. While it may well be that the change induced by grasping a threshold concept presents identically on an external level in both neurotypical and neurodivergent people, I felt as though this was something to be explored. Of course, the external presentation is not a full representation of the process, meaning that the first-hand accounts were required to gain a more accurate insight.

At that early stage, my knowledge of autism was limited to what I had learned through navigating the diagnosis process with my son, and attending various events and groups run by a local autism charity. Indeed, I had not heard the words “neurotypical”, “neurodiverse”, or “neurodivergent” at that point, never mind having any understanding of the nuanced reality of life as an autistic person.

With the intention of learning more about autism, and further exploring threshold concepts, the initial core method I planned on using was ethnography. The autistic people I had in mind initially were known accomplished autistic people such as Temple Grandin, Daniel Tammett, and my son. In other words, two of the most widely recognised autistic savants in the world, and the autistic person who was best known to me personally. In this first iteration of my study, I planned to carry out interviews alongside observation of my son, and I had a vague idea of using metaphor analysis (cf. Dodd, 2002; Dodd and de Koning, 2015) and the Gioia method (Gioia et al., 2012) for analysis. As will be outlined while describing the emergent research design which was used throughout the research, this approach did, broadly, remain part of the research, but in a somewhat different context and format. What actually did happen will be discussed throughout the remainder of this thesis, beginning with outlining the research setting.

3.2 Research Setting: Self-Acceptance in Autistic Adults

The empirical research which was conducted for this thesis involved autistic adults, who had received their diagnosis after reaching adulthood. Each of them used Twitter and was somehow connected to the community around #ActuallyAutistic. As such, each participant is a Twitter user, or was at the time of the research, who is comfortable enough with their identity as autistic to speak about it on social media, and who has achieved some level of professional success.

As there are myriad issues with obtaining a diagnosis of autism, for reasons which go beyond the scope of this research but have been briefly outlined in Section 2.2 , self-diagnosis was considered valid. Further details on measures employed to ensure "validity" of participants' belonging within the autistic community have been discussed in Section 4.3, with these mostly coming down to insiders within a group naturally being identifiable by other insiders.

The aim of the research was not to focus on the autism specifically, but rather to explore how mastering a threshold concept presents, with the autistic community as the research setting. As such, it is a crucial consideration that this research is not intended to serve as autism research in the sense that there is a tendency to assume that the inclusion of autistic or otherwise neurodivergent people means the research is focused on the neurological condition. Rather, it is research into transformational learning amongst a specific group of people, with self-acceptance of a new identity following diagnosis serving as the threshold concept in question.

3.3 Philosophical Framing

Given that this research is participatory autism research, in so much as it is research into the autistic community conducted by an autistic researcher, and co-created alongside participants as the research progressed, but also not what tends to be typically considered autism research, it was difficult to identify a philosophical standpoint which adequately reflected my perspective. In this section, I will discuss how I moved back and forwards between social constructionism and critical realism, before arriving at what can perhaps more accurately be described as "critical relativism". The approach which I adopted is outlined and discussed in more detail in Section 3.4. Some of the detail which is included here may seem somewhat redundant in that it outlines what was *not* used, but I believe it is essential to understand why certain approaches were not progressed, in order to understand why others were.

3.3.1 Social Constructionism or Critical Realism?

It is impossible to have no philosophy, with the opposite of adopting a philosophy being adopting a bad philosophy (Dobson, 2001), as there is a philosophical aspect to all actions, whether implicit or otherwise. There is no philosophy-neutral way to formulate a research problem in preparation for searching for a philosophy that fits. Due to this, it is inevitable that it is difficult to work out my philosophical approach and formulate the problem at the same time. Coupled with the fact that my research was continually evolving, this may be the conundrum at the heart of the difficulties I have had in definitively choosing a paradigm and, therefore, research methods which were appropriate for this study. I intuitively knew what I wanted to research; I just did not know which paradigm could accept it as I saw it.

The philosophical standpoint one adopts while considering any issue will be affected by prior knowledge and beliefs, and becoming aware of what these beliefs are, has been an essential part of my research to date, resulting in at least one significant shift in perspective. In fact, it is perhaps more accurate to say that this is ongoing, as I do not profess to have a full understanding of neurodiversity, transformational learning or, indeed, myself. Perhaps this is why my supervisor says that I have to stop doing my PhD, as I can never finish it…

Had I been conducting autism research in the form of researching purely to further understanding and acceptance of autistic people, this would likely have been a significantly more straightforward decision. Having undergone, and continuing to undergo, some significant paradigm shifts in recent years, the neurodiversity focus of the contemporary autism research with which I align myself involves a social constructionist perspective, although described as social constructivism within the sociology field in which it exists. Classic autism research views autism as a cluster of deficits preventing an autistic person from being truly human, and searches for ways in which to treat, cure, or even eradicate autism (and, therefore, autistic people). Participatory autism research, conversely, focuses on the positives of being autistic, flipping those perceived deficits into strengths, and highlighting that many of the issues are societal, not autism itself, although does not deny that the difficulties exist.

This social constructionist approach, as I see it, is not in any sort of self-denial, it is comprehensive, inclusive, and meaningful. From this perspective, autism is an example of natural human variation, a different operating system rather than a broken machine (J., 2014; Endow, 2017). Additionally, as these models focus on the impairments and deficits of autistic people, society in general has a distinct lack of understanding of the advantages of thinking differently. For example, one prominent model is that of weak central coherence (Jolliffe and Baron-Cohen, 1999) which states that the inability to see the big picture is a deficit amongst autistic people; while viewing this from the perspective that noticing finer details is, in fact, a strength, paints an entirely different picture (Mottron et al., 2006). These are very brief overviews of the problems with autism research, and the motivation behind a move towards participatory autism research. I absolutely agree with this approach, but it applies to just one part of my research – the setting in the autistic community.

My primary focus is on threshold concepts, transformational learning, and how these present, and this required expanding my perspective beyond simply an understanding of what autism is, towards an understanding of autistic minds progressing through the liminal journey. However, the openminded approach, the attempt to be comprehensive and inclusive, and most importantly – meaningful, are principles of social constructionism that I adhere to throughout.

These problematic features of traditional autism research, and their resulting impact on practice, are generally believed to stem from one fact – this prevalent form of autism research rarely involves autistic people (Milton and Bracher, 2013), other than as an oddity to be observed. In contrast, although still forming a small proportion of research in the field, participatory autism research is being conducted by an ever-increasing number of autistic academics, each of whom have obvious personal reasons for pursuing a more accurate societal view of autism. For example, Damian Milton's work on double empathy (Milton, 2012a) explains that autistic people understand other autistic people more easily, just as non-autistic people have a greater understanding of other non-autistic people. In other words, the fact that autism research has not historically included autistic people makes it impossible for it to be accurate, as highlighted by the relatively small number of participatory studies completed to date (Milton et al., 2019). I fully agree with this view, and intend to ensure all aspects of my research are participatory, however, am not convinced that social constructionism alone is the right approach for me in this particular study.

Social constructionism (Burr, 2003; Burr and Dick, 2017), based, as it is, on the notion that we, as humans, construct the world through a series of interactions, practices, and social norms, is undoubtedly relevant to participatory autism research. The primary discourse of participatory autism researchers is of autism as a social disability (see Glossary), whereby we, as autistic people, are not inherently disabled by being autistic, but rather by the series of social constructs which we must overcome daily. Only through challenging these norms, ideally through a shift towards autism research being conducted by autistic researchers, can the reality of autism be uncovered and understood. Of course, this is where an extreme version of ‘pure’ social constructionism also becomes problematic, given that it does not allow for a reality as such, but a series of individual realities.

While I, as both researcher and individual, understand that we each have our own perspectives on the world, which will inevitably mean that our perception of reality is different, my struggle occurs when attempting to reconcile this with producing meaningful research, with the potential to influence change. In my view, pure social constructionism is too subjective for this purpose, allowing too much freedom and subjectivity into how “reality” can be interpreted. In a rigorously pursued pure social constructionism, any opinion could be equally valid; in my view, while there are many possible ways of interpreting the world (and constructing it by those means), there are also inaccurate opinions, such as the previously described external, mechanistic, positivistic, etc. view of autism. While the points raised by social constructionists about the power of the language we choose to use and the importance of the way in which we interact with one another is certainly relevant while conducting participatory research, there appears to be something essential lacking. Perhaps it is more fitting to say that there is something essential to be added.

Perhaps one of the most impactful obstacles I have encountered along my research journey to date is the juxtaposition between my personal philosophy and my research philosophy. While I, on the whole, agree with the social constructionism approach of other participatory autism researchers, this is in some conflict with my general world view, which tends more towards there being a ‘truth’, and not simply shades of grey. Somewhat ironically, it is perhaps my autistic traits which both contribute to this personal philosophy, and embrace the dominant research philosophy. In an attempt to reconcile these viewpoints without compromising on the values and ethics behind my research, one alternative which I have considered while reading about various research philosophies is that of critical realism.

Offering some middle ground between believing in an absolute truth, and being overly open to interpretation of various phenomena and events, critical realists recognise that there is some reality which is independent of our beliefs and personal perspectives, but also that these experiences have value, and that our awareness and knowledge do have an impact (Roberts, 2001). As the name suggests, however, critical realism does involve being critical, and it is this aspect of the philosophy which most closely captures my own approach. Critical realism did allow for another perspective on my research, although I again came to a point where it felt as though something essential was lacking. Throughout my research, it appeared that unnecessary limitations were being imposed by whichever paradigm I attempted to adopt as my lens.

My current feeling on the matter is that neither critical realism nor social constructionism are a true fit, and a new paradigm somewhere between the two would be very much appreciated, although the following perspective on critical realism does, appeal: “We agree with interpretivists who point out that knowledge is a social and historical product and that “facts” come to us laden with theory. We affirm the existence and importance of the subjective, the phenomenological, and the meaning-making at the centre of social life. Our aim is to register and “transcend” these processes by building theories to account for a real world that is both bounded and perceptually laden, and to test these theories in our various disciplines” (Miles, 2014: 7). After all, what use is autism-related research that cannot be put into practice to actually help autistic people?

While the social constructionist view allowed for each participant’s account to be considered valid, it did not really allow for the interrogation of these accounts, in the form of social network analysis for two reasons. Firstly, the subjective accounts of the participants should be taken at face value, as their views are what they are and the researcher cannot really know better. similar subjective accounts can be interrogated in a conversation, when the participants can repeatedly express and possibly refine their views, but not the researcher doing this alone. Secondly, although not explicitly unacceptable, the highly quantitative nature of social network analysis feels alien, as it conveys the feeling of an imposed objectivity – as it can been seen from the analysis that has been carried out, this is far from the actual case, but as the Critical Realists say, verisimilitude is more important than veracity (cf.

Bhaskar, 2009; Bhaskar, 2008). On the other hand, critical realism did allow for this, but also required a level of generalisability that was too limiting. Although philosophy in itself does not necessarily dictate methods, or even the choice between qualitative and quantitative, my research currently involves significantly more extensive use of quantitative method than is typical for a participatory autism researcher, and I am not willing to compromise the richness and depth of the findings by claiming they are generalisable beyond the subset of late-diagnosed autistic adults which has been studied, at least in terms of that particular liminal journey. The findings relating to the threshold concept model, specifically post-liminality, may well be applicable elsewhere.

While I initially intended for the project to focus on the lived experience of my son (and later myself), and other autistic people who were likely to have experienced a threshold concept, using purely qualitative methods, this has now been extended to include some quantitative elements. What started as a plan to conduct metaphor analysis on interviews, still does just that, but in conjunction with text analysis of Twitter data. On one hand, this may not appear to be a major shift, given that it remains text analysis of first-hand accounts of lived experience. On the other, I am now using the volume of Twitter data to add an element of authenticity and depth, which cannot fully be obtained from a small number of interviews – in this case, at least. The pool of participants remained self-selective, given that it was limited to openly autistic people who choose to speak about their experiences.

With this in mind, what most accurately describes my perspective is phenomenal theorizing, or phenomenon-driven theorizing (cf. Ployhart and Bartunek, 2019; Bas et al., 2022), where no specific lens is adopted. When any lens is chosen through which to observe a phenomenon, the limitations of that lens are imposed onto the research. A researcher committed to observing through a lens can only ever see what that lens allows. Rather than imposing such restrictions onto my work, I instead focused on the phenomenon itself, and allowed what I learned from the phenomenon to guide each stage of the research. For example, when initial reading suggested that I may not be as far removed from the topic as I had believed, I explored (and subsequently embraced) my own *insiderness* (see page 125). When Twitter communication appeared to hold some significance, I explored several methods of investigating this, some with more success than others. These are all discussed in more depth throughout this thesis, but can all be described as examples of the flexibility and adaptability afforded by phenomenal theorizing. When taking this approach, uncertainty is an opportunity, and the only limitation is what can be learned from the phenomenon itself.

To give an example of how the reflexivity allowed by this approach enhanced my research; while it was essential for me to immerse myself in autism research in order to fully understand what was around me – after all, although I have been an insider amongst the autistic people I have been interacting with, I did not know this until my research was already underway. Alongside gaining an insight into the experiences of autistic people in general, and the impact of existing research and practice upon their experiences, I had to understand how this worked in terms of myself too. I reflect upon this process in Chapter 7, however, what is relevant at this point is how becoming able to separate (or, perhaps, consolidate) my personal investment and interest in autism and neurodiversity from the aims of my research enabled me to alter my philosophical standpoint from which to consider and discuss it.

Although not strictly autism research, in that I am not looking at what autism "is", this study constitutes participatory autism research in that it has been conducted by an autistic researcher working, and co-creating, with autistic participants, while exploring threshold concepts in an autistic context. Due the above-described process, I have arrived at a philosophical and methodological framing allowing for an in-depth exploration of threshold concepts and associated community membership. The work which I have done on this may contribute towards furthering understanding and acceptance of neurodiversity, and certainly provides some insight into transformational learning amongst a subset of neurodivergent people.

However, the insights from this study look promising to be valid beyond the scope of autistic or neurodivergent people; leading to a better understanding of the threshold concept experience/journey, which was the purpose of my research in the first place. In line with this focus, I consider myself to be an *autistic* researcher, not an *autism* researcher. This may appear to be a quibble over semantics, but goes a long way towards explaining why it was so difficult to define my research philosophical stance.

3.3.2 Combining Bayesianism and Reflexivity in Interpretivist Research

In these later stages of the research, there remains no existing philosophical standpoint with which I can fully align myself and my work. As discussed in section 3.3.1, critical realism is too close to the positivistic, and social constructionism is too far in the other direction (or no direction?). While both do allow some level of flexibility, I do not believe that my approach is represented by either. Rather, it is more aligned with phenomenal theorizing (see page 106), where no single philosophical lens is adopted, in recognition that doing so immediately imposes limitation. As such, I have described my approach as quantitative interpretivism, drawing upon Bayesianism and reflexivity to combine both quantitative and qualitative methods to gain a richer and more meaningful understanding of the lived experience of participants. This approach is not unique, but it is unusual enough to warrant attention and explanation (see Harrington et al., 2021).

In Section 3.9, I discuss the merits of using a Bayesian philosophy to incorporate quantitative methods into a qualitative study, as well as addressing some of the expected criticisms of taking such an approach. This has been covered separately from the main philosophical framing of the research, as it appeared to make more sense to discuss following the introduction of the quantitative methods.

3.4 Research Design

As I discuss throughout this thesis, an emergent research design (Lincoln and Guba, 1985) has been utilised while conducting this research. The philosophical underpinnings of my research have been outlined in the previous section, where I explained the difficulties which I had faced in positioning this research in a way which both allowed the participatory approach to autism and neurodiversity research that is imperative to increasing understanding, and an exploration into learning within communities and networks which goes beyond what people express or, indeed, are aware of themselves. This was undoubtedly complicated by my own dual roles as researcher and as participant, although these terms do not adequately convey the roles in reality. Through taking a reflexive approach, which was flexible, emergent, and opportunistic, I arrived at a combination of methods that both reflects my philosophical assumptions and enables the uncovering of the kind of meaningful insights I had hoped to achieve.

Due to the nature of this research, and my philosophical standpoint, there has been no aim to arrive at findings which are generalizable. Learning and identity are fluid and continually evolving, so it is unlikely that even the same group of participants would give exactly the same accounts of their own experiences if interviewed again. Of course, there are elements which are generalizable in a broad way, such as mastering a threshold concept triggering a shift in perspective, for example, or achieving self-acceptance being a largely positive experience that helped a person find where they belonged. In other words, the learning can be generalised, but not the immediate findings (Stierand and Dörfler, 2012; Dörfler and Stierand, 2019). What I have been seeking here is plausibility, where the findings and the intuitive development of the research made sense in the given context.

As I discuss throughout this thesis, the research design evolved continually as I learned more about the topic, and unexpected new avenues of inquiry were made available to me, as indicated in the principle of research indirection (Dörfler et al., 2018). This involved using tried-and-tested methods, and tweaking and pivoting when I discovered that these did not quite fit with what I had to work with, and what I wanted to achieve. A brief overview of the research design is outlined in Figure 16 below, although it is impossible to fully capture how intertwined all elements of the research were in reality, and just how complex a process this was.

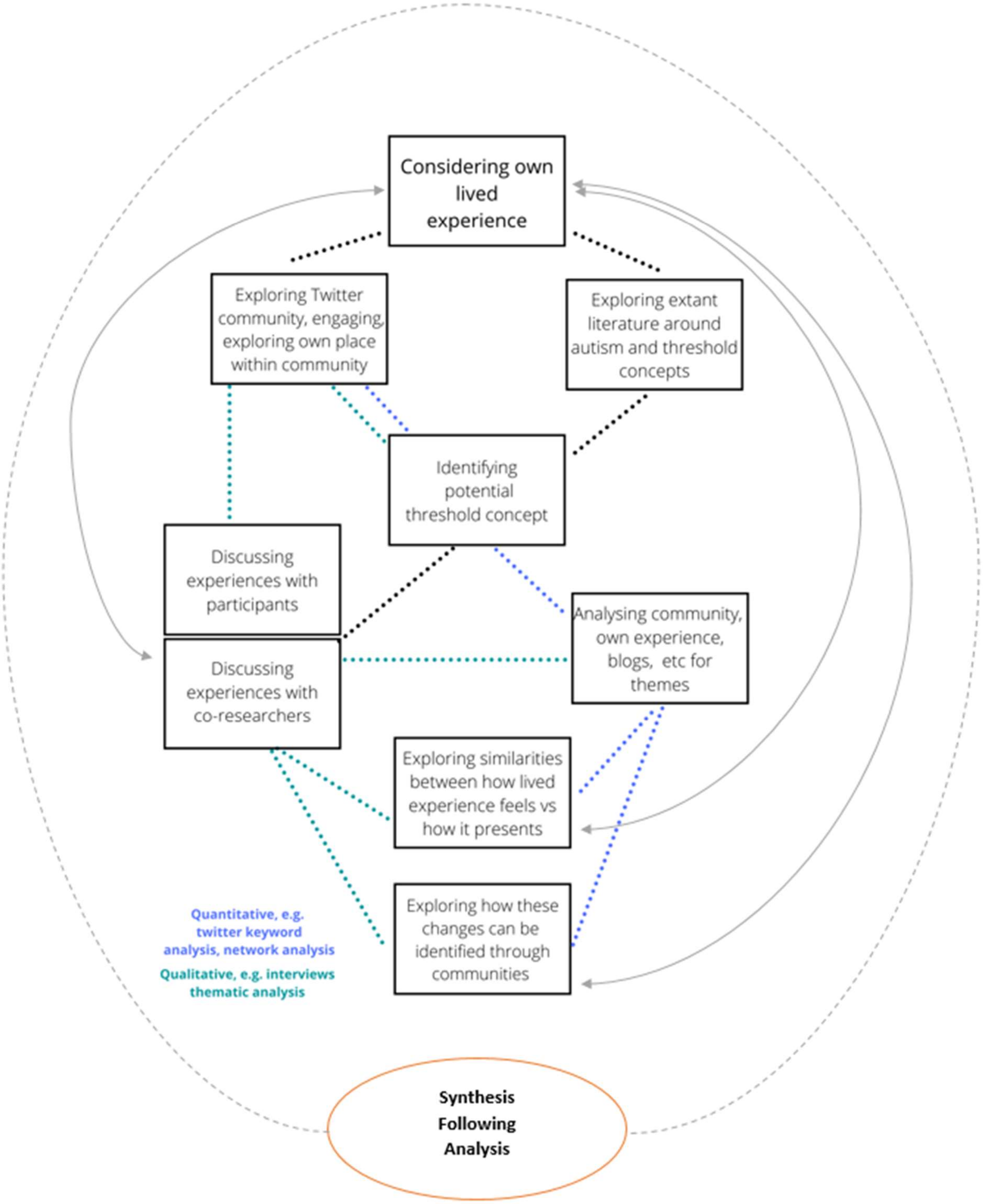


Figure 16 - Overview of research design

As my research involves autistic and otherwise neurodivergent people, but does not focus on the neurodivergence itself, but rather learning within a setting where people are neurodivergent, there were, to my knowledge, no previous studies to draw upon. There is research about autism (see Section 2.2), there is research about threshold concepts and transformational learning (see Section 2.3), and there is research about the personal nature of knowledge (Polanyi, 2002), but bringing the three together required some level of trial, error, and intuitive judgement when it came to research design.

I did, of course, begin the research with assumptions. These included an expectation that threshold concepts would present somewhat differently in those who think differently, and indeed that it would be important that the participants were autistic. It is, indisputably, important that they are autistic, but not in the ways in which I had initially assumed. Through immersing myself in this community of which I unexpectedly found myself a member, and remaining willing to be guided in different directions as the research progressed, this is broadly how the research design came to be.

I am in no doubt whatsoever that my own neurodivergence is what made this research possible, at least, in the form in which it happened. This served both to establish myself within the community, although I am not entirely comfortable with this term as it suggests I was there for a purpose. The trust I gained from other community members is undoubtedly due to being an insider, and recognised as one of their own, but it was not at all an engineered positioning to benefit the research. Just as I was speaking to participants about their own experiences regarding late-diagnosis, I was undergoing my own. As such, the research was co-created with other members of the autistic community, both consciously and unconsciously. This is why I am comfortable with labelling it a form of participatory autism research, or a participatory autoethnography (Harrington et al., 2020).

As is quite fitting for research which involves a marginalised group of people who are continually told they are “not quite” fitting in enough, “not quite” conforming to expectations enough, and in some cases “not quite” autistic enough either, this research has involved combining elements of a number of methods which are “not quite” what I needed while exploring this transformational learning through an ongoing process of sensemaking, where emotions played a key role in understanding and interpretation. I outline the specific research methods used shortly, following an overview of the ethical considerations.

Before I continue to discuss the different research methods which were combined during this exploration of threshold concepts in late-diagnosed autistic people, it seems prudent to outline what exactly I mean by the term “emergent research design”. In short, it means that this was a process, over several years, of continually revisiting and challenging my own previous assumptions in light of what I had most recently learned. In turn, what I have most recently learned affected in which way I continue the research process. In order to do this, I had to accept that there was no way of concretely setting out what would be done, when it would be done, and what the intended outcomes of those actions would be, in line with the principle of research indirection (Dörfler et al., 2018). Rather, my ultimate intention was to gain a better understanding of this phenomenon within the subset of autistic people to which I belong, employing whichever methods seemed appropriate and relevant at a particular stage. In doing so, I explored both the individual and community aspects of this transformational learning journey, and how they each impacted upon the other.

The emergent research design which was employed throughout this research can perhaps be best described as aligning with the emergent case study research discussed by Lee and Saunders (2017), as illustrated in Figure 17. A case study approach was deemed appropriate for this research due to the flexibility this allows, particularly as a case can be defined in a way which is appropriate for a given context. In this context, considering the people involved as cases provided a way in which to explore the multiple characteristics of each person, and the rich descriptions from various dimensions of the phenomenon which was being explored .

Contrary to the more traditional linear approach to case study research, whereby the research is fully planned in advance, emergent case study research has, in this instance, enabled me to study my own experience as a late-diagnosed autistic person traversing the path towards self-acceptance, and those of the participants sharing their accounts of a similar journey. Given how rare research involving autistic accounts of autistic experience remains, it was impossible to conduct meaningful and insightful research into this topic without maintaining an open mind towards potential changes of direction. This is made even more essential when my own previously unknown status as a member of this community became known. The new understanding which I gained at each stage of the research was incorporated into subsequent stages, which, in turn, involved revisiting earlier stages.

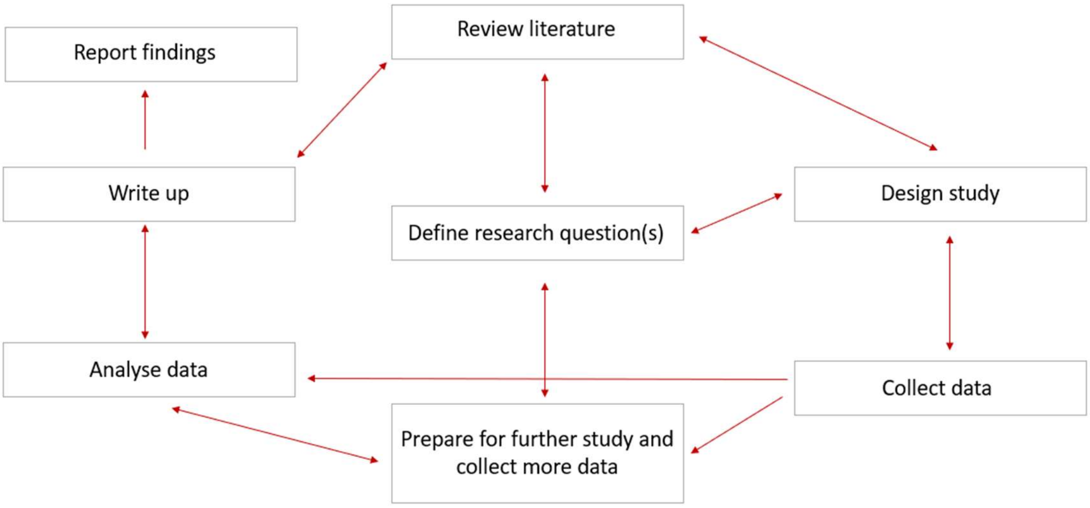


Figure 17 - Emergent approach. Adapted from Lee and Saunders (2017)

While this research has not, perhaps, involved case studies as they are commonly known in business and management education, it could be said that each participant (including myself) told their own story, which acted as a type of case study while studying the liminal journey towards self-acceptance as a late-diagnosed autistic. My learning of my own neurodivergence early in the research project triggered the first instance of emergence in the research design, as it became evident that my perspective on the topic was somewhat different to expected. At this point, the research question, such that it was, shifted from looking at how threshold concepts presented in autistic adults (where I was an outsider researcher looking into the group), to looking at threshold concepts in a group to which I belonged. The research question itself underwent a process of evolution throughout the study, in recognition of the strong potential of doing so rather than deciding upon an absolute research question in advance (cf. Stake, 1995).

As is discussed throughout this thesis, this was not a one-off change leading to a straightforward study of how this form of transformation learning occurred within a specified group of people, as it may have been if focusing on a particular topic or discipline, but the beginning of an investigative journey that brought much more learning along with it. Firstly, my newfound knowledge about myself enabled the realisation that a useful threshold concept to at least tentatively focus on was self-acceptance. This was the first tangible example of the insight into the phenomenon that would not have been possible without my insider perspective, and served to progress the research from an abstract idea to study how threshold concepts may present in autistic people, to studying a specific threshold concept unique to those who belonged to the group in question.

This knowledge also enabled the later changes in the research, both in terms of the methods used and the interpretation of the data which was gathered from interviews, conversations, Twitter interactions and, eventually, Twitter network analysis. The emergence, in the case of this research, came in the form of reflecting upon each piece of new knowledge, and reflexively considering it alongside what had come previously, in order to draw insights and learn from the community which was being studied. As is discussed in more detail later in this thesis, this research would not have been possible without taking such a reflexive approach.

To avoid repetition later, I will not detail this further here, however, to sum up, the emergent approach which was adopted here involved accepting “we cannot control what we know and when we know it. What we can do is systematise what we do know to seek to identify relationships, and we can detail how we found out those things so that others can understand the value of that knowledge” (Lee et al., 2021: 13). Taking this approach meant that I could continually adjust what I was doing to take account of what I was learning along the way (cf. Dörfler et al., 2022; Lee et al., 2022). Conducting this research into a particular phenomenon while experiencing the phenomenon myself offered a unique opportunity, the essence of which would have been missed without such an open an emergent approach.

Table 2 - Orthodox v emergent case study research

	Orthodox	Emergent
Initial type of primary knowledge	Propositional from formal theories that are brought in from the outside	Possibly partly propositional but also derived from within the case and often experiential, empathetic, and tacit
Point of conduct of principal literature review	Outset	Throughout
Point of definition of principal research questions	Immediately after principal literature review	Any time before completion of fieldwork
Nature of choice	Integrated strategy with clear protocol	Series of strategic choices that are fluid and emergent throughout the case
Process of case	Primarily linear	Primarily iterative

To give a brief overview of how this research design fits with the characteristics of emergent case studies outlined in Table 2:

- My initial basic knowledge came from reviewing existing autism literature, alongside what I had learned over the previous decade or so of a personal interest in autism. However, that which I encountered along the way paved the way for the ongoing evolution of the research.
- While a literature review was conducted at the outset of the research, this was revisited, revised, and added to as the research progressed. For example, the addition of communities of practice and sensemaking to the initial threshold concepts, autism, and knowledge levels.

- The research question involved threshold concepts and how they present in autistic people from the outset, but underwent several changes before arriving at the final research question
- As discussed in detail throughout the thesis, numerous choices were made to enable the research to make the most of opportunities and new knowledge which arose. The iterative nature of the research is also discussed throughout.

A timeline of this emergent case study approach is provided in Table 3 below. This table does not illustrate the entirety of the research process, but the events which could, with hindsight, be described as turning points.

Table 3 - Emergence in this research

Date	Milestone	Activities	Challenges
June 2018	Research into threshold concepts in autistic adults begins with literature review	Literature review into autism. Informal interactions with autistic people on Twitter Pursuit of own diagnosis began in September 2018	Literature review into autism and threshold concepts continued. My perspective on autism had begun to evolve, and a realisation that the planned approach to the research was unsuitable became evident.
Autumn 2018	Focus turns primarily onto autism	Initial literature review impacts on perspective Recognised own lack of knowledge Immersion into contemporary participatory autism research	Currently uncertain about how to approach research. The planned approach was wrong, my previous knowledge about autism was wrong, but how to work out what was right? Focus shifted onto arriving at a definition of autism from which to explore threshold concepts.

Date	Milestone	Activities	Challenges
October 2019	Diagnostic appointment with Scottish Autism	Own experience of diagnostic process reinforces how problematic it is	Clinical experts state cannot be autistic because have children and working on PhD - reinforces fundamental misunderstandings contributing to missed and misdiagnoses. Autistic community on Twitter – clearly had much in common, beyond just feeling like outsiders or having a particular diagnosis. Self-diagnosis/self-identification is accepted amongst the autistic community in general – why is this?
November 2019	Attended Scottish Autism conference in Glasgow	Recognised by autistic academic as “well, we know you’re one of us”	Recognised sense of belonging with finding people you fit with through an autism diagnosis, (key part of threshold concept framework). Idea of self-acceptance as potential threshold concept had come to mind before, but this particular interaction solidified it. How could this be researched? Keywords and sentiment analysis on Twitter attempted

Date	Milestone	Activities	Challenges
July 2020	Interviews with participants	Sense that something was missing after reflecting upon interviews	Participants speak about finding belonging in community, but no agreement around where this community was. Each implied that autism was not it, but was a part of the process. Own experience and earlier research meant more aware of nuances in various comments. Although it could have been said at this point that self-acceptance led to belonging in a community and therefore qualified as a threshold concept, strong intuition that there was more to be investigated. Again, how to research this?
September 2020	Network analysis	Network analysis confirmed presence of inner “self” network and outer “autistic” network	Closer investigation of individual networks of participants showed that they were related, but there was more. Strong autistic in each network, but not (wholly) in closest contacts. Thoughts turned to what this meant. Clearly, there had been a threshold concept relating to self-acceptance as autistic, but this seemed to facilitate belonging in different community. What does this mean in terms of threshold concepts? Could there be an extra step in liminal journey? Revisited own journey towards self-acceptance to look for similarities, bearing in mind that identifying threshold concepts involves hindsight. Transcripts also revisited.

Date	Milestone	Activities	Challenges
9 April 2021	Interviewed as participant	Skype call with first supervisor revealed evolution of how I told my own story. Experiences are the same, but language, openness, and willing to discuss more difficult aspects changed significantly Analysis of transcript gave insight into the questions raised by interview analysis	Earlier account of my self-acceptance compared with current account, with several aspects becoming clearer. Firstly, what I said early on did not quite fit with what was happening (as I had seen from the participants), and my own networks and communities had changed along the way, consistent with what I had seen with the participants (discarding previous beliefs as part of liminal journey). The extra step in threshold concept mastery now seems even more apparent. What does this mean going forward?

While I acknowledge that taking an approach where the research methods evolved as insights were gained from initial findings may be open to criticism about seeing what I wanted to see, and moulding the research methods to fit, I would counter that it is, in fact, demonstration of a high-level of self-awareness and awareness of my research environment, which enabled me to do justice to the opportunities which arose. Bracketing (Dörfler and Stierand, 2021) was used to ensure that this potential issue did not happen. Through recognising and embracing these opportunities, I not only ensured that all available avenues of research were explored, but also that initial findings which appeared to answer the question of how threshold concepts present in autistic people were not incorrectly taken to be the entirety of the ”story”, as can happen when conducting research as an insider in a familiar context (Fleming, 2018).

3.5 Ethical Considerations

The deeply personal nature of the topics explored in this research means there have been some ethical considerations clear from the outset. To counteract these in so much as is possible without impacting on the quality of the research, participants have been assured full confidentiality, unless they request otherwise. This option has been included for the benefit of those participants who specifically want their voice to be heard, and was envisaged to apply only in a very small number of cases, if at all. The outcome of this was that several participants, who would otherwise have been unable to contribute, were enabled to add their voices to this research, which they felt passionately enough about to share deeply personal experiences.

The findings are discussed in terms of keywords and common trends, rather than in terms of any potentially identifying personal situations. As mastering a threshold concept will always follow a difficult period, there are levels of difficulty, and of how personal the scenario in question was. One of the points which is important to bear in mind when conducting this research is just how emotive the liminal phase may have been. If a participant chooses to talk about an education-related threshold concept, it may not pose any great difficulty.

However, given that I am focusing on autistic people, preliminary research, coupled with my own experience, indicates that the threshold concepts are likely to be more closely associated with highly emotional experiences – for example, my own break from traditional cultural norms when getting divorced, or identifying and accepting myself as autistic. Great care has been taken to respect the emotions which may be stirred by discussing such topics. Participants were informed of their right to withdraw from the research at any point, as some did choose to do. No information provided prior to this has been included, either in the research itself, or in the writing of this thesis.

Perhaps the most significant ethical concern related to the inclusion of my teenage son in the research. For this reason, he has been removed from the study, albeit it is likely that his experiences, and my own as his parent, do feature to some degree in my autoethnography, and they definitely shaped my preunderstandings. In terms of the autoethnography, I have made every effort to ensure that any specifics which have been included in this thesis only contain personal information of my own. While it is impossible to remove other people entirely, I have avoided any comment or speculation on other people's behaviour, discussing only from my own perspective.

Finally, where the accounts provided by two others about how they viewed my transformative experience have been included with their express permission, having allowed them the option of requesting that their accounts were not included verbatim. One account has been anonymised and presented in the form of relevant quotes only. Similarly, all Twitter data used has been done so entirely anonymously, with the exception of two professional accounts belonging to autism activists, Donald Trump's now deleted Twitter account, and the official YouTube account, each of which has been used only briefly for illustrative purposes while discussing the #ActuallyAutistic network.

Approval for this research was granted by the ethics committee of the Department of Management Science, Strathclyde Business School.

3.6 Research Methods

Now that I have provided the background to the research, outlined the research design, and the ethical considerations, I discuss the research methods which were used throughout. Due to the emergent nature of the research, there are some methods which were used before being discontinued when new knowledge revealed that they no longer fit. These methods have been included here briefly as they form part of the process of conducting this research, and enabled me to identify those which did fit. It should be noted at this point that, while several methods have been used, these all informed and were informed by one another, rather than serving as separate stages of the research; in this sense the 'combination of methods' may fall short of indicating the full complexity, but it still seems to be the most adequate term.

As I have outlined while positioning this research, the purpose here was to gain novel and meaningful insights which reflect the lived reality of the participants, not to claim that there is an objective truth or accuracy which can be applied across other groups. The flexibility of my research design allowed me to pivot and change direction when the research, and my own intuition as an insider, suggested it was necessary (Dörfler and Eden, 2014; Stierand and Dörfler, 2014; Dörfler and Eden, 2019).

I refer to this research as a “multi-modal exploration of lived experience”, rather than a mixed-methods study, in order to emphasise that I have used different theoretical and philosophical frameworks in pursuit of the meaning of the interactions, conversations, observations, and experiences which were combined to form the empirical aspect of this research. In contrast, a mixed method study would involve a combination of quantitative and qualitative methods, while multi-method studies simply mean using multiple methods that can be all qualitative or quantitative or mixed – but neither mixed method nor multi-method imply multiple perspective at a philosophical and/or theoretical level (Saunders et al., 2019) In the literature, multi-modal research has been used to combine different perspectives while exploring complex issues, such as far-right activism against immigrants (Doerr, 2017), culturally themed selective web archiving (Huc-Hepher, 2015), and the use of audio and infographics to more adequately disseminate the accounts given by research participants in qualitative studies (Chandler et al., 2015). Similarly, the use of a multi-modal approach to this research enabled a more in-depth dissemination of the accounts given by participants discussing their personal experiences. Reflecting the multiple perspectives was of key importance, given the complexity and sensitivity of the topic being explored. The methods which I have used, the intended purpose of each, and what each method added to the research are outlined in Table 4; the philosophical and theoretical perspectives are elaborated in detail in Section 3.3.

Table 4 - Methods and their value

Method	Intended Purpose	What Was Gained
Unstructured interviews	Understand first-hand accounts of lived experience	Insight into reality of liminal journey. Indication of more to be seen beyond what was explicitly communicated
Twitter keyword analysis	Identify threshold concept through use of common language	Appeared to be a failure at first, although contributed to realisation that this could not be reduced to keywords alone
Social network analysis	View Twitter from perspective other than keywords. Emphasis on communities and networks	Insight into differences between levels of Twitter community. Confirmation of what was inferred from interviews about belonging
Autoethnography	Provide a richer account of liminal journey than could be provided without compromising participants' anonymity	Richer insight as intended. Also served as tool for analysis and increasing my own understanding. Autoethnography and interviews informed each other in terms of analysing and making sense of findings

3.6.1 Working with Unstructured Interviews

The first method which was used here, and had initially been intended to be the primary method used for the research, was interviews with members of the autistic community. As this research aimed to explore the lived experience of individuals, it seemed obvious that speaking to people who had had these experiences would allow me the best insight into how the journey towards mastering a specific threshold concept was perceived by the learner themselves. The interviews were mainly unstructured and led by the participants, in order to avoid influencing their responses in so much as is possible. The participants were provided with an information sheet and some basic information on threshold concepts, as I recognised that they were unlikely to be familiar with the term, but no set questions were used.

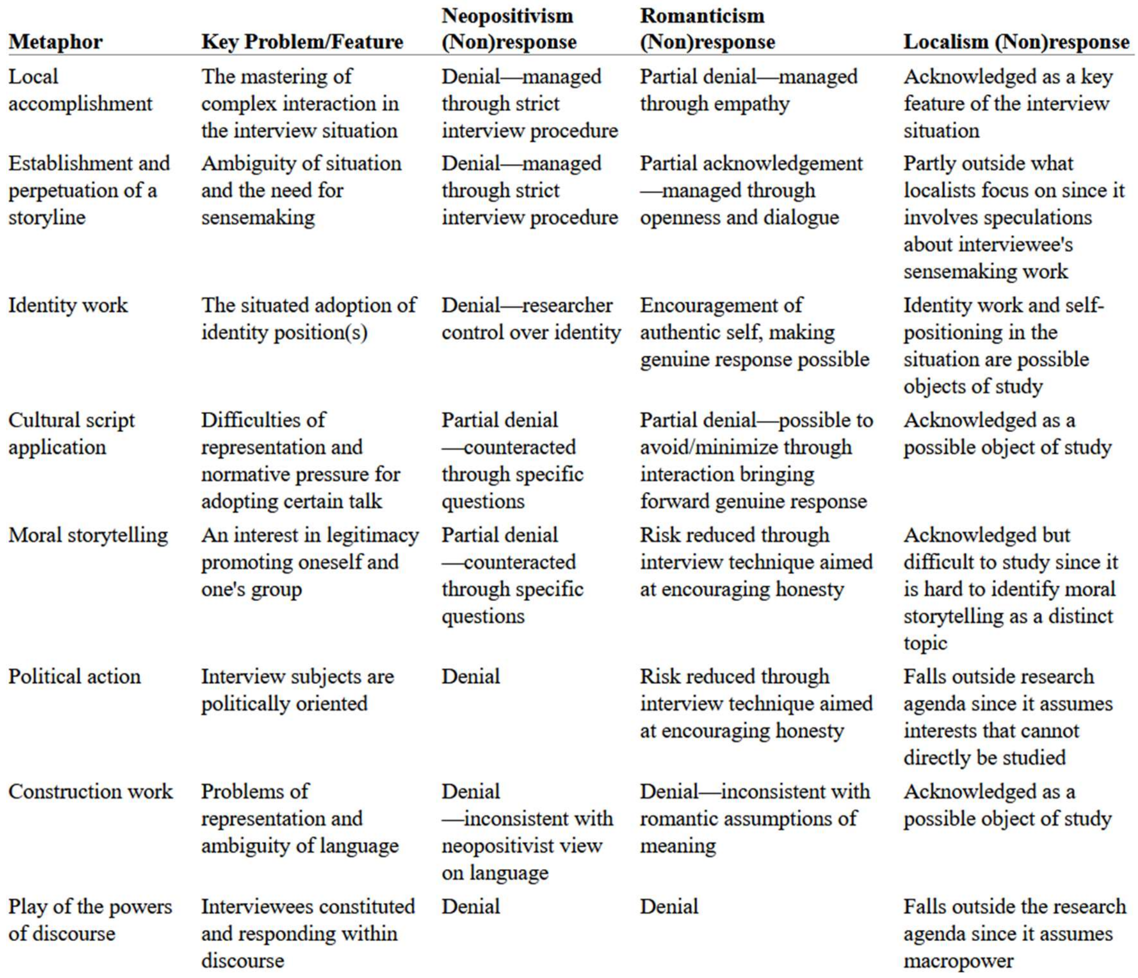
I had initially envisaged that semi-structured interviews would be used, where I devised a set of loose questions or broad themes which would guide the conversation in the required direction, but retain the flexibility to change the questions, or add additional questions during each individual interview, based on both the answers given and the non-verbal cues exhibited (Easterby-Smith et al., 2015). However, I decided upon unstructured conversation-style interviews instead, to allow the participants to control the direction of the conversation in line with their personal experiences. I was aware of the potential limitations of this approach, where the participant made assumptions about what I wanted to hear, or where the data ended up being near impossible to interpret due to the lack of direction, so had provided clear information at the outset around what my topic of interest was. I had prepared some prompts in case they were needed by the participants. So, perhaps the interviews were not entirely unstructured, but they were less structured than how semi-structured interviews are described in the methodology literature (Saunders et al., 2019; Bryman, 2015). That being said, they were broadly in line with the phenomenological interviewing discussed by (Seidman, 2006) although not following the three-interview structure recommended there.

My positioning within the autistic community did, of course, afford me a perspective from which I could understand and interpret the comments made by the participants, and also be treated with less suspicion than an outside interviewer (Bryman, 2015), but I was aware that I must also be careful not to project my own experiences and opinions during the conversations. I took the utmost care throughout to pay attention to what the participants were saying, and what they were indicating through hesitation and body language that they did not want to say. When prompts were needed, I did so by posing a question that sought clarification on previous points, rather than offering an answer or solution of my own (Charmaz, 2014).

I recognised that interviews of this kind could be very time-consuming, and that the findings may be difficult to interpret, but believed them to be the most appropriate interviewing method for this research due to the potential for incredibly rich and meaningful insights (Bryman, 2015; Saunders et al., 2019). Later conversations also included questions and topics which had arisen during the earlier conversations, in keeping with the approach of relational reflexivity which was adopted throughout (Hibbert et al., 2014). This reflexive approach utilises the space between the *otherness* of myself as a researcher (where I am interviewing the participants about their experiences), and the *insiderness* of myself as a member of the community (where I am a person with whom the participants can draw on shared qualia), with similar lived experience, (Stierand and Dörfler, 2014; Haynes, 2017) facilitating the use of my own tacit knowledge (Cunliffe, 2003) to co-create with the research participants through engaging in dialogue (Munkejord, 2009). As is mentioned throughout this thesis, my own membership of the community in question, and open-mindedness in terms of adopting an emergent and reflexive research design (see page 108), proved to be invaluable resources here.

This largely unstructured approach to interviewing is what allowed the participants to lead the conversations, as discussed in Section 4.3, and which ultimately enabled the discovery of the importance of communities, and the role of identity and social surroundings in learning and development (Wenger, 1998), and specifically to that which happens in this particular domain. A reflexive approach to analysing the interviews, which is perhaps better described as reflecting upon the interview process, was taken, in line with the assertions by, for example, (Cunliffe, 2003; Alvesson, 2003) that interview data must be considered from several angles and perspectives, rather than being taken as truth. A transpersonal aspect of reflexivity was used to bring the insights over from the autism language, which inevitably was part of the interviewing process and helped achieving those insights, to the more generic management language through discussions with my supervisors and friends (cf. Dörfler and Stierand, 2021). The value in interviews is not just in the words, but also in the metaphors used, the human interaction involved, and what can be learned from what is left unsaid.

Alvesson (2003) provides a summary of eight metaphors of interviews, from which the approach taken here most closely aligns with the romanticism (non)response of identity work, although some elements of other metaphors are also applicable. To elaborate on this a little further, the objective of the interviews was to obtain a rich and meaningful insight into the lived experiences of the participants. This could only be achieved through this encouragement of authentic self, where I did not make any attempt to guide the conversation, but allowed the participants to tell their stories in their own words, staying true to their experiences.



Metaphor	Key Problem/Feature	Neopositivism (Non)response	Romanticism (Non)response	Localism (Non)response
Local accomplishment	The mastering of complex interaction in the interview situation	Denial—managed through strict interview procedure	Partial denial—managed through empathy	Acknowledged as a key feature of the interview situation
Establishment and perpetuation of a storyline	Ambiguity of situation and the need for sensemaking	Denial—managed through strict interview procedure	Partial acknowledgement —managed through openness and dialogue	Partly outside what localists focus on since it involves speculations about interviewee's sensemaking work
Identity work	The situated adoption of identity position(s)	Denial—researcher control over identity	Encouragement of authentic self, making genuine response possible	Identity work and self-positioning in the situation are possible objects of study
Cultural script application	Difficulties of representation and normative pressure for adopting certain talk	Partial denial —counteracted through specific questions	Partial denial—possible to avoid/minimize through interaction bringing forward genuine response	Acknowledged as a possible object of study
Moral storytelling	An interest in legitimacy promoting oneself and one's group	Partial denial —counteracted through specific questions	Risk reduced through interview technique aimed at encouraging honesty	Acknowledged but difficult to study since it is hard to identify moral storytelling as a distinct topic
Political action	Interview subjects are politically oriented	Denial	Risk reduced through interview technique aimed at encouraging honesty	Falls outside research agenda since it assumes interests that cannot directly be studied
Construction work	Problems of representation and ambiguity of language	Denial —inconsistent with neopositivist view on language	Denial—inconsistent with romantic assumptions of meaning	Acknowledged as a possible object of study
Play of the powers of discourse	Interviewees constituted and responding within discourse	Denial	Denial	Falls outside the research agenda since it assumes macropower

Figure 18 - Eight Metaphors of Interviews (Alvesson, 2003)

Due to the ongoing COVID-19 restrictions, the interviews took place either over Zoom, via email conversation, or a combination of the two. The second option was made available due to the preference expressed during personal conversations I had both witnessed and participated in on Twitter, where autistic people commented on feeling more comfortable communicating in writing. This addition made the study more accessible to participants, and mindful of their individual needs (Olkin, 2004; Hollomotz, 2017). The Zoom interviews were recorded on the Zoom platform, and transcribed manually. I also made handwritten notes of points which could not be conveyed in a recording, for example, changes in body language or demeanour. Email exchanges were saved securely on university servers, along with those interview transcripts and notes.

3.6.2 Social Network Analysis

Another (meta-)method which was used when conducting the empirical element of this research was social network analysis, involving the community which has developed around the #ActuallyAutistic hashtag on Twitter (Harrington and Dörfler, 2021). Social network analysis is a form of network analysis, a quantitative approach which has been applied in a wide range of scenarios, from public health (Luke and Harris, 2007) to power distribution (Choi et al., 2003), terrorist and organised crime networks (Sparrow, 1991), water distribution systems (Yazdani and Jeffrey, 2011), and, of course, social networks (Freeman, 2004).

The history of network analysis is complex, drawing on a number of fields, however, much of the literature traces it back to mathematician Leonhard Euler (1707-1783) and the Königsberg bridge problem, for example (Newman, 2003). The purpose of network analysis is to explore how various actors interact and impact upon one another, with the specifics of this varying depending on what is being investigated. A range of centrality measures are used in variants of network analysis (Paton et al., 2017), with little universal agreement on which is most important.

While working with the Twitter social network data for this research using NodeXL, a total of 74,000 tweets containing #ActuallyAutistic were retrieved. These were analysed using eigenvector centrality to measure influence in the network, or the importance of each node (user) when considered alongside its neighbours (Parand et al., 2016). Betweenness and closeness centrality were also measured to create a better image of who was active and important within the community (Junlong and Yu, 2017; Grandjean, 2016), and to allow for visualisation. These particular measures of centrality were used due to their prevalent usage in existing social network analysis research, and maintained as they provided the illustration of the participants' networks which were relevant to the research topic in question. Clustering was also used in order to obtain illustrations of the networks and communities which the participants chose to embed themselves within, indicating where they had found belonging. Visualisations of these networks were created and stored visually, with the findings used while revisiting the interview transcripts and reflections.

While social network analysis was the only quantitative method which was included in the final combination of research methods, the decision to use it arose from a process of trial and error. The earlier stages of the more quantitative exploration of Twitter data included text analysis, and an attempt at sentiment analysis (see Harrington and Dörfler, 2020). Although these did not become core components of the research design, they were instrumental in the process of identifying those methods which did. As such, the social network analysis, in its various guises, constitutes a part of the evolving interpretation of the phenomenon in question (Cassell and Lee, 2017).

Why Twitter?

Twitter was primarily chosen due to the prolific network of autistic people using the platform to communicate. Although Twitter is generally considered a source of plentiful yet not particularly rich data, it appears to be of particular value when exploring the autistic community, a finding which has been based largely on the lived experience of the lead author and participants.

Whilst I am deliberately avoiding making sweeping generalisations about autistic people, and would emphasise the dangers of doing so, many autistic people, including both myself and several of the participants, find that communicating in writing is more comfortable and effective than communicating verbally, social media platforms such as Twitter are incredibly useful. The ability to easily surround oneself with like-minded people can be a weakness of social media in other contexts, however, here it gives a voice to those who would otherwise not be heard, and allows those who do not feel they fit with other groupings of people in their lives to find somewhere where they are surrounded by people they can relate to and, just as crucially, who can relate to them (Crompton et al., 2020).

The near-global reach of Twitter also has its advantages in this context, as members of the heterogeneous autistic community can find others with whom they can relate. Given the myriad issues around autism diagnosis and understanding (Milton and Moon, 2012; Milton, 2012a; Milton, 2012b; Milton, 2016), and the relatively small number of autistic people – or, more pertinently, people who meet the afore-mentioned problematic criteria – this can be near impossible to achieve offline. Of course, as the COVID-19 pandemic hit in the middle of this research, this became even more of an issue, albeit one which also had its advantages. It became impossible to meet people, like-minded or otherwise, in person, but became much more acceptable to communicate virtually.

While I do not dispute that this explanation may appear anecdotal, I firmly believe that the strength of this research lies in the insider perspective, and the value of being a member of the community in question should not be underestimated (Brannick and Coghlan, 2007), I do not proclaim that this is true for every autistic person, merely that it is true for myself and those who have been kind enough to share their own personal experiences with me.

In the following section, I will discuss how earlier attempts at Twitter analysis prompted the inclusion of social network analysis.

The Precursors to Social Network Analysis

By "precursors", I do not mean the history of social network analysis as a research method, but rather those methods which I had attempted to use when the feeling that some form of Twitter analysis would be valuable to the research first arose. It may seem odd to include a detailed account of methods which did not work, but, given the fact that this research has been conducted as an ever-evolving process, it is important to include all aspects of that process.

As I have already elaborated, despite taking an interpretivist stance, I had an intuitive feeling that the qualitative element of the study was not quite enough (see Dörfler & Eden, 2019 for a case of the researcher's intuition in the research process). I could, and did, obtain valuable insights through the interviews, and through exploring my own lived experience, but I felt that there was something to be added by taking a multi-modal approach. As I had already become part of the Twitter autistic community (see Table 6), and recognised that there was much to be learned from it, I decided to learn R with a view to analysing Twitter text. This text analysis was intended to allow me to reach a wider pool of late-diagnosed autistic adults who had reached self-acceptance, although I was aware that this would be on a much more surface level.

This was perhaps a pivotal moment in the research, in that it presented me with the opportunity to challenge the assumption that interpretivist research can only be qualitative. It was while studying R for text analysis that I first encountered subjective Bayes, and started to realise that it fit very well with the reflexive approach that I was already following. The similarities between the two are outlined in Section 3.3.2. The process of reviewing and revising what we (think we) know is a constant feature of this research, as I focus on getting to the essence of the matter, and making sense of a phenomenon.

The Twitter text analysis, and analysis of the various PDFs, blogs, and other documents which had been provided to me by the participants, did not become a core part of the research for myriad reasons. When conducting analysis using keywords, sentiment analysis or similar, there is a reliance on being able to find a consensus in the words which the participants use. While there were some common words and sentiments, these tended to apply only to very general, surface-level aspects of working towards self-acceptance. This is another part of the research where my positioning as an insider was key. During the interviews, the participants spoke to me as one of their own, the value of which cannot be overstated. In their tweets, blogs, and other writing which they chose to publish publicly, they wrote knowing that their words would be read by people who did not understand them, and therefore chose their words carefully. I discuss this in more depth later in this thesis (for example, see Section 4.4), but the key point which I took away from this was further certainty that Twitter was a source of meaningful data, but that I would need to take another approach to find it.

3.6.3 Autoethnography

Positioned as I am as both researcher and participant, my own lived experience is unavoidably a core element of this thesis. While writing my autoethnography, a term which was first used in the 1970s to describe these first-person accounts of lived experience (Heider, 1975), I have deliberately written and spoken as naturally and as un-edited as possible, as the value lies in how true they are to the actual experience itself. Of course, as much of the human experience is ineffable, there is only so much that can be translated on paper, but I have made effort to be true to my experience, as uncomfortable and vulnerable as this has felt at various junctures. In the context of this research, autoethnography is used both as a method and as a self-narrative (Boylorn and Orbe, 2014); it is both the method for exploring the context, and the outcome of having done so (Haynes, 2017).

In keeping with the principle of research indirection (Dörfler et al., 2018) that is at play throughout, I did not follow any prescribed autoethnography methodological recipe, preferring to see how this unfolded as I organically produced authentic accounts of my story at various points in time. In doing so, I have written what Madison (2005) defines as performative autoethnography, or "writing that shows, does not tell, hesitates, stutters, enacts what it describes, is evocative, reflexive; writing to embrace, enact, embody, effect" (Campbell, 2015: 96). There is also an element of critical autoethnography, where the narrative is used to highlight and tackle inequalities, and social and cultural unfairness and injustices (Boylorn and Orbe, 2014). In writing this autoethnography, I recognise both myself and the participants as "other". As such, the real value of an autoethnography does not lie in how accurate a retelling of events it is, it lies in how open and true a description of the author's experience it is, capturing as it does an intuitive, personal knowledge, embedded within a social context, and analysed relative to theory (Haynes, 2013).

While there appears to be some reticence around using autoethnography as a research method due to the subjectivity of the account, not to mention the reliance on an individual's memory of an event, this boils down to what amounts to an epistemological misunderstanding (Anteby, 2012), and failure to grasp that subjectivity is not a weakness. In other words, "whatever the substance of one's persuasions at a given point, one's subjectivity is like a garment that cannot be removed. It is insistently present in both the research and non-research aspects of our life" (Peshkin, 1988: 17), and that subjectivity should be embraced from the outset and allowed to inform and shape the research. After all, it is there, whether or not it is acknowledged, and a good autoethnography avoids being overly-analytical, instead embracing the vulnerability and honesty of evocative writing (Ellis, 2004).

In this vein, my autoethnography has been allowed to develop over the course of this research. While the two explicit accounts were written at the beginning and the end of the research, respectively (see Sections 4.2.2, 4.5.3, and pages 249 – 255) , my lived experience has been present throughout. As I learned from each stage of the research, my perspective on my own experience developed, and vice versa. This double-autoethnography, which illustrates the same phenomenon at different points in time, serves to provide a more in-depth account of the liminal journey I was undertaking as the research progressed (Learmonth and Humphreys, 2011), essentially presenting different versions of my evolving identity and sense of self. This is discussed in the reflections chapter (see pages 249 - 255), as I delve further into the cycle of research and experience, and how autoethnography represents both an epistemological and a methodological choice (Haynes, 2017).

The Synergy Between Autoethnography and Insider Experience

Being, as I am, a member of the autistic community conducting research into autistic experiences, both autoethnography and accounts of insider experience feature prominently throughout this thesis. While both of these, from my own perspective, are essentially one and the same, it is important to acknowledge that the terms are not generally interchangeable. Autoethnography, and the various forms it can take, has already been discussed in this chapter (see Section 3.6.3). Insider research (see Section 3.6.1), defined as that where the research is conducted by one who is a member of an organisation or community where the research takes place (cf. Brannick and Coghlan, 2007), enables greater insight and understanding than that which is available to a researcher without this positioning. Not all autoethnography involves insider research, and not all insider researcher involves autoethnography, but this particular research involves both.

As my experience of working towards self-acceptance is the same experience whether I am considering myself as a researcher, as a neurodivergent person, or simply as myself, the terms are interchangeable in this context, and will be used as such throughout this thesis. While I do highlight at times that I needed to shift my own perspective slightly to fully understand a development in the research, it is impossible to separate the various aspects of my experience, although every effort has been made to explore from all possible angles.

In brief, my positioning as an insider afforded me a level of trust amongst participants which I may not have had otherwise, while the autoethnographic accounts which I have provided enable me to explain the phenomenon in question to those who have not experienced, using myself as an example to avoid compromising the identity of other participants (cf. Stierand and Dörfler, 2014; Olekanma et al., 2022).

The Ethics of Autoethnography

The importance of conducting ethical research is indisputable; however, it is something that I initially overlooked when the research participant was myself. After all, if I have willingly written something down, how can it be unethical to share and publish it? Was I as committed to doing no harm to myself, as I was to other participants? Although I was more than happy to share my own accounts at the time of writing them, it was important to step back and consider how this openness may affect me at a later date, should my perspective change once more (as it undoubtedly will), or should I realise that I had been caught up in the excitement of this new discovery and shared more than I would really have liked to.

There is, of course, also an element of being aware of the other people in, and affected by, my story (Tolich, 2010). As it has been put by Chang (2008: 69), *"as you play a multi-faceted role as researcher, informant, and author, you should be reminded that your story is never made in a vacuum and others are always visible or invisible participants in your story."* For that reason, I ensured that I had permission from the friends who wrote accounts of how they saw my transformation before including them verbatim in this thesis, and have been careful to maintain the focus on my own experience (see Harrington (2020) and Sections 4.2 and 4.5.3), with as few details about other people around me as was possible.

One further concern is the impact which sharing deeply personal stories may have on my future life, both personal and professional. While I can, and have, protected the identities of participants, there is no way to anonymise my own contribution. I have, however, deliberately not discussed anyone else in a way which I would not be comfortable with them reading, and have not referred to other people specifically unless absolutely unavoidable. This means that I have not made assumptions about other people's intentions or motivations, for example, and have written from my perspective and how I experienced it.

To the best of my knowledge and ability, I have ensured that the autoethnographic writing included in this thesis fits with the 10 foundational guidelines for autoethnography (Tolich, 2010).

1. “Respect participants’ autonomy and the voluntary nature of participation, and document the informed consent processes that are foundational to qualitative inquiry (Congress of Qualitative Inquiry, 2007, cited in Tolich, 2010)
2. Practice “process consent,” checking at each stage to make sure participants still want to be part of the project (Ellis, 2007)
3. Recognize the conflict of interest or coercive influence when seeking informed consent after writing the manuscript – see (Jago, 2002; Rambo, 2007)
4. Consult with others, like an IRB (Institutional Review Board) (Chang, 2008)
5. Autoethnographers should not publish anything they would not show the persons mentioned in the text (Medford, 2006)
6. Beware of internal confidentiality: the relationship at risk is not with the researcher exposing confidences to outsiders, but confidences exposed among the participants or family members themselves (Tolich, 2004)
7. Treat any autoethnography as an inked tattoo by anticipating the author’s future vulnerability.
8. Photovoice anticipatory ethics claims that no photo is worth harming others. In a similar way, no story should harm others, and if harm is unavoidable, take steps to minimize harm.
9. Those unable to minimize risk to self or others should use a nom de plume (Morse, 2002) as the default.
10. Assume all people mentioned in the text will read it one day (Ellis, 1995, cited in Tolich, 2010: 1607-1608).

Not all of these are applicable to this particular autoethnography, but the general ethos of being mindful about the impact on both the author and those around them is. There are undoubtedly aspects of my life which are deliberately not included in this research, although have been acknowledged while writing and speaking about the experiences. This is partly due to my own need for privacy, but also because my story is not only *my* story, and I am only entitled to tell my part of it.

In summary, the autoethnography which has formed part of this research has been allowed to develop organically, and has been written unedited for the most part, although with consideration for others who inevitable feature in my story. While this does make me somewhat vulnerable and exposed in certain ways, I have made the decision to go with what felt intuitively right, with the objective of providing as rich an account as possible, similarly to how I allowed all interview participants the freedom to guide the interviews, and the information they chose to share.

3.7 Research Participants

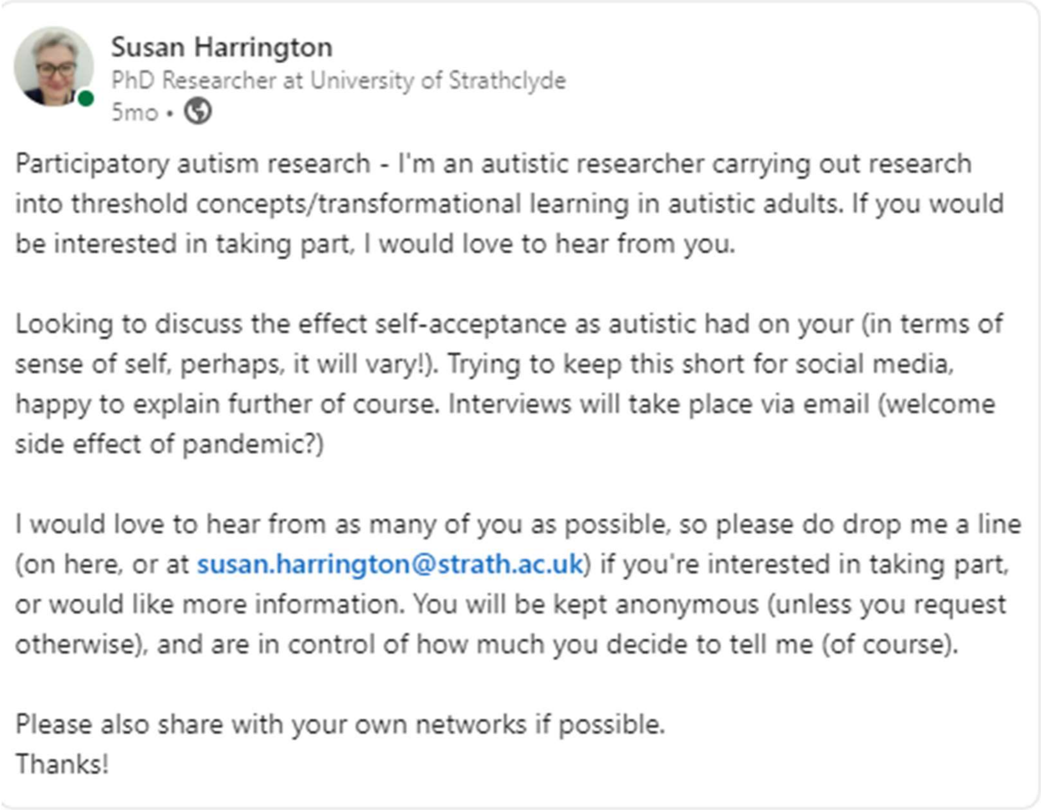
Forming part of a research project exploring threshold concepts in autistic people as this did, the initial objective was to speak to autistic academics and professionals, who felt they had had at least one transformative experience over the course of their life to date (this could include formal education or more general life experiences) and were happy to discuss these. In order to gain information that was as rich as possible, the restrictions on participant qualification were kept as minimal as possible, whilst avoiding any ethical concerns.

As such, it was decided that the participants should meet the following criteria:

- Over 18
- Either formally or self-diagnosed as autistic
- Academic or professional
- No co-occurring learning disability which may impact upon ability to give informed consent

Self-diagnosis is considered valid both in this research and by the autistic community in general (Luterman, 2015; McDonald, 2020), due to the limitations imposed by an inadequate diagnostic process, which is informed by the medical model of disability (Pellicano et al., 2014; Pellicano, 2018). Indeed, my own acceptance as an insider within the community speaks for the validity of self-diagnosis amongst autistic adults.

Recruitment of participants was conducted via Twitter, as this had been identified as the most effective way of reaching those within the demographic. A call for participants (see Figure 19), which was circulated via my own Twitter network, received 40 positive responses within an hour, 12 publicly on Twitter, 10 via Twitter direct messaging, and the remainder by email. Just under half of these resulted in interviews. Some decided they were not able or willing to discuss personal experiences after all, although they had initially felt they would like to take part[1], some did not respond to the participant information sheet and consent form which was sent to each Twitter user who replied to my post, and two declined after briefly exploring the University's affiliations with existing autism research and research networks, and deciding that they were not happy with the association.



Susan Harrington
PhD Researcher at University of Strathclyde
5mo •

Participatory autism research - I'm an autistic researcher carrying out research into threshold concepts/transformational learning in autistic adults. If you would be interested in taking part, I would love to hear from you.

Looking to discuss the effect self-acceptance as autistic had on your (in terms of sense of self, perhaps, it will vary!). Trying to keep this short for social media, happy to explain further of course. Interviews will take place via email (welcome side effect of pandemic?)

I would love to hear from as many of you as possible, so please do drop me a line (on here, or at susan.harrington@strath.ac.uk) if you're interested in taking part, or would like more information. You will be kept anonymous (unless you request otherwise), and are in control of how much you decide to tell me (of course).

Please also share with your own networks if possible.
Thanks!

Figure 19 - Call for participants

13 participants were recruited through this single tweet, with one participant agreeing after being approached directly before the tweet was posted, and another contacting the researcher following a re-posting of the same tweet a short while later.

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[1] As further testament to the importance of my being an insider, one participant did not feel able to continue discussing their own experiences beyond an initial email, and was therefore discounted. However, they did offer emotional support to me, should I need it while working with such emotive accounts, and contributed once more when the importance of community arose.

In terms of demographics, approximately half of the participants – 6 out of the 13 - were either autistic academics or otherwise involved in participatory autism research or autism advocacy, five were employed elsewhere, and two were unemployed at the time of interview, but felt that the topic of self-acceptance as a transformative experience resonated strongly with them.

Table 5 - Communication with participants

PARTICIPANT	DATE	FORMAT OF COMMUNICATION
Participant 1	July 2020	Brief email exchange (4 emails) to arrange Zoom conversation. Preferred to keep conversation to Zoom.
	July 2020	Zoom conversation (1 hour 24 minutes)
Participant 2	July 2020	Ongoing email conversation (5 emails)
Participant 3	July – October 2020	Ongoing email conversation. 11 emails, each quite lengthy and in-depth. Answers given to follow-on questions
	August 2020	Zoom conversation (1 hour 17 minutes)
Participant 4	July 2020	Brief email exchange (3 emails). PDF forwarded, including detailed account of journey to date.
Participant 5	July – Sept 2020	Ongoing email conversation (9 emails). All communication via email. 2 very lengthy emails included main account, with shorter follow-on questions
Participant 6	July – August 2020	Ongoing email conversation (13 emails). One long email including main account, with shorter exchanges before and after. Answers given to follow-on questions
Participant 7	July 2020	Short email exchange (3 emails)
Participant 8	August 2020	Brief email conversation (8 emails). Mainly clarifying details of research and arranging Zoom conversation.
	August 2020	
	October 2020	Zoom conversation (57 minutes)

		Brief follow-up conversation on unrelated event Zoom
Participant 9	August - Sept 2020 Sept 2020	Ongoing email conversation (15 emails). 1 very lengthy to provide background for Zoom, plus very detailed answer to follow-on questions after Zoom Zoom conversation (1 hour 22 minutes)
Participant 10	July 2020 July 2020	Email conversation (9 emails) clarifying purpose of research and arranging Skype conversation. Answers given to follow-on questions. Skype conversation (1 hour)
Participant 11	Sept 2020	Email exchange (4 emails). Detailed account given, plus response to follow-on questions
Participant 12	Sept 2020	Had withdrawn in August after initial email exchange (not included in research). Length email sent in response to question about online community and belonging
Participant 13	Sept – Oct 2020 Oct 2020	Ongoing email exchange (7 emails) Zoom conversation (1 hour 5 minutes)

3.8 Analysing the Data

As the data which was to be analysed involved highly personal experiences, it was imperative that I choose methods which allowed enough flexibility. The emergent, process-based research design meant the process of analysis was far from linear, involving numerous iterations of revisiting the data from the interviews, autoethnography, and social network analysis, drawing out new insights as my own knowledge and perspective evolved.

The unit of analysis throughout this research has been the individual, that is, the person undergoing the liminal journey in question. However, this has involved exploring these individuals' places within various communities, as will be discussed later. The term “community” is applicable in several ways here, so each has been labelled distinctively for ease of reference (Table 6). The communities which make up the constellation (Wenger-Trayner and Wenger-Trayner, 2015) of communities featuring in this thesis are detailed in Table 6:

Table 6 - Defining the communities

Labels used in the dissertation	***Membership***
Autistic community	Autistic people as a whole. This is a very simplified generalisation, but is used for ease of reading. Can also be described as “amongst other autistic people”.
#ActuallyAutistic	Those who use the #ActuallyAutistic hashtag to identify their tweets. Used by autistic people to amplify their voice on autism matters, and also by non-autistic people to signify allyship
Twitter community/Twitter autistic community	Wider community of autistic adults on Twitter. The above hashtag may be used by these people, but their community is built on their personal interactions with relatable others
Late-diagnosed autistic adults	The subset of the above community which provides the context for this research. These are those who were diagnosed as adults, and have been forced to re-evaluate their sense of self as a result.
Personal networks and communities	The networks and communities that participants belong to following self-acceptance. Autism is a feature, but not necessarily a focus

As a community is made up of the individuals within it, the unit of analysis remains the individual, even where looking more closely at the community or one of its subsets. The community here provides the context. This is in alignment with the phenomenological concept of *Dasein*, which is usually translated to English as *context*, but it should correctly be regarded as a *way of being* (Dörfler and Stierand, 2021; Heidegger, 1923: 51).

The first component discussed here, interviews and their analysis, focused on the individual participants. As the intention with the interviews was to learn from what the participants were saying about their own experiences, rather than imposing set themes and potentially missing valuable insights, a reflexive thematic analysis (Braun and Clarke, 2006; Braun and Clarke, 2019) approach was initially attempted. Indeed, several methods of analysing the interview data were considered, but did not fully fit with what I was trying to achieve from the research.

As mentioned earlier, metaphor analysis (cf. Dodd, 2002; Dodd and de Koning, 2015) was the method initially considered at the outset of the research, as I recognised from an early stage that it was likely that participants would use metaphors when speaking about their own lived experience, and that these would need to be explored and understood in order to access the underlying message, (Cassell and Lee, 2012; Cornelissen and Kafouros, 2008; Cassell and Bishop, 2019).

While this did work to a certain extent, it did not allow for capturing the impact of my own lived experience, and the insider perspective that offered while speaking to the participants. Much of the valuable information that came from the interviews was not that which was explicitly said by the participants – there was a lot of non-verbal interaction which made certain points make sense in context, but probably would not mean much to anyone else looking only at the transcripts. While there is a common myth that autistic people cannot read body language or understand other people, this arises from the double-empathy problem (Milton, 2012b), and we, autistic people, can relate to and understand other autistic people just fine. As such, where a transcript showed a phrase such as a participant saying they felt “a bit crap” (see page 176) compared to other people, it seems straightforward enough to recognise what the participant is saying. However, only having lived through a similar experience allows the understanding of how much of an understatement “a bit crap” was, and how enormous an impact there was when one becomes able to move away from seeing autism as “a shameful secret” (see page 176).

One of the main problems I encountered while attempting to analyse the interview data was that it was impossible to (adequately) code what was not said. Transcripts and coding can only incorporate what is said aloud, and words alone cannot possibly capture the ineffable; that which is created by two people with shared experiences discussing those experiences, and understanding them as an outsider could not (Williams, 2021). Those moments of shared experience (cf. “interlocked indwelling” in Pyrko et al., 2017) and understanding were invaluable, but could not be captured. Indeed, the biggest obstacle while analysing the interviews was that most of what I learned did not come from analysis, as such, but from being a part of the community.

While coding may be widely accepted as the way to analyse and work with interview data (Saldaña, 2016), in this case it simply did not work, to echo Packer (2010) in saying that “the strongest objection to coding as a way to analyse qualitative research interviews is not philosophical but the fact that it does not and cannot work. It is impossible in practice” (Packer, 2010: 80). This is not to say that coding does not work at all, it is simply that it did not work in this instance, and could not work for the purposes required. As mentioned above, it is impossible capture in words alone just how transformative this experience was. There are evocative words which can be used to describe it – “transformative” being just one – but the interpretation of these words still draws on the reader’s personal experiences. Words alone cannot adequately convey the essence of the phenomenon, as discussed in Section 3.6.1, this aspect is well captured in the phenomenological concept of qualia.

Had I insisted on depersonalising the interviews to the point of hanging everything on themes and codes, regardless of how fluid those were, I would have done a great disservice to both myself and the participants. Instead, I chose to follow my intuition towards the subsequent social network analysis (see Section 3.6.2).

Following an established method, such as reflexive thematic analysis (Braun and Clarke, 2006; Braun and Clarke, 2019), metaphor analysis (Dodd, 2002; Dodd and de Koning, 2015), or the Gioia method (Gioia et al., 2012), did enable me to identify some themes amongst the interview data, but also led to sense of frustration. Despite there being clear themes (see Figure 21) and commonalities across the transcripts, and the emails used as preferred by certain participants, it did not feel as though this got to the heart of the communication. There was plenty of valuable insight available from these themes, but it did not capture the quintessence of the interactions between two insiders. I keenly felt that there was more of substance to be drawn from these interactions; after all "the invisible appears only to the eyes of those authorised to observe it" (Ophir and Shapin, 1991: 13 - 14).

Much of what I learned from the interviews developed from the time I spent reflecting upon the interview experiences, rather than analysing the transcripts in terms of keywords. While analysis was carried out, as detailed in subsequent chapters, this served as a prompt for the next stage of the research, rather than as a finding in itself. As such, a combination of methods which enable me to illustrate the research process in a relationally reflexive way, or one which "legitimizes insights from the situated life-with-others of the researcher" (Hibbert et al., 2014: 278). Attempting to stick rigidly to existing methods was not only hampering my ability to demonstrate what was uncovered through the interviews, it was preventing me from seeing what was there. "The ideal of eliminating all personal elements of knowledge would, in effect, aim at the destruction of all knowledge. The ideal of exact science would turn out to be fundamentally misleading and possibly a source of devastating fallacies" (Polanyi, 1967: 20).

Indeed, in hindsight, the biggest obstacle I encountered while analysing the data was my own initial insistence upon trying to make existing methods work, rather than trusting my own intuition and using autoethnography as an analysis tool as well as a way to gather data (Haynes, 2017). Of course, it was still a necessary part, as had I not attempted to use these methods, I would not know that they did not work.

While I was analysing the interview transcripts, and while I had been conducting the earlier iterations of the quantitative components of this research, I had been unable to express what I was seeing, and how it was important. At each stage of the process, I have seen what needed to be done next, but could not explicitly explain how or why. I was guided by intuition, not by what was in words in front of me, and this is how I obtained the insights I did. I learned to use my emotion as a research tool (Rivera, 2018).

However, it is considerably more difficult to explain this in a way which complies with the expectations of research, than it is to understand within myself that what I see is what is happening. For this reason, and for the purposes of providing clarity for the reader, I provide two accounts of the research process – one in the discussion chapter which is written from a researcher perspective, and one in the reflection, which serves partly as my contribution as a participant. Of course, there is significant overlap between the two, as it is impossible to separate them entirely, but the two accounts should work together to provide a more coherent whole, which makes sense to those not directly involved.

It is perhaps most accurate to describe the analysis which was conducted throughout the research as a process of ongoing sensemaking. Elements of the aforementioned methods of analysis were used, and combined with one another to engage in a reflexive process of visiting and revisiting the data to draw out as rich and meaningful insights as possible, that is, focusing on interpretation and action, rather than choice, and continually asking myself "what is going on here" (Weick et al., 2005). In this way, what I knew from my own experience enabled me to gain insights from what the participants told me, which, in turn, impacted on how I understood my own liminal journey. Through continually revisiting and revising my perspective on the various elements of the research, I developed a greater understanding, and the ability to draw rich, meaningful insights into a deeply misunderstood subset of society.

My own positioning as an insider within the community in question was a key resource, as my own insight and understanding allowed me a great level of understanding. Through using this insider perspective, I employed sensemaking as a tool for analysing both the qualitative and quantitative data gathered throughout the study. Paull et al. (2013) discuss using sensemaking to work with surprises, allowing deeper investigation and interpretation of the data, which allows for important findings when studying phenomena, making it what appears to be the most powerful analytic method for this specific research.

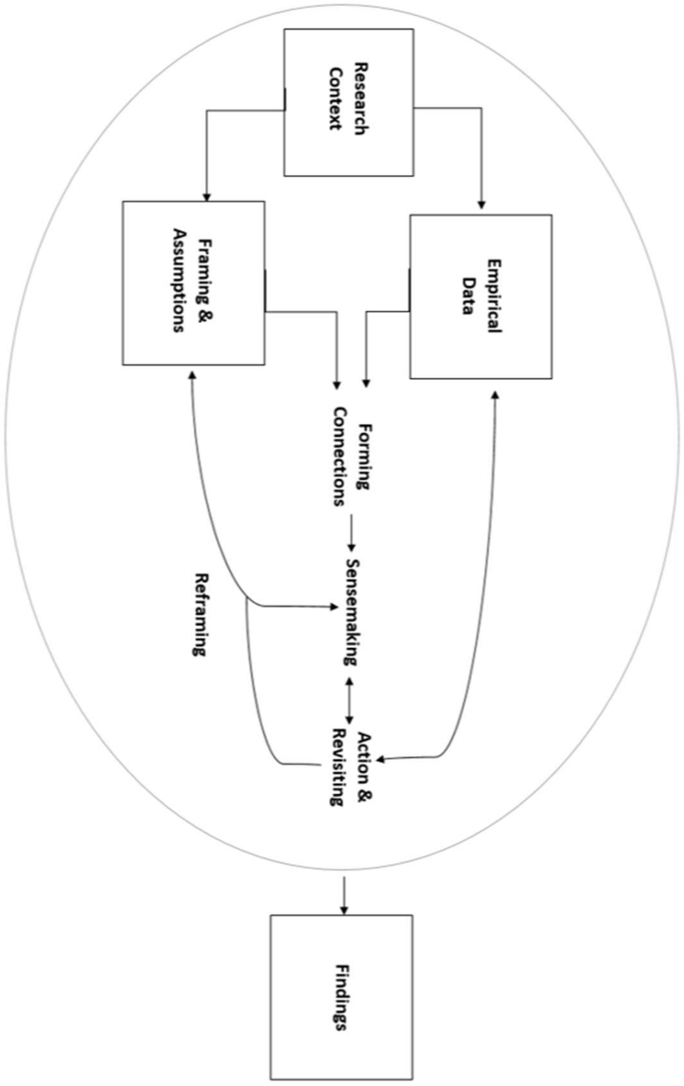

Figure 20 - Sensemaking as a research method

This process of sensemaking was used while analysing both the interview and social network data, as well as for revisiting my autoethnography towards the end of this research, exploring how what I had learned during the empirical data collection and analysis had impacted upon my own perspective. In terms of adding validity and trustworthiness (Jootun et al., 2009; Rettke et al., 2018) to the research, the findings were discussed (anonymously) with two participants, as a form of sense-checking and co-creation (Orr and Bennett, 2009), and an interviewing-the-researcher exercise was conducted with my primary supervisor, where we engaged in transpersonal reflexivity (Dörfler and Stierand, 2021) to further unpack the findings together.

So far in this chapter, I have outlined the research design, and the methods which were used while collecting and analysing data. I have briefly explained the philosophical standpoint through which this research was conducted. As this research has involved a more quantitative approach than may be expected from interpretivist research, I feel that this warrants a more in-depth explanation. It also reflects better how my own view evolved, as I was growing as a researcher. My arguments in favour of using quantitative methods in an interpretivist framing follow.

3.9 In Favour of Quantitative Methods in Interpretivist Research

This section of the thesis discusses some of the difficulties which I have encountered while attempting to identify the philosophical underpinnings of my research, as well as the eventual culmination in recognising that the most suitable approach was that of phenomenal theorizing, rather than any single philosophical lens. While discussing this, I will present my argument in favour of using quantitative methods in interpretivist research. I do not argue that interpretivist research must incorporate quantitative methods, merely that they should not be disregarded without careful consideration. A brief exploration into the work which set the foundations for Bayesianism, and resulting comparison with reflexivity, is laid out to demonstrate the similarities between these two approaches, and how they can be combined whilst obtaining rich insights into a social phenomenon.

The not-insignificant overlap between how one would take a Bayesian approach to a quantitative problem, and how one would embark upon a reflexive qualitative study serve, in my view, to illustrate how both quantitative and qualitative data can be explored from an interpretivist perspective. While conducting this research, and first tentatively suggesting that I may employ quantitative methods such as social network analysis or sentiment analysis using Twitter data, almost all of the responses I received were that research cannot possibly be considered interpretivist once a quantitative element has been introduced, although, fortunately, this was not my supervisor’s view. In the following paragraphs, I argue that this perspective is far too reductive, and that quantitative methods can indeed be used effectively to complement and add to the findings from an otherwise qualitative study. The key determining factor in whether or not research is interpretivist lies in how the data are analysed and considered, at a philosophical level, not in the form which they take. This is intended to serve as a general perspective on the advantages and further insights enabled by the addition of quantitative methods where appropriate, although some details from this particular study into threshold concepts and transformational learning are used for illustration.

It should be noted that this is intended to serve as a high-level indication of an evolving approach, where further exploration and development continues. Rather than forming a statement that quantitative methods are always a strong addition to interpretivist research, this is primarily a musing around some of the methodological and philosophical issues which have arisen. The development of this approach, as it stands currently, reflects a somewhat disorganised thinking process, resulting from conversations between three researchers that spans various areas of the methodological and philosophical realms of research, including theoretical and meta-theoretical levels, methods, tools, methodological approaches – and the philosophical underpinnings of the same – various ways of thinking, inferences, and perhaps most importantly, reflection and reflexivity. As such, this approach is not simply my own thinking about my specific research problem, but one which has been developed in collaboration with two more experienced researchers, each of us having very different backgrounds, but arriving at the same viewpoint from these varying starting positions.

The motivation behind the development of this argument is trying to do good research, while navigating the barriers which have been presented to us, and which we do not believe to exist in reality. The primary viewpoint underpinning this argument is one in favour of there being just two types of research – good research, and bad research. It is unnecessary to enforce any further separation. The boxes which have been created, and tend to be used while conducting research, can serve the useful purpose of helping to organise and orient our thinking but, if these are regarded as real and immovable, can quickly become obstacles standing in the way of producing good research.

To provide an example of this, one can consider the belief that all swans were white until a black one was found, a parable which serves as a metaphor for an event which is surprising, has a great impact, and is then rationalised with hindsight (Taleb, 2007). One may also consider the classification of living creatures into mammals who breastfeed their offspring and birds and lizards who lay eggs. The platypus, a semi-aquatic mammal from Australia, does both. These distinctions are a perfectly legitimate and acceptable way to classify living creatures, so long as it is not forgotten that they are constructs, and not infallible. I believe that the apparent automatic exclusion of quantitative elements from interpretivist research is similarly misguided.

While first looking into the possibility of including quantitative methods in an interpretivist study, it is interesting to note that, while any decent research philosophy or research methods class tends to emphasise that positivist does not necessarily mean quantitative, and interpretivist does not need to mean qualitative, it is near impossible, in my experience, to find examples of interpretivist research which is not qualitative in nature. There are examples of positivist qualitative studies, mostly thanks to the case study methods used by Eisenhardt (Eisenhardt and Bourgeois III, 1988; Eisenhardt, 1989; Eisenhardt and Graebner, 2007; Eisenhardt et al., 2016) and some efforts to challenge the exclusion of quantitative data from qualitative research more generally, for example (Maxwell, 2010; Sandelowski, 2001), and I have subsequently been made aware of the existence of what may be described as quantitative interpretivist research in the critical accounting field, for example (Dillard and Vinnari, 2019; Grisard and Picard, 2017; Cooper, 2015; Lee and Humphrey, 2006), but it remains very much a rarity.

Given that the focus of interpretivism is on the meaning and the intentions, it does make sense that qualitative methods would dominate, but is it really possible that interpretivists (with very few exceptions) never do quantitative studies? Based on my experience with an interpretivist study that benefitted significantly from quantitative methods, I argue that it is not a case of qualitative, quantitative, or both as a concrete decision, but maintaining an open-mindedness which facilitates conducting good quality, impactful research.

To return to the comments opposing the very notion that research can be both quantitative and interpretivist, perhaps the most perplexing feature of this viewpoint is that it indicates a lack of the open-mindedness that I would expect from researchers. As such, I am attempting to respond convincingly and forcefully to these comments, re-emphasising my goal to conduct good research. Admittedly, I could have produced good research in this particular study based on the qualitative element alone, however, I was not satisfied with "good" when I knew there was better to be had (acknowledging, in the interpretivist mindset, that good can be many different things – here good is what I felt to be good and better). With this in mind, the rest of this argument is structured as follows: firstly, I describe the Bayesian philosophical approach which proved useful when building a philosophical approach appropriate for this research. Next, I illustrate the links between a Bayesian approach and reflexivity. Finally, I discuss how a multi-modal approach, comprising both qualitative and quantitative methods, has allowed me to uncover, explore, and present a richer representation of the research than could possibly have been achieved if limited to pre-existing boxes, and address some potential criticisms of this approach.

3.9.1 Bayesian Approach, not Bayes' Theorem

Perhaps one of the most important points to bear in mind while considering this argument is that the terms "Bayes" and "Bayesian" do not necessarily refer to Bayes' Theorem (Bayes and Price, 1763), but to the philosophical works of Thomas Bayes (1702-1761). Given his background as a Presbyterian minister and philosopher, Bayes appears to have discussed his theories on probability in quite a subjective manner, stressing the importance of prior knowledge in assessing probabilities. Indeed, it was not Bayes himself who constructed the theorem as we know it today; rather, this was a later development based on his writings (Stigler, 1982; Hooper, 2013) and, therefore, an interpretation right from the start. This point is discussed later, in conjunction with the value of insider experience in interpretivist research.

Indeed, one excerpt from the essay which formed the basis of Bayes' Theorem seems particularly pertinent to this argument of compatibility with interpretivist research, that is "all men may know the works of God, and through those works know God, but only men of great faith know God directly" (Stigler, 1982). While the religious connotations are irrelevant to the argument, although inevitable given Bayes' background, the quote appears to suggest that there are levels of knowing something, and being closer a phenomenon allows a more in-depth knowledge and understanding.

Of course, it is impossible to know exactly what Bayes was thinking when he wrote this essay, given both that it was published posthumously, and that his introduction and some explanations of his writings are missing from published records, this does appear to suggest support of subjectivity and interpretation. Despite numerous differing interpretations of Bayes' true intention behind these words, I consider this to be an indication of the scope to interpret quantitative data in a way which is compatible with interpretivist research. Indeed, the wide range of interpretations of Bayes' work, and the applications of the resulting theorem, are, in themselves, evidence of its subjectivity. Furthermore, there is subjectivity conditional to other subjectivity, which, based on previous experience, is taken here to mean that Bayes intended to explicitly incorporate subjectivity in his work. As such, Bayes could, in many way, be considered a precursor to the intentionalist and subjectivist turn commencing with Husserl's (Husserl, 1913a; Husserl, 1913b; Husserl, 2006) work on phenomenology, see also Heidegger (1975).

3.9.2 Relating Bayes to Reflexivity

Reflexivity, or "the process by which research turns back upon and takes account of itself" (Alvesson et al., 2008: 480) is considered by many, including myself, to be an essential component of good qualitative research (cf. Alvesson and Sköldberg, 2000; Cassell et al., 2009; Haynes, 2012; Hibbert et al., 2014).

In this vein, Bayesian approaches can also be described as utilising the afore-mentioned process whereby research revisits and takes account of itself. As such, just as considering quantitative data as standalone, without taking into account the inevitable assumptions, subjectivities, and prior knowledge is overly reductive, so too is any refusal to acknowledge that even those interpretive works which exclusively employ soft methods and qualitative analysis do, in fact, involve some level of numbers and "quantities", whether explicitly or otherwise.

While analysing qualitative data, those themes which are considered important are those which appear most frequently. What is this, if not putting a qualitative interpretation on the frequency, or quantity, of mentions of that particular theme? As qualitative researchers we do, of course, understand that this is a very simplified account of what happens during the analysis process, however, it remains valid, and it forms the basis of content analysis, which Saunders et al. (2019) depict as quantitative analysis of qualitative data. Indeed, although one of the objections which has been encountered is that "once you include numbers, you are not an interpretivist", numbers themselves are qualitative concepts. Put very simply, a number has no meaning in itself, other than that which has been assigned to it – a point which has been discussed at length by researchers studying the history and sociological impact on how mathematical theories, notation, and similar were created (Restivo, 2017), as well as those arguing in favour of a more rounded approach to qualitative research (Dey, 2005).

The details on how this approach was put into practice while conducting this research are provided in the relevant chapters of this thesis, as the methods and findings are discussed. For now, I discuss the shared characteristics of Bayesianism and reflexivity, and how the two work together.

3.9.3 The Shared Characteristics of Bayesianism and Reflexivity

Ultimately, the position taken here is that quantitative and qualitative methods can successfully be combined in interpretivist research, and is not strictly limited to Bayesian methods. However, as previously stated, the similarities between Bayesianism and reflexivity serve as a strong starting point for an approach on which development is ongoing.

In very simple terms, both Bayesianism and reflexivity involve starting with a viewpoint, beginning a study, and continually revisiting and revising initial views based on what is found and what is learned. Reflexivity, as mentioned previously, is the process where research examines itself (Alvesson et al., 2008), developing ways of exploring not only what we see while we research, but also how we see it, why we see it that way, the inevitable impact of previous knowledge and experiences upon our research (Hibbert et al., 2014), and "thinking about how our thinking came to be" (Haynes, 2012: 73). When contemplating reflexive research, one may think of the approach in terms of a combination of both reflection and interpretation, and must always treat reflexivity as a process. During this process, all assumptions – philosophical, theoretical, methodological and otherwise – are continually challenged and revised in the context of the research (Cunliffe, 2003). There is no absolute truth or knowledge, only those which exist within a specific context. There also exists here some key differences between reflective practice and reflexivity. To summarise very briefly, Cunliffe (2004) discusses this as reflective analysis involving some form of objective observation of a group or event, whereby reflexivity involves exploring and challenging norms, exposing unspoken assumptions, and uncovering possibilities. This is, perhaps, illustrative of another difference between positivist and interpretivist approaches.

Bayesianism, on the other hand, while perhaps most commonly associated with Bayes' Theorem (Bayes and Price, 1763), refers to a related set of perspectives which have been explored across an array of subjects including statistics, psychology, education, and philosophy of science (Bertsch McGrayne, 2012). Bayesianism involves rejecting the notion of absolute truth, focusing instead on degrees of belief (Eriksson and Hájek, 2007; Hawthorne, 2005), updating existing knowledge based on new knowledge and, generally, recognising the strengths of subjectivity while taking a pragmatic approach to research and science (Goldstein, 2006). Bayesian thinking involves recognising that there is more to a situation that can be determined from a single observation or experiment, and there is a tendency amongst Bayesians to criticise others for their lack of transparency around their own subjectivities (Greenland, 2006). Where does a prior come from, if not previous experience and knowledge? In other words, it is not very far removed from the basic principles of reflexivity. While there are Bayesians who approach their work in a more objective manner, I argue that the ability to use a Bayesian approach in a varying range of manners indicates that it is, in fact, subjective and context dependant.

The Bayes' quote used earlier in this chapter, "all men may know the works of God, and through those works know God, but only men of great faith know God directly" (Stigler, 1982: 253) appears to me to share the appreciation of experiential learning, and learning within a specific context, as both reflexivity and researching as an insider. You may learn about a subject, and feel you know it well, but you do not truly know it until you have experienced it.

Through discussing and exploring these similarities between Bayesianism and reflexivity, and their use in explaining the merits of using both qualitative and quantitative methods in interpretivist research, my current perspective is that both approaches involve:

- Conducting research with an open mind, adapting to any new knowledge as it arises
- Avoiding an assertion of absolute truth, focusing on what emerges from the research rather than how, or if, it can be generalised
- The importance of context, and previous beliefs and knowledge
- Working towards a (research) process of "becoming", rather than a definitive answer or outcome

The way in which this combination of quantitative and qualitative methods has enabled each element of my research to develop is discussed throughout this thesis, and a simplified illustration of what was a complex process of continual revisiting and revising is provided in Figure 1. In this instance, the quantitative element would not have been meaningful had I not known what I was looking at, and what I was looking for, while viewing social network data, and the most impactful findings from the research would not have been possible if I had stuck to the qualitative methods alone. Each of the methods has its own merits, but is most valuable when forming part of a research design where several elements were interwoven to work as one whole.

3.9.4 Addressing Some Expected Criticisms of Using This Approach

As mentioned earlier (see Section 3.9), the argument in favour of using both qualitative and quantitative methods in interpretivist research is not an entirely new one. In addition to being used in some areas, such as critical accounting, for example, the use of both appears to have been perfectly acceptable until relatively recently. When we look at the philosophical underpinnings and social contexts which contributed to the development of mathematical theory – such as the work of Thomas Bayes – and more contemporary studies into the sociology of science (Bourdieu, 2004), my view that this distinction is unnecessary becomes more cemented. In fact, some of Bourdieu's work, such as Homo Academicus (Bourdieu, 1988) suggests that he and Bayes may have shared some deeper views on science than one may initially think. Why, then, has it become so commonplace to believe that quantitative methods and interpretivism are mutually exclusive?

While the answer to this question is beyond the scope of this discussion, and is unlikely to be a simple one, it appears that perhaps the dogmatic use of solely qualitative methods in interpretivist research is a strong reaction to the dogmatic use of objective, primarily quantitative methods in positivism. It does not seem unreasonable to suggest that this may be a reaction which is yet to settle at a more realistic middle-ground, although middle-ground is perhaps not the most appropriate term here, given that I am not arguing for a mandatory mix of approaches, but the freedom to be led by the research without being constrained by a reluctance to include certain methods. The best approach, I argue, is the utilisation of a combination of methods which are appropriate to the study in question, whichever form they may take.

When considering a real-life situation or studying a phenomenon, the interpretivist arguments that using statistical analysis is reductionist and isolationist is, in fact, reductionist in itself. To gain a truly holistic and contextual understanding, both words and numbers must be considered in so much as they fit with the research. The distinction lies in how all data and information is interpreted in the context of the research, not in the form in which it is presented. It is important to be clear that I am not advocating for a rule that both qualitative and quantitative methods must be employed, or even that they both must be considered, but that a level of open-mindedness which allows both to be considered where appropriate is essential for good research.

3.10 Concluding the Chapter

In this chapter, I have discussed the methodological approach which was taken while conducting this research. I have outlined each of the methods which were used while gathering and analysing data for the empirical element of the study, and discussed the role of reflexivity and sensemaking in exploring the available data to a depth where meaningful insights about a very personal experience could be obtained.

Through beginning with interviewing late-diagnosed members of the autistic community about their journey towards self-acceptance following this diagnosis, and writing my own autoethnographic account, I took a reflexive approach to the research, resulting in the addition of social network analysis. While employing quantitative methods such as this is not standard in interpretivist research, I have detailed why it is not only an acceptable addition, but serves as a recommendation for increasing open-mindedness when considering potential methods.

By immersing myself in a reflexive process while allowing the research to emerge and develop, I have gained a valuable and insightful illustration of the problem which was being explored. The strength of this research lies in the insight which is enabled by my positioning as an insider within the community in question and, as my own perspective developed reflexively alongside the research, so too did the research design. While I acknowledge that I did not take a standard approach to this research, I firmly believe that this was an approach which suited the context exceptionally well.

In the following chapter, I show how this approach was put into practice, how each of the empirical elements worked together to inform and be informed by one another, and how this led to the findings. I also demonstrate how my almost-dual role as researcher and participant enhanced the research, and how and why this is significant.

4. Analysis

Having outlined the methodological approach in the previous chapter, I now discuss the analysis of the data which was collected during the previous stage of this research. Through taking a reflexive approach to the research, what may appear to be three discrete methods; that is, interviewing, autoethnography, and social network analysis, worked in conjunction with one another. In this chapter, I share the analysis I conducted whilst exploring threshold concepts amongst autistic people, carried out over two years interacting with other members of the autistic community, and reflecting upon my own lived experience in light of this.

As I adopted the roles of both researcher and participant throughout this study, I explain the impact of each role on each stage of the research as I discuss this analysis, and how I worked with the data to obtain meaningful insights. I also briefly discuss some earlier attempts at conducting research into Twitter data which were not included in the final combination of methods, but which played an instrumental role in the research process.

4.1 Structuring the Chapter

The various elements of the analysis are presented in the chapter in chronological order in so much as is possible. The reflexive nature of this study means that there were periods of revisiting earlier components of the research e.g., Twitter network analysis and the interviews informed each other, and I revisited my own autoethnography later in the process, once I had learned more from the progression of the research. There are also elements of recognising that I needed to think more like a participant or a researcher at specific stages of the analysis, and I will signpost these as clearly as possible.

The transcripts from the interviews, which were analysed using both coding in NVivo and my own reflection upon the interview experience as an insider in the community, are presented early in the chapter, as these gave rise to the exploration of participants' Twitter networks. The themes which emerged from this analysis of interview transcripts and recordings, namely the importance of community, transformation of the participants' sense of self, and accepting and validating themselves, is discussed using anonymised quotes for illustrative purposes.

From this point, much of the focus of this chapter will be on the role of communities and networks in achieving self-acceptance. It was this particular theme which led to much of the findings of the research, and I strongly believe it to be a key element. It was the evident importance – both explicit and implicit – of communities, networks, and a sense of belonging while traversing the liminal space which prompted the later stages of the research, and led to the most meaningful findings.

Some of the methods and approaches which are discussed in this thesis did not directly contribute to the research but were instrumental in finding an approach which did yield meaningful insights. For example, the text analysis on Twitter content, PDFs provided by participants where they had outlined their experiences previously, and existing threshold concept literature ultimately did not contribute to the final findings, but did highlight how personal experiences of this magnitude cannot be reduced to word-counting. Using these methods also led to those which did prove fruitful, for example, Twitter social network analysis.

Through trying some methods which did fit with the research, and some which did not, I was able to identify a combination of methods which worked together to enable the discovery of rich, impactful insights into the mastery of a threshold concept. This research also raised some questions about potential additions to existing threshold concept characteristics and the point at which the liminal journey ends.

By the later stages of the research, I could intuitively move between the social network analysis, the interviews, and my own autoethnography, seeing new links and insights as my own knowledge increased. This chapter has been written mostly from the perspective of being able to do this, with the exception of the initial interview analysis.

4.2 Initial Autoethnography

While I cannot provide verbatim transcripts of the interviews without compromising the anonymity and confidentiality of the participants, I can provide my initial autoethnography. It goes without saying that everyone’s experience of what is broadly the same journey is very different, however, this provides some illustration of how it feels to learn that what you had believed yourself to be for your entire life is not actually true. The participants had learned about their own neurodivergence at different ages, but each of them was an adult when they either discovered for themselves that they were neurodivergent, or they were diagnosed without necessarily having suspected it prior to a medical professional suggesting a referral could be helpful.

In order to give some understanding of the process, I include my account that was published as a chapter in The Neurodiversity Reader (Harrington, 2020). This is my autoethnography as it stood in 2019, when I was first coming to terms with my own neurodivergence. As such, it serves as a detailed account of lived experience that provides context for those readers who have not had the same experience, but need some understanding of it. Including my autoethnography greatly increases the level of detail which can be included without compromising the anonymity of other participants. I revisit this later while discussing how this autoethnography evolved alongside the research.

4.2.1 Background to My Autoethnography

Although it may appear to be somewhat removed from the research topic, the first finding from the research was that I am autistic. This immediately changed the perspective from which the research was conducted, making me an insider rather than an outsider observing a community. While I could attempt to retell this story now, it is more authentic to include the account which I wrote at the time, followed later by some reflection and detail on the evolution of this autoethnography, and what this means in terms of the research. Including accounts from both early and late stages of the liminal journey which was being explored illustrates the magnitude of the impact of achieving self-acceptance, as well as how the participants' level of comfort with their current audience can affect how their story is told. It is important to point out here that autoethnography and insider perspective are not being conflated, but my autoethnography showcases what makes me an insider and, in this sense, the autoethnography informs the insiderness.

The book chapter, an excerpt from which follows, was written as I came to terms with my neurodivergence. This was written for a general audience and could, therefore, be read by anybody, including those who are strongly disparaging of neurodiversity and hold a very narrow-minded view of what an autistic person looks and acts like. The second account developed organically towards the end of the research, during a conversation with a person I trusted very much, and I had full control over how much to include in this thesis – similarly to how the interview participants knew that they were speaking to another neurodivergent person, and would not be identified publicly.

The first iteration of my autoethnography, (Harrington, 2020), follows.

4.2.2 The Eternal Bookworm, and the Moment the Penny Dropped

When Research Uncovers More Than Expected

> Although I started researching from the point of view of an autism parent, being an unapologetic bookworm and devourer of information meant it didn't take long before I started reading about autistic women and girls, and the sheer number of undiagnosed autistic women. And then the penny began to drop. I had started mentioning my research to various people, leading to a friend opening up to me about having recently been diagnosed in her early 40s, and I was curious. As mother to an autistic son, I had heard plenty of light-hearted (albeit, actually quite offensive) comments about him having inherited it from me, but never paid too much attention until this point. In fact, if I wasn't researching autism, I probably still wouldn't have paid much attention. I've always felt I was a bit of an outsider, that person who's not quite in a group but also not quite *not* in it, but that was just me. Even reading everything I could find about autistic women and girls wasn't out of the ordinary, as far as I was concerned.
>
> I love reading. I will read anything, and once I start, I cannot stop until I'm done. Ok, so my research wasn't specifically related to women and girls, but you know, I am a woman, and I have the seemingly inevitable middle-aged woman rage about being disadvantaged because of my sex, so off on a reading spree I went. I'm what you might call a completer-finisher. I get a bee in my bonnet and I'm not happy until I've sorted it. If you can see where this is going, you are already well ahead of where I was at the time. Anything I could get my hands on, I read it. Blogs, books, academic papers, none

of it was safe from me and my curiosity. And eventually - because I may be reasonably intelligent and an avid reader, but I'm not always the quickest at realising what's going on beyond what is explicitly spelled out - it hit me. These people were writing about me.

I had essentially become thoroughly engrossed in reading checklist after checklist of how my own life had played out so far. Not only was I researching an as autism parent, with the hope of contributing to making the world a bit better for my son, I was researching as an autistic woman, based on over three decades of first-hand lived experience. I might not have known it, but perhaps that's even better. Maybe there's some added value in not knowing that there was a reason why I behaved (or didn't behave) in a certain way. From a research perspective, it feels purer that I am looking back on my history which was entirely unaffected by any accommodation or adjustment for my autistic traits. That means that, when I look at how this transformational learning occurs in autistic people, I'm looking at how it occurred in me while I was being treated as neurotypical. Would knowing I was autistic have made a difference to how I lived my life, and how my parents approached certain situations? Probably, just as I would treat my son differently if I did not know he was autistic. The world is full of should and should nots, all of which have been designed to accommodate NTs and, growing up as an NT, this is what I was expected to adhere to. From a personal point of view, and a mental health point of view, there have definitely been negatives to that but, with my researcher hat on, I feel there is value to it.

Maybe that's something that I'm trying to convince myself is true as a kind of antidote to the feeling of not fitting in, being a bit weird, not always being quite sure why things I said were so funny… To be bluntly honest, trying to convince myself that the years of anxiety, depression, frustration, and despair were worth it. I'm not for a moment claiming that my life has been miserable, of course, but there have perhaps been more troughs than peaks. Anyone who is neurodivergent – a term which spans much more than just autism - can more than likely relate to the feeling of "why on earth can I not just do what everyone else seems to find so easy?"

This is not intended to be full of self-pity, so I'm not going to dwell on the feelings that being neurodivergent has either directly or indirectly contributed to throughout my life, but rather on how I can now use those feelings, emotions, and experiences to help ensure that it's better for those who come after me. If that's not motivation to put my all into this research, what is?

The Dawning of My Realisation

Going back to reading about undiagnosed autistic women, and what I now refer to - even if just in my own head - as the checklist of my life, here's some of what pushed me towards finding an online AQ test and getting some kind of confirmation of what I now strongly suspected. I am, of course, aware of the issues with the AQ test, and don't agree with the various empathising/systemising, mindblindness, and extreme male brain theories that are behind it (Baron-Cohen, 1995; Baron-Cohen and Hammer, 1997; Baron-Cohen et al., 2001b; Baron-Cohen et al., 2001a; Baron-Cohen, 2002; Baron-Cohen, 2004; Baron-Cohen, 2009), but it's what I had to work with, so I used it. There is a definite need for better autism diagnostic tools, or perhaps a need to do away with the notion that autism is something that needs to be diagnosed, and not just a "normal" variation of the human mind (after all, what is normal anyway?), but that's a discussion for another day. And one which I am more than happy to bore anyone to death with - open invitation to anyone who wants it. That's before I get started on the difficulty in having a GP take me seriously (" you're 36, what difference will a diagnosis make now?") and the incredibly long waiting list, which I am still occupying a space on. While I've been writing this, I've had a letter confirming that I am on the waiting list, and a questionnaire for my parents to fill in, so fingers crossed it won't be too much longer (although, that leads to the spiral of "what if I don't get a diagnosis…).

If you're reading this and wondering what, exactly, it was that led me to this rather important moment of self-understanding, perhaps because you're having a similar experience yourself, here's my basic list. Much of it is random things I remember reading *somewhere* and identified with when I first began exploring the possibility of being autistic myself and, to be very clear, I am not attempting to generalise at all, merely to outline and explain what stood out to me, but here it is:

- *Married young, got divorced*
- *Diagnosed with anxiety and depression for pretty much my entire adult life (and, with hindsight, it was always there)*
- *Difficulty maintaining friendships*
- *Terrible at exams, no matter how well I know the material (I also don't do well with being asked direct questions)*
- *Sensory problems with food textures and certain sounds*

There are quite a few but they're not what's important about me. Neither are your own, or anyone else's, perceived deficits what defines you. In the interests of discussion, I will say some more about how and why I identified with these particular traits.

Being an avid reader. Much as the stereotypical male autistic child lines up cars, or memorises facts about dinosaurs, I read absolutely everything. I learned how to read at a very early age - around 3 - and from that day onwards, I read. Everything. Cereal boxes, the small prints on ads, every book I could get my hands on… I read them all. One of my favourites was encyclopaedias, and my family still talk about how, aged around 7, I told my teacher that she was wrong, there is an animal whose name starts with Q, and it is called a quagga. To the teacher's credit, she believed me, wrote it on the board, and went home to find out if I did indeed have some very specialist knowledge. I did.

Being terrible at exams. This is very much a divisive one, as a look at a recent thread on my Twitter account will show (@susanisainmdom), but one thing that struck a chord when I read it in Laura James' Odd Girl Out (James, 2017) and elsewhere, was my inability to perform well at exams. I never did badly as such, but I could never quite achieve what I was capable of. Hence starting university at 31, when my youngest child went to school and I could get in through an access course rather than relying on my Leaving Certificate results (360 points, for Irish people who know what that means and just how, well, mediocre, it is). On a similar vein, if you ask me a question, I'll stare at you blankly for a few seconds, even if I know the answer. This doesn't mean that I don't know, or that I can't remember, I just cannot retrieve what I know on demand. It took me four attempts (at the age of 34) to pass my driving test, because I cannot bear being watched or tested.

Being oversensitive. This is another thing that was said about me a lot when I was younger. If you confront me, I will cry. If I am angry, I will cry. Basically, I cry. I cannot process emotion until I have cried and gotten past that initial feeling of "OHMYGODMASSIVEEMOTIONANDTOOMANYFEELINGS" and been able to work out what I'm really feeling. This may be 10 minutes later; it may be a week later. Whenever it occurs, I'll want to talk to you about what I really meant when I said something that wasn't actually what I wanted to say. Chances are, you'll have forgotten by then, but I'll need to get it out of my system anyway. I also take on other people's emotion a lot. I over-empathise to the point where I am drained and exhausted. In fact, there are times when I would welcome some degree of not being able to empathise, but I can categorically state that is not a universal autistic trait.

There are also plenty of perhaps more stereotypical traits that I can now relate to. I've always been a picky eater because I cannot tolerate certain textures. When my sons were babies, the sound of them crying physically hurt me, to the point where I would dread them waking up. If plans get changed, I get a little panicky. I DEFINITELY have special interests.

Much of what is said about autistic girls and their special interests being people rather than things seemed to describe me to a tee. I hate mess, but struggle to get the motivation to clean the house. I'm either unstoppable or unstartable, and can identify strongly with pretty much everything I've read about monotropism (Murray et al., 2005), in particular with the link between monotropism and flow made at a talk by Damien Milton I attended at PARC's 2018 conference in Glasgow.

I've been diagnosed with, and medicated for, anxiety since I was about 19. I had PND after both births. I've always felt like I don't fit in, like I'm somehow different, and I'm always, ALWAYS, tired. This world is not made for me, or people like me, and it is exhausting.

But this is all ok now, because I know why it happens, and I can make sense of it.

How My Own Autism Helps Shape My Research

My PhD topic relates to threshold concepts (Meyer and Land, 2003) and transformational learning, and how these present in autistic people. Briefly, a threshold concept is an element of learning which transforms the learner. It's not just learning some new information, or acquiring new knowledge, it involves a significant personal change which is very difficult, if not impossible, to undo or unlearn. The "downside" of this transformation is that the learner must go through a difficult process to get there.

Just as a child becomes an adult only through navigating puberty (which can be a troublesome time for those around the young person in question, never mind the young person themselves!), and a caterpillar becomes a butterfly in the cocoon, I have been through a troublesome, transformative, and irreversible experience which has undoubtedly changed my sense of self, and how I appear to others.

When I first became interested in threshold concepts, I was under the impression that I was neurotypical and, as such, was experiencing life and its various challenges much as everyone else could be expected to. So, although my research topic has remained the same, my perspective on it was virtually turned on its head just a short time into the project. The thing that may seem surprising to anyone who has not had such a realisation about themselves is that this was an entirely positive experience. The preceding 36 years, however, could most definitely be described as troublesome and difficult to navigate…

Admittedly, I do have some minor concerns about being accepted for who I am, and some internal debates around just how open I should be about being an (for now, self-diagnosed) autistic woman. Although, in fact, realising that I am autistic myself has been infinitely less challenging than awaiting diagnosis for my son. After almost 8 years of very little sleep, severely delayed speech, various other missed “milestones”, and a constant, overwhelming feeling of “why on earth can I not just do what everyone else seems to find so easy?” his actual diagnosis was very much welcomed. I felt no shame in having an autistic son, but what I did feel was worried.

Worried about his future, and how his life would turn out. Worried about how people would perceive him and treat him. Worried about how he would cope when I wasn’t around anymore to help. Worried about how I could make sure that he, for want of a better phrase, lived his best life.

Although autism research was not my initial choice - ironically, I felt like I was living in an autism bubble and should do something different - I very quickly realised that I could make this experience count. As the psychiatrist who diagnosed Jack said, he wasn’t doing (or not doing) specific things to be difficult, he was having a difficult time. Why would any parent not want to take the opportunity to make even the tiniest difference to that, not only for Jack, but for all the other autistic children and adults who are going to need to navigate this world at some point?

Who knew I was one of those autistic people? If reactions are to be believed, around half of my friends for a start. Especially the one who tried so hard not to head-tilt and say “well, duh”, that it was incredibly obvious that’s what she was doing. That’s still one of my favourite moments, it was hilarious. What I can say, even just a few months on from the realisation that I am neurodivergent, is that accepting myself for who I am has been life changing. I’m more comfortable in myself, I don’t try to be what I “should” be (most of the time, I’m still working on this), and I’ve now got a fantastic partner who accepts and loves me for who I am, and shares my disdain for the word “should”.

Autism, in itself, is not necessarily a problem. There may be other co-occurring disabilities and health problems making the lives of autistic people difficult, but autism is, generally, a disability in a social sense, rather than a medical one (Woods, 2017). Autism is not something to be cured, or eradicated, or prevented, or whatever else the numerous proponents of devastatingly dangerous “treatments” would like us to believe. The problem is the world we live in, where each of us is expected to conform to a sense of normal that doesn’t really exist. We’re supposed to act in a certain way, like certain things, enjoy being gregarious, extroverted, multi-talented, well, robots, who all come from the same mould. That isn’t reality. What is real is that humans are individuals, and each and every one of us should be celebrated.

The Importance of Making a Difference

It did not take long, once I became aware of autism, to also become all too aware of just how much misinformation there is about autism. I was probably guilty of believing some of it myself, before I was to all intents and purposes forced to pay more attention to autism, what it actually is, and what it is not. I’m deliberately not going into detail about my son’s autism, because that is his story to tell, if and when he decides he wants to.

I can’t change the world. I can’t single-handedly remove the prejudices, stereotypes, and negativities about anything that is deemed to be “other”, whether that is autism, gender, religion, race… the list is endless because, when normal doesn’t exist, the truth is that we are all “other”.

I am enough. Both of my sons are enough. We are all enough.

That is why learning from lived experience is incredibly important, and that is why I, and numerous other researchers (not to put words in their mouths) are working to be heard. To have the value of all neurodivergent people recognised, acknowledged, and actively embraced. Yes, we are different. Yes, some of us can be disarmingly blunt, or stim in a way that makes other feel uncomfortable, or have any number of annoying habits. But so can neurotypical people. Because diversity of any kind should be celebrated, and that is exactly what I intend to do I have already learnt a massive amount from my own experience, and it's only been around a year since I realised that was, in fact, my personal experience of being autistic.

Jack has taught me an incredible amount over the past 14 years too, not least of which is that autistic people can be just as caring, funny, bright, and downright stubborn and annoying as their neurotypical counterparts. Much of my experience of parenting Jack is exasperating beyond words, but there is a lot of pride involved in knowing that I have created this person who has enough conviction in his beliefs to hand his mother his beloved Xbox and say, "I'm not going to school". As an aside, parenting his NT brother is also exasperating beyond words at times. I suspect it's the responsibility of raising decent human beings that is a problem, not their individual neurotypes.

So, how does this all fit in with my research, in terms of learning from my lived experience? Quite simply, although my research topic has not changed, the perspective from which I am approaching it has, vastly. The realisation that, despite thinking that I was NT for 36 years, I am actually one of the autistic people I was seeking to help. I'm deliberately not going into huge amounts of detail about my research, as I want this to focus on lived experience. For now. Through that experience, I have become both researcher and research participant, alongside mother of a potential research participant. I have an insight I did not know I had, and I continue to learn from that every day. Perhaps most importantly, I'm learning that my own experience is not the same as anyone else's and, although I can do my utmost to help as many members of the autistic community as possible with whatever my research output turns out to be, it won't apply to everyone. Just as the past and current theories of autism do not apply to everyone.

At present, I do not believe that there is a single definition of autism, nor any one theory or model which can be applied appropriately and helpfully across the board. In fact, I'm not sure I believe there should be any single autism model or theory, nor that autism is anything which requires a theory.

I'm also left-handed and, while that would have been treated as "wrong" in the not so distant past (Flatt, 2008), it's now just an accepted deviation from the "norm" of being right-handed, although the world is still predominantly aimed at right-handed people (scissors and tin-openers, I'm looking at you). Left-handed tools and versions of everyday products have been made available, and nobody judges you as "other" for being left-handed. Maybe this is the ideal for autistic people. Having said that, I reserve the right to change my mind on this, just as I've changed my mind on so many other things over the past year of research, and 14 years of parenting.

Recognising differences, learning from new knowledge and experiences, and being open-minded to the realisation that you've been wrong, and willing to put that right, are what I think are important about conducting research based on lived experience. And that research is essential. As Donna Williams put it *"…Right from the start, from the time someone came up with the word "autism" [it] has been judged from the outside by its appearances, and not from the inside according to how it is experienced."* (Williams, 1996: 14). It's time to start focusing on what it is, from the inside, according to those who really know. This is what my experience has taught me.

Finally, I would like to be clear that I am not at all stating that all autism research has been wrong. There's been a lot of excellent, relevant, truly helpful research done, particularly in recent years. I would perhaps even argue that many of those early researchers who got it wrong, did their best based on the knowledge and information which was available to them at the time. ABA I will never defend or excuse, but plenty of the now-outdated research probably came from good intentions. When we refine and rewrite the literature relating to autism, we do that due to learning from lived experience. Autistic researchers, and those NT researchers who truly involve and

> listen to autistic participants are doing exactly that, and the importance of it cannot be stressed enough.
>
> The special interests/hyperfocus/monotropism thing though? That's true (in my experience). Take it from someone who's currently learning Arabic for no real reason, and has realised it's suddenly 3am more than once recently, following a totally oblivious few hours of "just one more Duolingo lesson" …

4.3 Analysing and Reflecting Upon the Interviews

At this point, I will leave the autoethnography for now and move on to the interviews, but will return to discuss how I revisited my own account at a later stage. This appears to be a good point at which to make this move as, although the different methods employed and the corresponding parts of this research were not independent of each other, with all three forming one whole rather than three separate perspectives on the research problem, the interviews did serve as a starting point for the subsequent elements. The role and importance of communities and networks became evident following the interviews, and so I now discuss the analysis of the interviews in order to illustrate how this theme emerged. The analysis which will be outlined in this section of the thesis refers to that which was initially conducted following the interviews, and which focuses on the individual Further insights, some on the level of the community but with relevance to the individual, were obtained from the interview data when it was revisited following the social network analysis, and I knew more about what appeared to be happening as participants progressed towards self-acceptance. This is in keeping with the phenomenological concept of qualia (cf. Tye, 2021) – as we had shared experiences, we could relate. My experience outlined in my initial autoethnographic account makes me an insider of the autistic community, which means that I am also sharing the qualia with my interviewees.

4.3.1 Themes Emerging from the Interviews

Prior to the interviews, some loose themes had been predefined. As I was interested in how self-acceptance felt for each participant, and how they had changed as a result, the main predefined themes were around self-acceptance, understanding of self, and transformational change. I had provided an information sheet explaining the basics of a threshold concept along with the participant consent forms, so each person understood these before the interviews began. Each interview, or conversation, started with an invitation for the participant to talk about whatever they felt was relevant, and were comfortable with discussing, while thinking about identifying themselves (or being identified) as autistic, and the subsequent changes in themselves and their lives.

During the conversations with participants, and when revisiting the transcripts and emails later while reflecting upon the interview experience, some definite themes began to emerge. Some of the themes, such as self-acceptance (coded as sense of self) and transformation (coded as lightbulb moment, after this term was used by a participant), were specifically mentioned in the introduction to the research (see Appendix 2: Threshold Concepts Information Sheet), and in the participant information sheet, so were fully expected to appear regularly in the transcripts. However, others, such as community, were not deliberately included in the interviews, but featured heavily as an emergent theme in each.

World Vew		1	2
Understanding V Memorising		1	1
Sense of Self		11	19
Relationships		3	4
Quote		11	27
Personal Threshold Concept Suggestion		2	4
Negative threshold concept		1	2
Masking		2	2
Lightbulb Moment		8	13
Issues and Obstacles		4	6
Imposter Syndrome		1	1
Downside of disclosing		2	4
Control		1	1
Community		8	13
Benefit		2	2
Background		2	2

Figure 21 - NVivo themes

Each of the interviews had an underlying theme of difficulty in childhood and early adulthood, followed by some level of accepting differences and coming to terms with being autistic. As can probably be expected when talking about such a personal and emotive topic, some participants were more forthcoming than others. While there was a general consensus that self-acceptance as autistic was a transformative moment, there was also some rejection of it. The presence of self-acceptance as a theme was not surprising, given that it was the example provided to potential participants, and that which was used to open each conversation.

However, what was less expected was the frequency at which comments about self-acceptance were quickly followed by, or interwoven with, a more negative perspective (perhaps signifying some kind of struggle with the self or others, in keeping with the difficult terrain of the liminal journey (see Figure 12). While my own experience, and my interaction with the Twitter community had made it evident that self-acceptance as autistic would be a highly relatable topic, it was not until after the interviews that I realised that it was not quite that straightforward.

In the following sections, I share some quotes from the interview transcripts, which I have selected as they represent the various themes well, whilst also protecting the privacy of the participants. The transcripts have not been included in full for the same reason. The participants may be identified without any obvious personal details, should certain elements of their story be known.

4.3.2 Self-Acceptance and Validation of the Self

The first theme discussed here, *self-acceptance*, was the potential threshold concept mentioned in the introduction to the research that was given to prospective participants, so it unsurprisingly featured quite heavily in the interviews. Being one of the pre-defined themes, self-acceptance tended to come up relatively early in the conversations, serving as a starting point from which the more emergent developed. As discussed later, although self-acceptance was undoubtedly a strong starting point for the conversations, and remained the underlying topic of the discussions, it was just that – a starting point.

Some examples of how this self-acceptance, and the often-traumatic experiences leading up it, were discussed follow.

> *"I think discovering neurodiversity made me feel validated, like my sense of self had more worth, you know? Other people agreed that my life was worth something, and I wasn't on my own anymore. There's a big difference between parents and teachers telling you 'there's nothing wrong with you, you're just different' to reading about other autistic people, and how being different is actually a GOOD thing. That's the main difference that made me understand myself better, the social model of disability. Rather than 'there's something wrong with you, but that's okay' it was 'there's something wrong with society, and that's not okay.' (Participant 1)*

> *"The more I learnt about autism the more knowledge I had, and knowledge is power. I was able to advocate and articulate myself and be proud of my identity. Before it had been a shameful secret I'd only tell people in confidence like you'd tell them you had a fungal foot problem!" (Participant 6)*

> *"But I started to see that, you know, maybe there was something about me. That was different to other people that have either a clinical identified reason that wasn't "you're a really shit person, who is really shit at life". I mean, one of the big things that executive dysfunction is that before I read that I have only explanation. I thought I wasn't kind. I thought I wasn't nice because I couldn't do really basic and get calls or sending an expected it to somebody or remember that birthday or remember to ask because that you know something was going on in their life and before before detox and counselling helped with it, but in the really dark times before that, I just thought I was a horrible person also potentially a psychopath because I have alexithymia, which has identified in my diagnosis interview with Sarah Hendrix" (Participant 3)*

While each of the participants spoke about their own experience, working with other autistic people gave some a further insight into how powerful self-acceptance can be, and an appreciation of how important it is to recognise the value of enabling people to understand themselves. In the quote below, one participant is talking about both her own journey, and how she has seen it unfolding in others.

> *"And then within a very short space of time, they're very often, you can watch them grow in confidence and self-belief and the identity and self-acceptance is actually an enormous part of that is understanding that you're not… You're not a broken version of a normal human being. You're a really wonderful version of a slightly different human being, which is the autistic person and and yeah so that's, you know, self-acceptance." (Participant 8)*

4.3.3 The Negative Aspects of Working Towards Self-Acceptance

Alongside the discussions about how diagnosis (whether formal or through self-identification) allowed each participant to come to terms with themselves, and see themselves in a more positive light following a lifetime of feeling like they did not fit in, or were missing things that everyone around them seemed to get, came descriptions of the less pleasant side of gaining a better understanding. Bearing in mind just how traumatic it can be to grow up as an outsider or misfit, as expressed by interview participants in conversation, and in published works, for example (James, 2017; Kurchak, 2020), it is not uncommon for those who learn about being neurodivergent as adults to harbour some level of anger or resentment over what now seems to be unnecessary hardship. Sometimes, this is short-lived as one comes to terms with their new perspective on themselves and their lives, but it can be quite a significant issue. This applies to even those who had a stable and happy upbringing, and can be exponentially worse in those who were subjected to abuse, or forced to undergo abusive treatments and therapies, such as ABA (Milton and Moon, 2012).

As the following quotes illustrate, self-acceptance tends to be complex. Participants who felt they were fully prepared for diagnosis, and had been certain that they were autistic before their assessment, sometimes found that having it confirmed officially triggered mixed emotions.

> *"…expected that having my suspicions confirmed would be a really positive experience and life would go on as usual, but I found the whole thing really*

over whelming and emotional. The initial two weeks after my diagnosis were very hard, I was very teary and didn't like being on my own (which is super strange for me, being on my own is how I relax). It was a gradual process to feeling normal again, mood wise." (Participant 2)

"This is a process though and takes time to work through; it is similar to the stages of grieving, in a way. I had to say goodbye to the person I had been trying to be all my life and become a new me, hopefully a more authentic me. But in order to be your authentic self you need a loving, supportive network of people who accept you and your diagnosis, and this is not often possible for the person who has been masking their difficulties and camouflaging themselves to fit in throughout their whole life." (Participant 4)

"…he asked me if I had chosen to live that way and I said, 'Well. Say there's a box of chocolates. Someone says you can choose any chocolate you want. Ah, oh, not that one. Not that one either. Oh no, you can't have that one. And in fact, the only one that's left that you are allowed to choose is the marzipan one and you really want a chocolate, so you choose it. Have you really chosen it? The alternative is not to have a chocolate at all.'" (Participant 7)

"I'd say that being diagnosed/thinking of myself as autistic has been a very significant change in my life and so does probably fit most of the criteria for a threshold concept. I can't go back to my previous, unexamined, sense of self. But this brings with it awareness of many of the common conflicts between the autistic person and their environment (environment in a broad sense, including social). I think I have limited scope for changing this environment (I don't want my marriage to end, for example) so I experience some unresolved conflict." (Participant 5)

> *"It did have an impact people did treat me differently. And I still find that people who should know better. To them, I'm just the autistic person as opposed to someone with a huge a lifetime of qualifications, professional training, professional experience, life experience, and the and the autistic person who's got a PhD and founded [an organisation] … You know, and actually, we need to, you know, which needs to be there and that sometimes I just want to head out to people that don't report, but to be honest there. SOMETIMES IT'S SO INSULTING, you know, it's like reduced down to being the, you know, the autistic person. But, I mean, we just don't know. I do mean that it's like that, you know, like I said, I've had become a two-dimensional thing. […] And I suppose there's some kind of I don't know the word for it, not quite shame, but if you discover that everything that you've believed has been categorically wrong. That's probably going to give you some negative thoughts about yourself, at least temporarily, like how can I be taken in by this outfit?" (Participant 8)*

These mixed feelings about the participants' own senses of self were also evident in my own accounts when I compared what I said about my own neurodivergence at different stages of the research (see 4.5.4, 4.5.5, 4.5.6 and my reflection which forms Chapter 7).

4.3.4 Transformation of Sense of Self or Worldview

With the exception of one participant, each interview involved some mention of transformed worldview as a result of self-acceptance as autistic. The one who stated that this did not apply – a point which they raised at the start of the interview, in response to the threshold concept information sheet that had been provided – did confirm that their sense of self had changed dramatically, but did not agree that this necessarily equated to a change in worldview.

> *"And then within a very short space of time, they're very often, you can watch them grow in confidence and self-belief and the identity and self-*

acceptance is actually an enormous part of that is understanding that you're not… You're not a broken version of a normal human being. You're a really wonderful version of a slightly different human being, which is the autistic person and and yeah so that's, you know, self-acceptance" (Participant 8)

"I am now more aware of certain aspects of myself, what is a direct result of my autism. I think I've also learned to be a more aware of my own needs and a little less hard on myself when I need some extra care. But there is always more to learn in that respect, it's still ongoing" (Participant 8)

"I just read everything that I possibly could and with it came, came up the realization that this applies to me. […] And if this applies to me then explained, a lot of the problems that I had in life that have contributed to that crash, contributed to the alcoholism, contributed to alcohol to cope. […] There was an autism diagnosis would help me to explain myself in a way. I've never been truly able to before, because everything that comes with an autism diagnosis. Whether you call it different weakness deficit advantage, brilliant brain Einstein or incapacity all of those things were things I had been tenuously aware of in myself." (Participant 3)

"I remember even as a small child feeling that there was something vitally important that had been told to everyone except me, or that everyone else must have psychic powers and I had been left out." (Participant 7)

"Thinking that everybody was doing the same because I literally thought, well, this is how people think, right. And then when I started talking to my partner pre diagnosis. She was like, "what are you talking about, like, I don't do that". And then I would ask my brother, and he's like, I don't do that. And I'm like, what, what do you mean, you guys don't do this like don't actually supposed to do this. And they're like, no, that's not what we do. And I was like, huh, okay" (Participant 9)

> *"Being diagnosed meant having answers, meant fitting in with a different bunch of people - being like a certain subset of the population, not as I'd previously thought, a bit crap compared to most of them. It was only quite recently I actually had to realise that this joy at being diagnosed is very much specific to late diagnosed people and loads of those diagnosed young are just low level pissed off in a 'why me? this is HARD' sort of way. Which I also totally get because I bet if you'd told me at 15 or younger, I'd have hated it. Though I do think there's loads of autistics out there who manage to bang on about how brilliant it is being autistic in one post then follow it up immediately with one about how they had sensory overload leaving the house and the NT world hates them. No, I don't much get that either. So being diagnosed/recognising yourself is amazing and the rest of it - the being autistic bit - is like everything else. Some good, some annoying, some downright shit." (Participant 3)*

The last line which has been included in these quotes – "so being diagnosed/recognising yourself is amazing and the rest of it – the being autistic bit – is like everything else. Some good, some annoying, some downright shit" – is one of those which prompted me to look beyond the statements of self-acceptance being an overall positive experience, and to look further than the identities as autistic people. If there are bad elements to being autistic, are there also bad elements to interacting with other autistic people? In this instance, this would relate to being part of the Twitter autistic community.

The comment mentioned earlier, about a changing sense of self and a changing worldview not necessarily being related, was also a catalyst in this process.

4.3.5 Meta-Schema Formation

This section of the discussion lays out some of the quotes which represent what I am referring to as meta-schema formation. This is where the smaller parts come together to form the whole new "self" that is accepted following the liminal journey. The term "meta-schema" is also intended to fit with the concept of knowledge levels (Méro, 1990; Dörfler, 2010), as discussed in the literature review, and as an alternative for the portal analogy used by existing threshold concept literature, for example (Meyer and Land, 2003). Rather than viewing mastering a threshold concept as passing through a portal, it could be described as meta-schema formation, or the development of an updated, high-level belief system through which an individual's elementary schemata (in any case lower-level schemata), or smaller beliefs and perspectives, are formed. In other words, a change which also influences the overall perspective on self, worldview, or both.

> *"And I was sitting in the senior academic who was talking I was sitting directly next to me and I was turned and looking at her and she taught me that same list of people. And I think she turned to me specifically and said something about, you know, people who have a sense of service. […] And that's why they know basically they sign up to do all of these different things to help the department. And it was it was hearing her say this sense of service and specifically directing the description to me. I felt like I really quite literally had one of the kind of house moments of like the committee goes on talking. And I kind of and went off somewhere else a bit. But that was really like quite a light bulb moment. And this is where the explanation gets a bit personal, because I've been told my whole life, especially by my mother, what a terrible, terrible person I was just constantly every day that you are a really terrible person.* […] *You know, maybe some of those other things are just just not true, perhaps, or maybe… maybe I do have a sense of service, maybe, maybe that's what it is, rather than feeling like I need to try to atone for something or it is it was very strange and kind of uncomfortable, but also in the slightly longer-term sort of lightening. […] Yeah, I don't know if I looked quite peculiar at the meeting or not or managed to just like, keep sort of nodding along with, you know, talking about tutoring and whatever. But it was it was quite unexpected and out of out of nowhere in the middle of*

this committee meeting. But it was certainly a House moment.” [2] *(Participant 10)*

“And some really big pennies dropped right from the start looking back over life I've kind of described it like being given a pair of glasses when you didn't know you needed glasses you felt the world look like that to everyone… Now, two weeks ago was like the first time in my entire life that I could look back sort of with the new glasses right and I went like, oh yeah, like that. Obviously, you know and… and sort of that was what allowed me to move forward and to say oh yeah now. Okay, so now I understand why my mother got mad at me and it was because of this mismatch and communication which had to do with my autism.” (Participant 7)

“And again, in hindsight, and I'm almost examining this as I talk to you, but in hindsight it almost may be almost like a rebirth in a way” (Participant 1)

“There was one woman in particular who would drive two hours each way to get or an hour and a half each way maybe and the first couple of meetings. I mean, I've never forgotten it, because it was transformational for me as well. It was extraordinary. And she just sat there she wouldn't say anything during the meeting. And then at the end of it. She’d just go “I just never met another woman like me before. I've never met other women like me before in my life.” And then she kind of went away and then she came back the next day she did the same thing she did. She was with [the group] for a while, but I remember looking at that, just thinking, and that's just enormous that is absolutely enormous.” (Participant 8)

“Then obviously sent me into an internal rabbit hole of personal threshold concepts. Divorce, detox, CBT.... Part of the reason I got a bit cross about

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[2] The term “House moment” was used by the participant to express their understanding of a threshold concept. This relates to a conversation between Lyra and a former nun in The Amber Spyglass (Pullman, 2017), where an analogy is used to discuss a transformative experience.

> *the autism diagnosis is I thought I'd gone through a big life transformation with packing in drinking, I was all 'WHAT NOW I'VE DONE THE WHOLE SIGNIFICANT LIFE CHANGE THING.' I've kind of got the hang of life being more a series of continuing change though. Dammit." (Participant 3)*

4.3.6 Community and the Importance Thereof

The theme of community, and the importance of belonging within a community, is one which was not deliberately included in the interviews, but which repeatedly came up. All of the participants spoke about finding somewhere they felt they belonged, which may have been prompted by threshold concepts enabling membership of a particular community, but which also arose several times during conversations.

Prior to, and indeed during, the interviews, I had been somewhat aware that community would be important, however, it had appeared that finding one's place as an autistic person would fulfil this. After conducting each of the interviews, and reflecting upon the process, it was this unplanned emphasis on community which prompted me to add the next stage of the research, which explored participants' social networks in terms of the community they had built around themselves, rather than focusing on the community they belonged to due to being autistic. The term "community" , as used here, refers to any community, and not specifically to any one of those defined in Table 6.

> *"…Got on very well with and one or two really taught me through the whole journey of pride and language mattering and I kind of got that after a while… Black and gay... it's… big, big because it's, it's… It's fundamental to huge chunks of your life, who you end up with, why you're treated or, you know, cultural histories… That being black and gay doesn't mean that you're going to like rap and drag you might just as much like Beethoven and vote Tory. I don't know. It's, it's not actually part of your personality only in the way that it's affected how you've been treated and your personality… I'm gonna definitely want to think about this more. So I wonder if… I wonder if the shared experience that the… the glue that keeps a community together. I wonder if that's more about the shared experience of trauma of being*

misunderstood, and actually a lot less about being any commonalities between autism. […] "Then when I started professionally supporting other autistic people, I'd have doubts about the validity of my diagnosis. I'd ask myself how it can be possible that I can work full time and support others who are struggling with the exact same condition that I have (in name at least). There aren't many public-facing successful autistic people, especially not 5-8 years ago. Where there was a group of them was in the conference/research world, so I gravitated towards there. Meeting other successful or semi-successful people, either by measurement of employment or by social relationships, was helpful. I felt like I was more like them than the people I support - yet we all had the same label." (Participant 1)

"It's not just about that it is actually so much more than that, it's very much about people having positive relational experiences. And sometimes, you know, like they're just not used to having friends like that where people to get them. It's about shared language. It's about identity, it's about. It's about community." (Participant 8)

"It's not about just the diagnosis. It's about the community and about identity" (Participant 4)

"And then, um, I went out with a girl who was studying social science at Coventry Polytechnic, where I was moving into town. And, uh. And so she's doing a bit of psychology, but a social history and stuff… I helped her out with its research and some of our studies and things and really doing some of the library books on a list and then she seems to suggest that I got this stuff better than she did initially, and was like, why aren't you doing this at university yourself? And, um, and that... This just not knowing that sociology exists. It is a subject that you can study, up until I was twenty-one. And so throughout my school life, I was the subject didn't quite fit with my interests and, uh, I was my favourite subject. So things like philosophy and sociology …So I kind of found these areas kind of by chance and by meeting people

> *and, uh, that kind of opened the door to the idea like. Do this is a subject. Got a degree…" (Participant 11)*
>
> *"…my best friend's a 40-year-old man who's clearly autistic and all my other friends I've downloaded off the internet because it's easier" (Participant 3)*
>
> *"This is a process though and takes time to work through; it is similar to the stages of grieving, in a way. I had to say goodbye to the person I had been trying to be all my life and become a new me, hopefully a more authentic me. But in order to be your authentic self you need a loving, supportive network of people who accept you and your diagnosis, and this is not often possible for the person who has been masking their difficulties and camouflaging themselves to fit in throughout their whole life." (Participant 2)*

There is more about effect on relationships and so on, but the more I read through the transcripts, the more I see that there's not really a tangible theme that led me to looking at communities and networks, so much as there was just a general vibe in the conversations. There are mentions of things like "people who get you" and similar, which is probably where the idea really came from, alongside someone mentioning they had joined Twitter to interact with other autistic people, and deleted their account after a few days, when they realised how toxic much of the Twitter autistic community is. There is a lot of focus on moving from trying to fit in, to one day realising you have found somewhere you do fit in (and it's generally not the place you were trying to get to). This general sentiment echoes what is posited by the neurodiversity paradigm (Singer, 2017) – autism and other forms of neurodivergence are not inherently disabilities, they are differences.

Much of the difficulty faced by the neurodivergent stems from a lack of understanding, and an overly rigid insistence on enforcing cultural norms (see social disability and socially situated difference in Glossary). As these issues are, of course, removed by surrounding oneself with like-minded people (Crompton et al., 2020), I was by now very curious about whether or not autism was what was really at the core of these people's identities, or if it was simply where they had managed to find a place where they did not feel as, for want of a better word, weird.

Was this autistic setting where they belonged, or was it where they found a sense of themselves, and became comfortable enough to explore the rest of their identities?

With this question in mind, I set about exploring the Twitter network of each of the participants, with a view to seeing how major, or minor, a role other autistic people featured. It is also at this point of the research that my emotions and intuition started to play a bigger role in how the research progressed. As already mentioned, I had assumed that the community to which self-acceptance allowed the participants and, indeed, myself, to belong to would be the autistic community. When following the pattern seen in existing threshold concept literature, this seemed the logical path to follow. If an accountancy-related threshold concept enables one to become and think like an accountant, and a physics-related threshold concept enables one to belong amongst physicists, surely the outcome from accepting oneself as autistic, or neurodivergent, was that sense of belonging amongst others with similar experiences and neurotypes (Crompton et al., 2020).

4.4 Cycling Between Social Network Analysis and Interviews

As mentioned previously, in the earlier stages of this research, my basic assumption had been that the outcome of accepting oneself as autistic following late diagnosis would be, in very simple terms, finding a sense of belonging amongst others in a similar situation. I did not assume that autistic people were a homogenous group, although perhaps did not quite recognise just how much heterogeneity would exist.

On the face of it, the interviews appear to support this view, with each of the participants talking to some degree about never having felt that they fit in until they found the autistic community, and recognised themselves in it. From the interviews alone, and indeed the autoethnography which I had written during the early stages of the research, it did seem that belonging came from finding these people who had similar experiences, both positive and negative, and who could relate to each other. However, my intuitive sense at this point was that this was not the full story. The quotes from the interview transcripts show this positivity and sense of belonging within the autistic community, even without specific questions being asked of the participants. Of course, it may be suggested that, as I was researching self-acceptance following a late diagnosis, and doing so in the autistic Twitter community as a member of the same community (see Table 6), there may have been an implicit understanding that this is what I was specifically looking for. I do not believe this to be the case.

The findings from here become somewhat more difficult to illustrate explicitly, given the role which my own experience, and the understanding this created between myself and the participants by means of this shared knowledge background (see Section 3.6, and page 132). There is no concrete way to explain why I decided that there may be more to be found by looking at the participants' personal Twitter networks, other than saying that I had a strong intuitive feel as an insider that this was important. The following sections detail what I found from this social network analysis.

4.4.1 Delving Further into the Interview Findings by Considering Communities

Defining the Community

As has been mentioned earlier in this thesis (see Table 6), while I refer to the "autistic community" throughout, this is done for ease of reading. There is not one autistic community, just as there is not one community comprised of everyone who is not autistic. Rather, there are a constellation of smaller communities and networks, overlapping with one another to varying degrees, the most relevant of which are outlined in Table 6. The specific community which is relevant at a given point is stated for context. Autism, for reasons which are beyond the scope of this research but have been outlined in the literature review (see Section 2.2.5), is a term which can encompass a broad range of very different traits and support needs. As such, it is not possible, nor ethical, to profess that any research or practice is generally applicable to autistic people. This thesis discusses how certain methods were used by me to explore and identify the communities to which a very specific subset of autistic people belongs.

To recap, the threshold concept which was explored was self-acceptance as autistic in late-diagnosed autistic adults. The particular subset, which was studied included those who were over 18, had no co-occurring learning disability, and considered themselves to be either a professional or an academic. Even this seemingly well-defined group of people have a level of heterogeneity which showcases the fact that all autistic people are not the same, despite common misconceptions in both research and practise, as discussed in Section 2.2.

Before continuing with this part of the discussion, I would like to revisit what is meant by the terms “the community” and “autistic community” where they are used here (see Table 6). Firstly, for ease of reading, I refer to the autistic community in the singular, however, this relates to a range of communities which are inter-related to varying degrees. As communities of practice have been mentioned earlier, it is perhaps pertinent at this point to briefly mention that “autistic community” encompasses both what Wenger et al. (2011: 11) refer to as a network – “the set of relationships, personal interactions, and connections among participants who have personal reasons to connect”, and a community – “the development of a shared identity around a topic or set of challenges. It represents a collective intention – however tacit and distributed – to steward a domain of knowledge and to sustain learning about it.” That is, what is being explored here is a constellation of communities (Wenger-Trayner and Wenger-Trayner, 2015), and not one standalone community.

Further research is required to explore each of these aspects as they relate to this particular group in more depth, however, the definitions of “community” in Table 6 are used for the purposes of this thesis.

4.4.2 From Interviews to Social Network Analysis

While conducting this research, social network analysis was one of several approaches adopted to gain as in-depth an insight into the participants’ experiences of threshold concepts as possible. Introduced in the later stages of the research, following autoethnography (Butz and Besio, 2009), interviewing, and some element of Twitter text analysis, the social networks of those participants who had most strongly communicated that they had experienced the threshold concept in question were analysed with a view to exploring whether or not their accounts, and their own perspectives on their own experiences, were reflected in the communities in which they currently belonged. As such, the social network analysis could only provide meaningful results when I knew what I was looking for, and would not have been as effective - or, indeed, at all effective – had we taken this approach in the first instance.

It was only through combining the rich findings from the interviews (the individual) with the ability to analyse Twitter networks (the individuals as members of this community) that I could obtain information that went beyond the numerical data generally offered by this social network analysis methods, reflecting the sense of belonging and community underlying each participant's Twitter network.

4.4.3 How Twitter Networks Can Indicate Post-Liminality

As mentioned earlier (see Section 2.3 and Figure 10), threshold concept experiences involve three phases; the pre-liminal phase where the new knowledge is first encountered, the liminal phase where the learner processes the conflict between this and their previously-held beliefs, and the post-liminal which occurs after the threshold concept has been mastered (Meyer and Land, 2003). It is at this post liminal phase where the learner finds their belonging within a community – this may be related to the discipline in which they are learning, or a group with which they identify. In this case, the research was conducted with membership of the autistic community in mind as a potential indicator of the threshold concept in question having been mastered. The rough idea behind this, based on both personal experience and informal interaction with other late-diagnosed autistic people, was that the three stages would look broadly as follows in Figure 22.

Figure 22 - Stages of self-acceptance illustrated in terms of belonging

As mastering the threshold concept is what enables the movement from the liminal phase to post-liminal, and is what allows membership of a particular community, what I was exploring was how this experience presents. In brief, the interviews involved participants discussing how the movement from the second to third phase happened for them. I had been expecting, albeit at least partly unconsciously, the “here” to be the autistic community, however, reflecting upon the interviews with other late-diagnosed autistic adults revealed that was not, in fact, the case. Rather, it was not the full story.

It would have been plausible to assume from the interview coding and the earlier Twitter analysis that the participants did feel that they had found their place of belonging in the autistic community, even if not specifically the Twitter-based one. There is no doubt that autistic people do feel a sense of belonging with other autistic people, as discussed by, for example (Crompton et al., 2020; Davis and Crompton, 2021). We do. But not with any and all autistic people, with those autistic people who are like us. Remember, it is not a homogenous group of people and, even if it was, autistic is not *all* we are. In terms of the analysis, this meant that the community and the individual were not truly separate units of analysis, as the community consists of the individuals within it, but it is also something more than the sum of its parts.

From the interviews, during which each participant discussed their own experiences of self-acceptance, there was a strong sense that what people were saying did not quite match up with what they had actually experienced. This is not to belittle those participant’s own experiences, nor to suggest that they have not had a troublesome period of learning about themselves, rather, it appeared to echo the sentiment of not all which is troublesome or difficult being threshold (Hill, 2010; Hill, 2020; Adler-Kassner et al., 2012; Land, 2015; Perkins, 2006; Yeomans et al., 2019), warranting further investigation. There was also a strong element of the richest insight coming from what was left unsaid, but which I understood as a fellow neurodivergent adult. I recognise that this mutual understanding of what was not explicitly communicated aloud is not evidence in itself. However, it was at least a catalyst in the various decisions made throughout the research, namely such prompts indicated to me that there was more to be found, and so I pursued it. Acknowledging and exploring the role of pre-understandings in such decisions is in line with the logic of bracketing (Dörfler and Stierand, 2021) – any pre-understandings and judgements need to be acknowledged so that they can be explored for insight rather than having an unidentified effect on the findings.

Given the importance of belonging and community in threshold concept literature, and, indeed, literature discussing participatory autism researchers as a community of practice (Wood and Milton, 2018; Milton et al., 2019; Fletcher-Watson et al., 2019; Guldberg et al., 2019), the next step in this exploratory research involved looking more closely at the communities to which those participants who appeared to truly have found a place where they belonged, do belong. This changed the illustration above to look more like Figure 23:

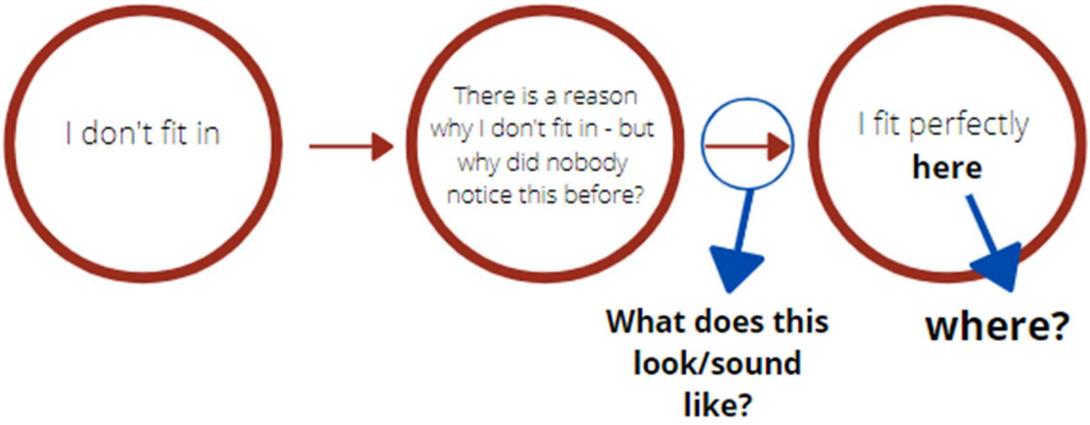


Figure 23 - Self-acceptance, as it related to a sense of belonging

As the objective here was to look at who was closest to each of the participants, with a view to identifying whether or not the autistic community was where they found their sense of belonging, I found that more traditional methods of conducting social network analysis did not fully apply, and certainly did not provide the clearest illustration of each person's social surroundings. In the following section, I outline the steps taken, with some explanation behind each.

4.4.4 Social Network Visualisation Using NodeXL

As the social network analysis followed in-depth interviews, the aim was to visualise each user's Twitter network, exploring the commonalities – or lack thereof – which may indicate a shared network. Each of the participants interacted with what was initially considered to be the general autistic community on Twitter, identified by the use of the #ActuallyAutistic hashtag, and had expressed finding this community useful, to varying degrees. At this point, it is perhaps useful to emphasise some key themes from the interviews and autoethnography which informed the network analysis:

- Although #ActuallyAutistic is a prolific hashtag used to signify that a tweet was made by an autistic person, it can be problematic in itself. The reasons behind this are beyond the scope of this research but, in brief, opinions are divided on whether or not the hashtag is useful, and debates are ongoing around how inclusive it truly is
- As the above suggests, there is not one autistic community, but a number of smaller communities forming the constellation that can be broadly identified using the hashtag
- Those participants who seemed to convey a sense of transformation most strongly also indicated that they had moved on from feeling like they belonged in the autistic community, or, perhaps, that this was no longer where they felt they belonged most
- While recent studies have reported the transformative impact finding other autistic people to talk to can have (Crompton et al., 2020; Davis and Crompton, 2021; Sinclair, 2010), the accounts of the participants appeared to go somewhat beyond this. Being autistic is undoubtedly part of the participants' senses of self, but it is not the whole picture, and therefore it would not make sense to stop here.

4.4.5 Exploring #ActuallyAutistic

Although I am aware of the limitations of the hashtag, #ActuallyAutistic remained the most representative way of accessing the wider autistic community as it exists on Twitter. While the interview participants mainly expressed that they did not feel that this was what they identified as their place of belonging, obtaining an illustration of this network was considered important for purposes of comparison, when viewed in conjunction with the findings from the interviews.

Using NodeXL, a total of 74,000 tweets containing #ActuallyAutistic were retrieved. These were analysed using eigenvector centrality to measure influence in the network, or the importance of each node (user) when considered alongside its neighbours (Parand et al., 2016). Betweenness and closeness centrality were also measured to create a better image of who was active and important within the community (Junlong and Yu, 2017; Grandjean, 2016), and to allow for visualisation. These particular measures of centrality were used as they are widely used in existing social network analysis research, and maintained as they provided the illustration of the networks which was required, as detailed below.

A graph was then created of the clusters within this network, another way of showing the level of connectedness or, in other words, community. It was this clustering which provided the most meaningful insight when used to view each of the participants' own networks separately from the overall network. The clusters of Twitter users in each of these six networks were explored manually, based upon the feeling which was taken from the interviews that their autistic identities may not be the same as their overall sense of "self".

Firstly, I discuss the social network analysis as it related to the #ActuallyAutistic network in its entirety. This initial analysis resulted in the 74,000 tweets being grouped into 26 clusters, or smaller networks within the network. As the image below (see Figure 24) roughly shows, this involves a number of quite distinct groups, each represented by a different colour, with a lot of interaction between the nodes. The interactions which were included (follows, followers, mentions, and retweets) are illustrated by the grey lines joining each node. When visualised on this scale, the various subgroups are visible, but not particularly meaningful beyond representing some interaction related to #ActuallyAutistic. As such, the quantitative element was present, however, it became clear that further interpretation, and exploration of what this actually meant, was necessary.

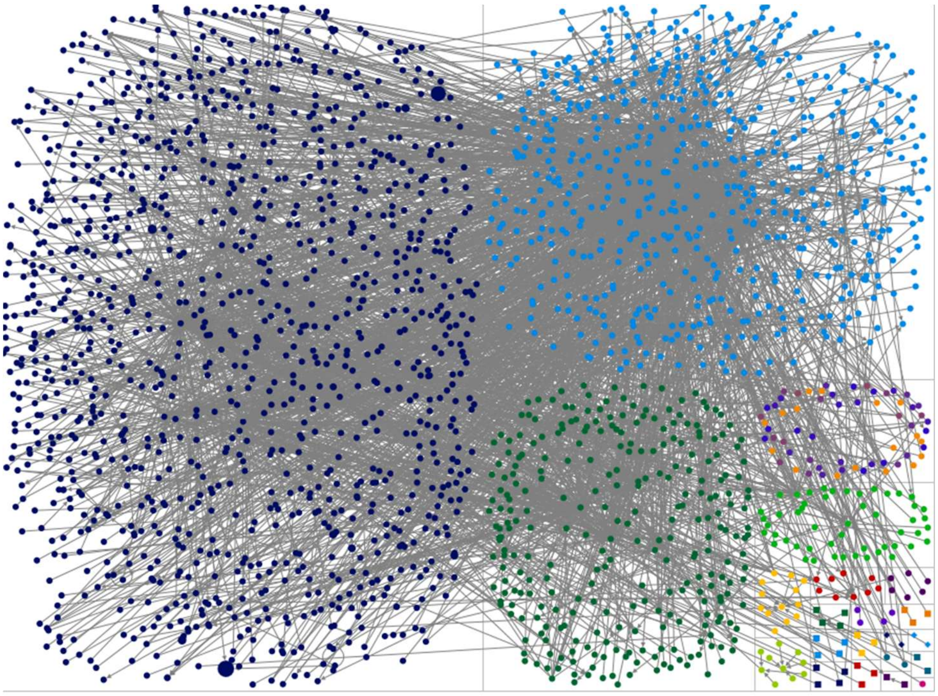


Figure 24 - Visualisation of #ActuallyAutistic Twitter network

While it may seem counterintuitive to include a visualisation which I am also saying is not particularly relevant to exploring the community element of this liminal journey, this does in fact contain some information that I then interpreted alongside the knowledge which I had gained from the interviews, prompting me to narrow the visualisation to certain participants, rather than continuing to analyse the network as a whole.

When a sociogram, such as that shown in Figure 24 above, is produced, the most influential person in a network is displayed as the biggest node. There are two in the sociogram above (Figure 24) which are clearly larger than the others, both contained within the dark blue network on the left. When we focus on these two nodes (see Figure 25 and Figure 26), it becomes quite clear why the quantitative network analysis could be more useful within an interpretivist framing – a positivist approach simply would not be sufficient for our purposes:

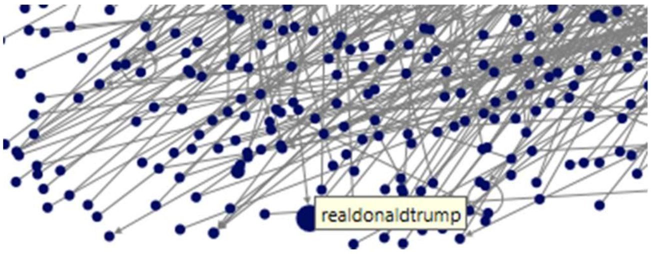


Figure 25 - #ActuallyAutistic most influential nodes - Donald Trump

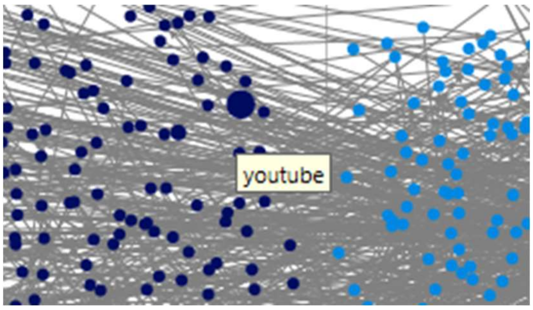


Figure 26 - #ActuallyAutistic most influential nodes - YouTube

When creating a visualisation of the network based purely on the quantitative measures, the most influential nodes are Donald Trump and YouTube. Given that YouTube will be mentioned in a significant number of tweets each day, and that this data was obtained around Greta Thunberg's 18th birthday, where her conflict with Trump was resurrected - not to mention that the U.S Presidential elections were in the near future – these being important nodes is fine in itself. If we were interested in the topics discussed by the network, this would be meaningful. However, it does not tell us anything about the people behind the nodes. Focusing on combinations of keywords does not produce any significantly more meaningful results in this case either, as it is unlikely that the people in whom we are interested happen to use the same words in their Tweets. This is in keeping with the outcome of analysing the interview transcripts – coding and keyword analysis would not work, as it effectively removed the personal aspects of the communications (see Section 3.8).

Had I been exploring a discipline-specific threshold concept, using combinations of keywords may have been useful in identifying, for example, communities of accountants, but autistic people are just a subset of people, and will therefore have interests and networks as diverse as any other group. We could not expect to use keywords to identify the communities where left-handed people or introverts felt they belonged either. However, this does prompt me to think that future research into the learning which happens within these communities which are accessed through mastering a threshold concept could yield useful insights.

Again, I circled back to the realisation that the quantitative social network analysis had provided some meaningful output, but I needed to look at the story behind it, rather than simply accepting the findings at face value. As an interpretivist, I recognised that while topics such as Donald Trump and YouTube may well have been mentioned with great frequency by autistic people, they were not likely to actually be at the core of what it meant to be autistic, or represent where these autistic people in particular felt that they belonged. What you say is not the same as who you are.

It was, by now, becoming increasingly evident that I needed to look beyond the autism to find the true sense of belonging, but some rather quick analyses of keywords such as "autism", "autistic", "self-acceptance", "transformation" were carried out to ensure I was not missing anything informative. As may be unsurprising by now, these searches produced very sparse results, as illustrated by Figure 27, Figure 28 and Figure 29 below.

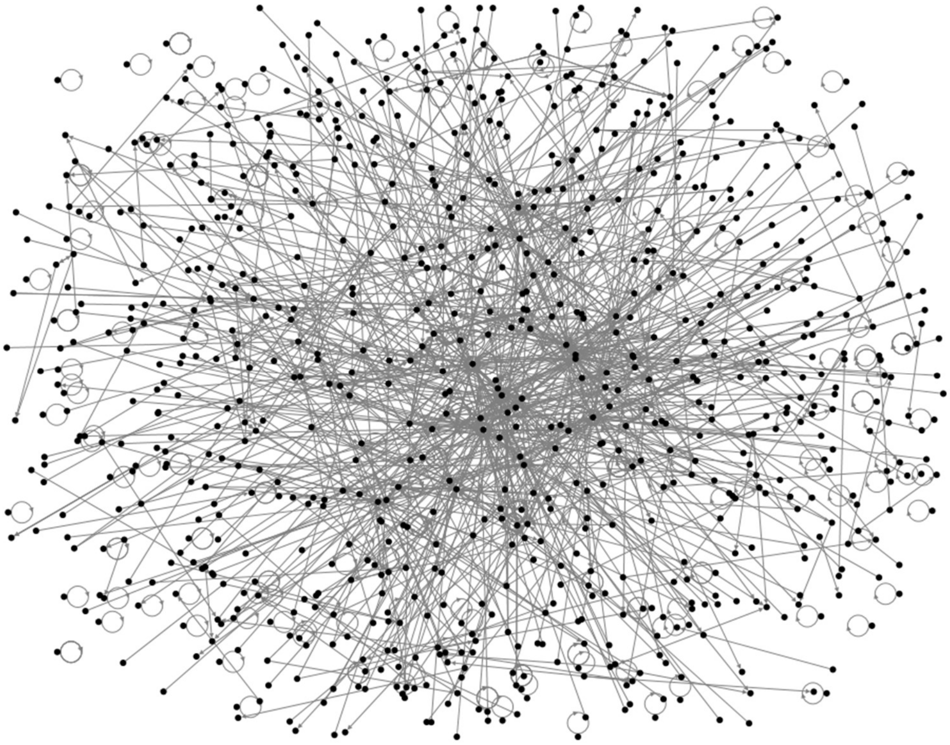


Figure 27 - Visualisation of #ActuallyAutistic

The first visualisation here is an overview of the network around #ActuallyAutistic. On first glance, there does appear to be interaction amongst those who belong to the network, but quite a lot of simple retweets without much interaction are already seen here (shown as a single node with an arrow circling back to the same node). Of course, this was just the beginning of exploring the network so, regardless of why the network was being analysed, more refinement would be needed.

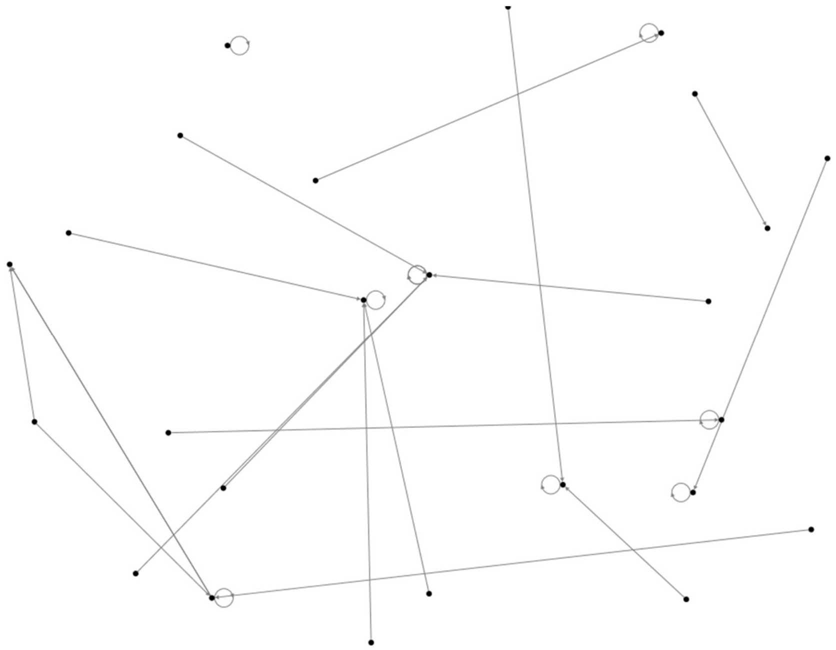


Figure 28 - Visualisation of #ActuallyAutistic AND "acceptance"

Next, with the objective of refining the sociogram to show more relevant insights, I created a version which visualised those tweets including #ActuallyAutistic and the word “acceptance”. Acceptance was one of those themes which appeared very important in earlier stages of the research, so it was interesting to see how sparse this visualisation is. At this stage, it seemed strange that there was so little overlap between what seemed to be the autistic community, and one of the key concerns expressed by autistic people and allies (both those directly involved in this research, and those whose work I had encountered informally).

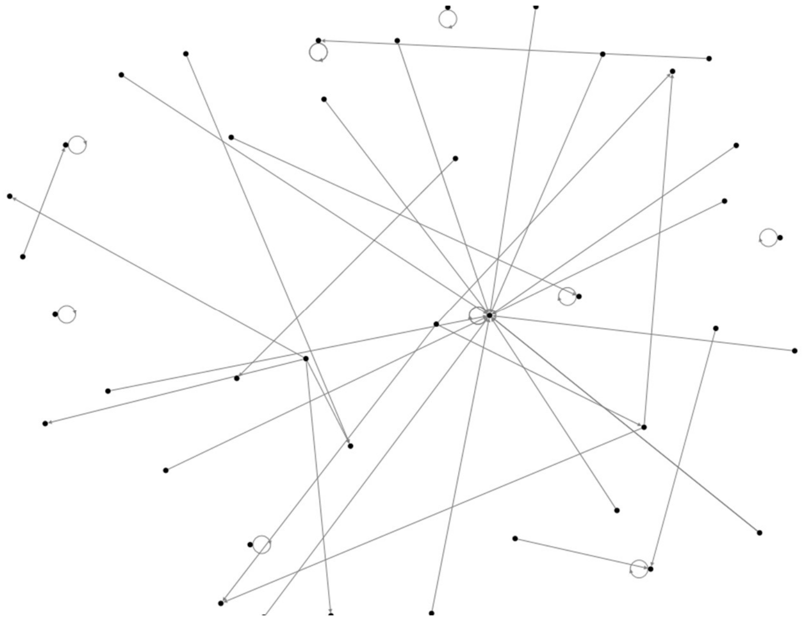


Figure 29 - Visualisation of "neurodiversity" AND "acceptance"

The third of the three visualisations shown here illustrates what was found when I searched for tweets including the terms “neurodiversity” and “acceptance”. Again, acceptance, awareness and understanding are major themes when discussing neurodiversity, so it still appeared that there was something off about this approach. Why were the common themes of discussion amongst autistic and otherwise neurodivergent people so rarely found in this #ActuallyAutistic network? The next search finally provided some insight into why this might be, prompting the next instance of emergence within my research.

One combination of keywords, “autistic” AND “acceptance” did produce more results, however, the majority of the tweets in this network related to autism acceptance, and seeking acceptance as an autistic person in society, not to any transformational experience relating to sense of self as an autistic person. This suggests that the value of the #ActuallyAutistic network lies primarily in it being a resource for autistic people. Recent research, articles, and blogs around the reality of being autistic and the importance of including autistic people in discussions around autism services are shared using this hashtag, meaning that interested people can keep track of developments around them. The network allows autistic people to connect with others, and to learn more about this aspect of themselves, the positive impact of which should not be underestimated.

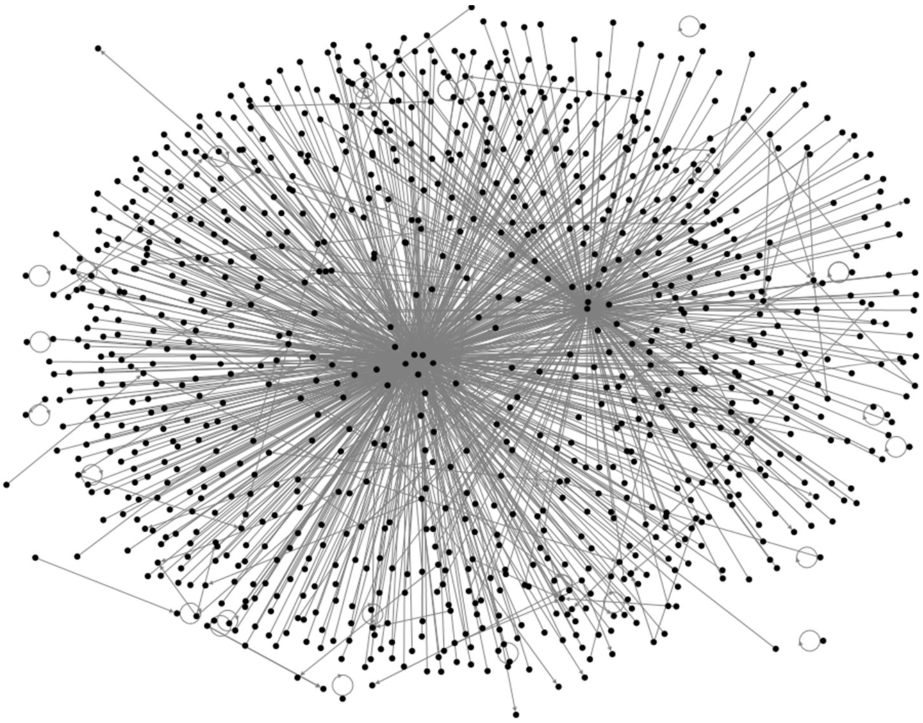


Figure 30 - Visualisation of "autistic" AND "acceptance"

Further examination of the #ActuallyAutistic network mentioned earlier also showed that those people who I know to be influential within the autistic community, and respected by autistic people, were not reflected as such when taking a bog-standard quantitative view – interpretation, fuelled by my developing understanding of the underlying processes and landscape was essential.

Following on from this, each of the anonymous Twitter users whose network within the #ActuallyAutistic network (see Figure 24) is shown in Figure 31 to Figure 33 below, is a known and respected member of the autistic community, with all three of them having been recommended to me as people to follow when I first ventured into the world of autistic Twitter as an (admittedly self-identified) autistic person. These networks have been anonymised as, while these users do Tweet about being autistic, and some engage in activism, they remain personal Twitter accounts.

Of course, there are numerous ways in which the data could have been cleaned and prepared to show these networks in more detail, and move away from the ubiquitous Twitter accounts such as Donald Trump's former account, and that of YouTube, but this still presents just a surface indication of the network, and not much about the community. The three networks shown in Figure 31, Figure 32 and Figure 33 belong to prominent members of the autistic community, yet have a tiny presence in the #ActuallyAutistic network overall. The red line in each of the three visualisations shows how each user's network exists within #ActuallyAutistic.

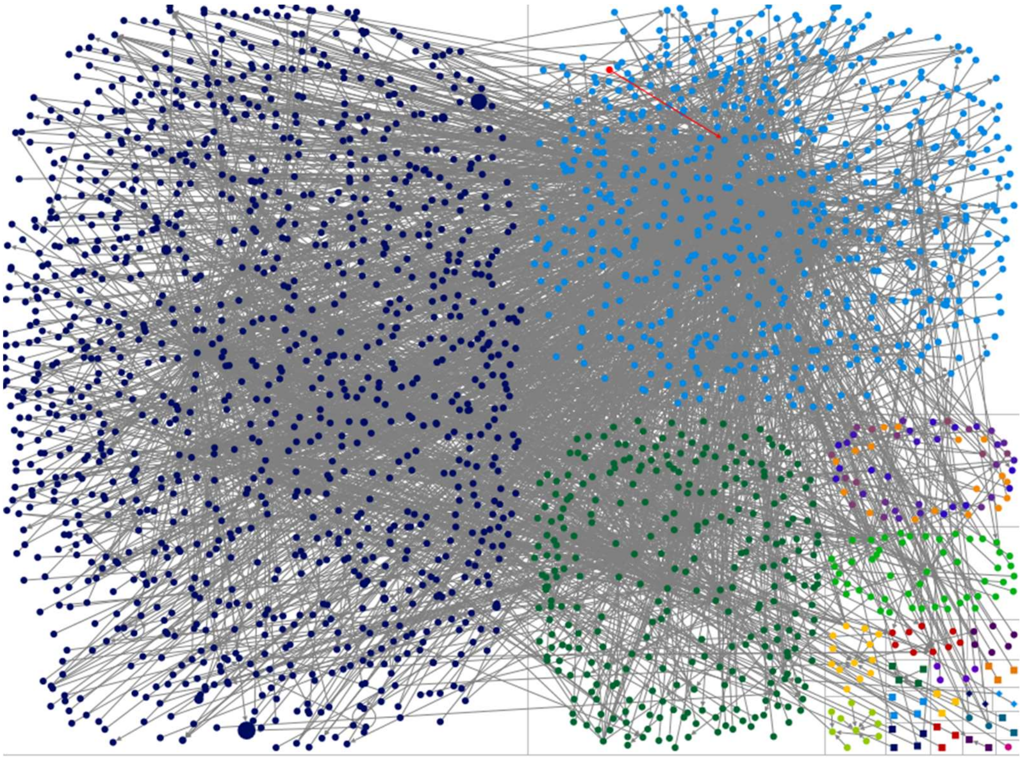


Figure 31 - Visualisation of Twitter network 1

Despite being prominent members of the Twitter autistic community (see Table 6 for definitions), each of these users had very little presence in #ActuallyAutistic. The first of these networks, as seen in Figure 31, has only one visible link here. This is not representative of their presence within the Twitter community which formed the context of this research.

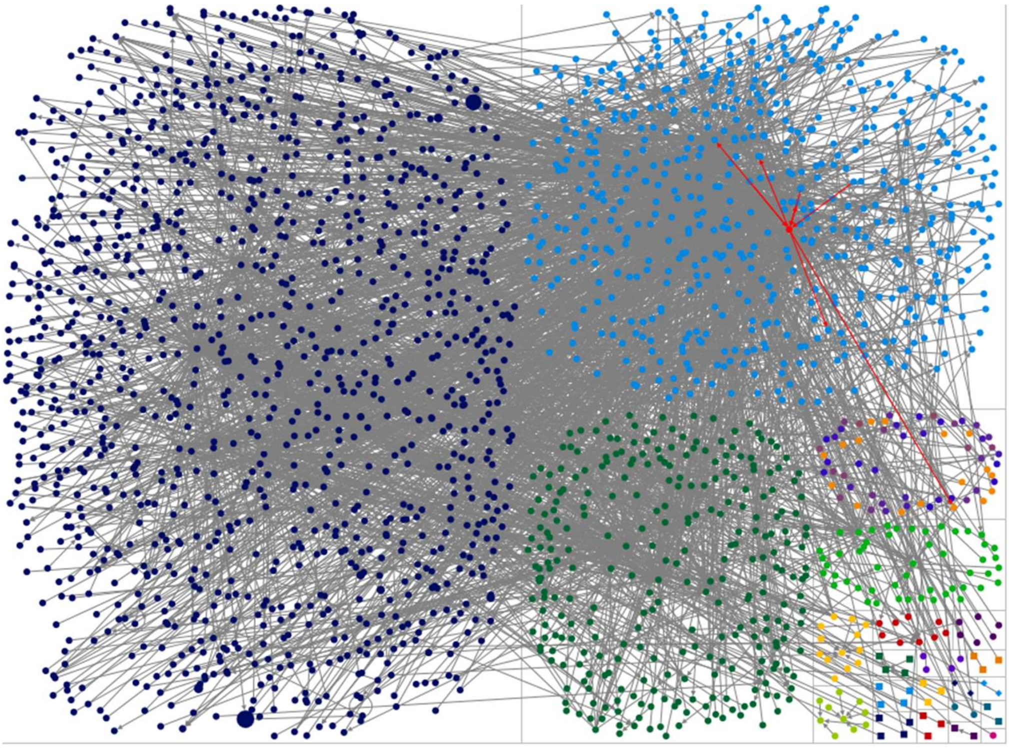


Figure 32 - Visualisation of Twitter network 2

Similarly to Twitter network 1, the second network shows very little presence in the overall #ActuallyAutistic network. This is, again, in stark contrast to how well known this individual's work is, and how well-regarded they are within the autistic community, and the subset of late-diagnosed adults on which this research focuses.

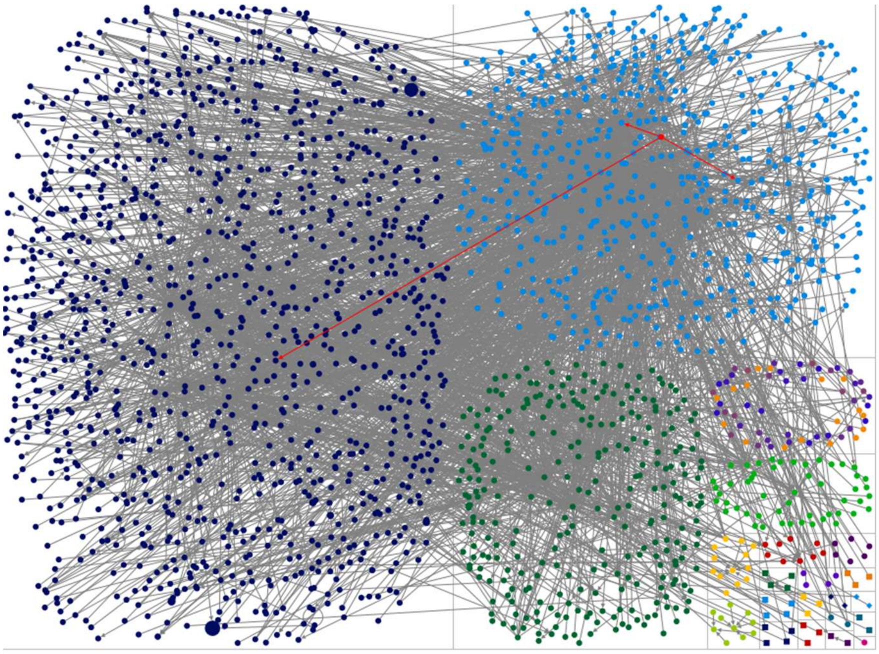


Figure 33 - Visualisation of Twitter network 3

Twitter network 3 is that of yet another well-known and respected autistic individual, who is very active within the Twitter community. These three visualisations served as confirmation that the #ActuallyAutistic network, and the general autistic Twitter community, were not quite where the richest insights into the phenomenon were to be found.

What this network does reflect well is those Twitter accounts which are used in a more professional manner to share information about life as an autistic person, and general autism related education, as was mentioned briefly earlier as a strength of the #ActuallyAutistic network. This stands to reason, given that these accounts are likely to be managed in a way which deliberately includes certain hashtags and optimises the number of views and interactions. Again, some examples follow in Figure 34 and Figure 35. These networks have not been anonymised, as they belong to professional autism advocates and activists, and do not relate to any of the personal information which has been shared in other stages of the research.

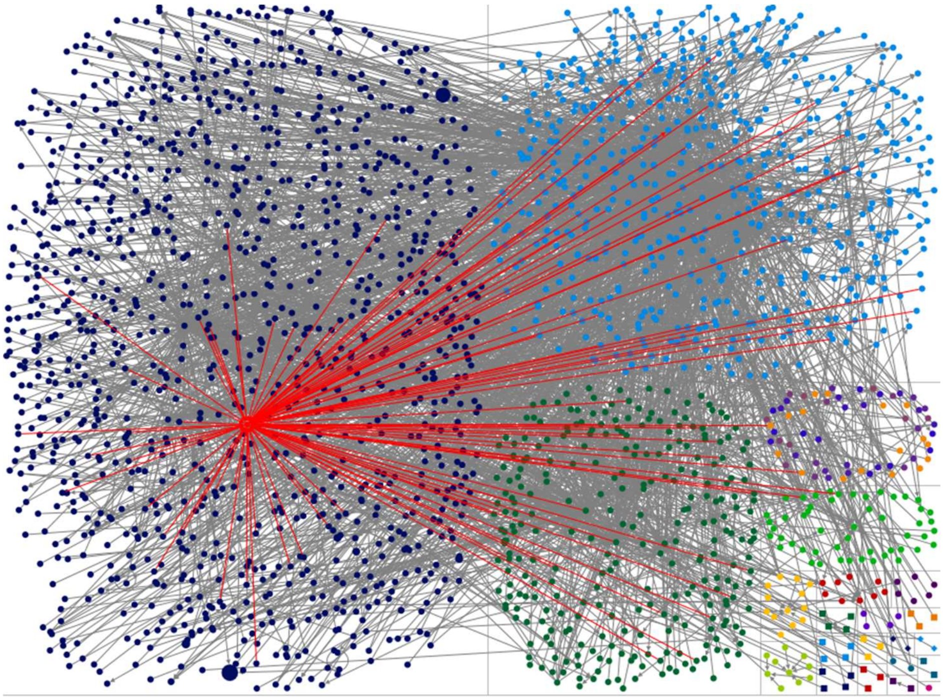


Figure 34 - Twitter network of @neuroclastic

The red lines in both of these visualisations show how connected these particular users are within the #ActuallyAutistic network. That is, they have significant reach, and are mentioned, retweeted, and quoted often. This is not to say that they are more important to the Twitter autistic community, but perhaps that they serve as resources, or post interesting content, similarly to the Donald Trump and YouTube examples earlier. They are spoken (tweeted) about, but this does not necessarily reflect anything beyond an interest in autism-related content.

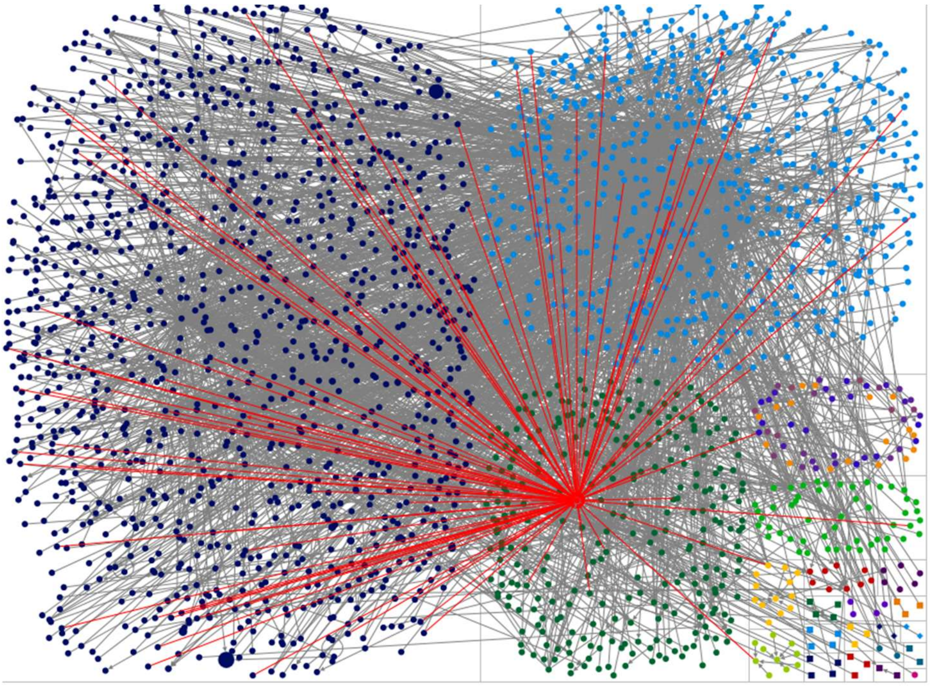


Figure 35 - Twitter network of @neurorebel

Had my main aim here been to confirm whether there was an autistic network, or an array of autistic networks, on Twitter, this type of network analysis would perhaps have been sufficient. There is undoubtedly a network formed around being autistic and, as autistic people themselves report, there is a transformative element to finding yourself surrounded by others who understand what you have been, and still are, going through (Crompton et al., 2020). Those autistic people who are using Twitter in a more professional manner are clearly achieving reach through the posts, and it is possible to easily connect with other autistic people using the network. However, our core question remained unanswered, as none of this reflects the lived experience of individuals.

From reflecting upon my own lived experience, and the accounts given by the interview participants, it appeared that this identification of the online autistic community – or rather ***an*** online autistic community – was just part of the picture. As a threshold concept is a very personal experience, and therefore will not occur in the same way to each person, even where the experience is given the same name. That is, self-acceptance will be a very different thing from person to person, and where that leads them will also be different.

One point which is incredibly important here is that autistic people are just as heterogenous a group as people in general. While there is a sense of belonging with other autistic people, this is not the only place an autistic person feels they belong. The interview analysis had suggested that self-acceptance allowed many of the participants to find where they felt they truly belonged, so this social network analysis was conducted with a view to visualising the networks around selected participants.

At this stage, six of the participants were selected, and more analysis was carried out on their own Twitter networks (see Figure 36). I, and my supervisors, believe that such a shift, which can be described as moving between big data to small data, can be a useful move in interpretivist quantitative studies. From looking at everyone, based on my interpretation I have switched to looking at only six participants, however, this means looking at these six participants including the full Twitter network, so the big data aspect is still there, as a context, the focus is on a small subset. To maintain confidentiality, no Twitter handles or other identifying information are provided in this section, however, general explanation is given.

These six participants were selected due to having at least suggested in their interviews that they felt the online autistic community did not feel like where they fully belonged, with some expressing that quite explicitly. As several of the participants had deleted their Twitter accounts by this point, they were also discounted. Any participants using a professional Twitter account, work-related Twitter account, research-related Twitter account or similar were discounted, as I wanted to focus on personal networks to reflect personal sense of belonging.

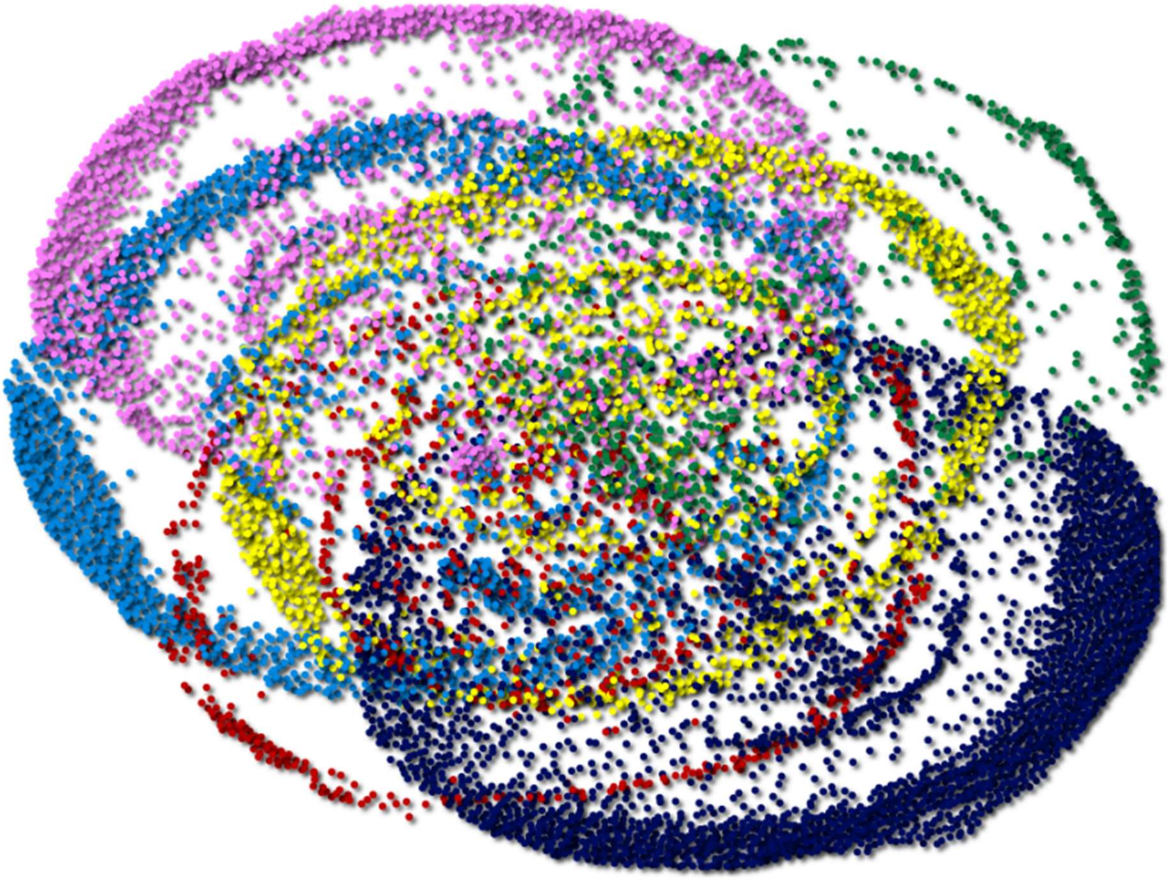


Figure 36 - Initial visualisation of participants' network

By again using NodeXL to retrieve data from these six accounts, and sorting using the same measures as previously, the above visualisation (Figure 36) was created. This shows significant overlap between each of the accounts, which was to be expected given each had been reached through the autistic Twitter community. Important to notice, however, is that each network also appears to have an inner circle and an outer circle, representing those accounts which the user is most closely linked to, and those which they perhaps follow, retweet, and mention, but perhaps consider more as a source of information, rather than personal contacts. It was these circles which I explored manually, armed with the gut feeling that one would be autism-related, and one would relate to other aspects of each participant's social network, perhaps facilitating a more holistic view of their identities and where they considered themselves to belong.

Using the assumption that the shared network was autism-related, and the more independent outer networks were personal, each of the networks was pulled out and visualised alone, resulting in the following, once the graph had been tidied (see Figure 37):

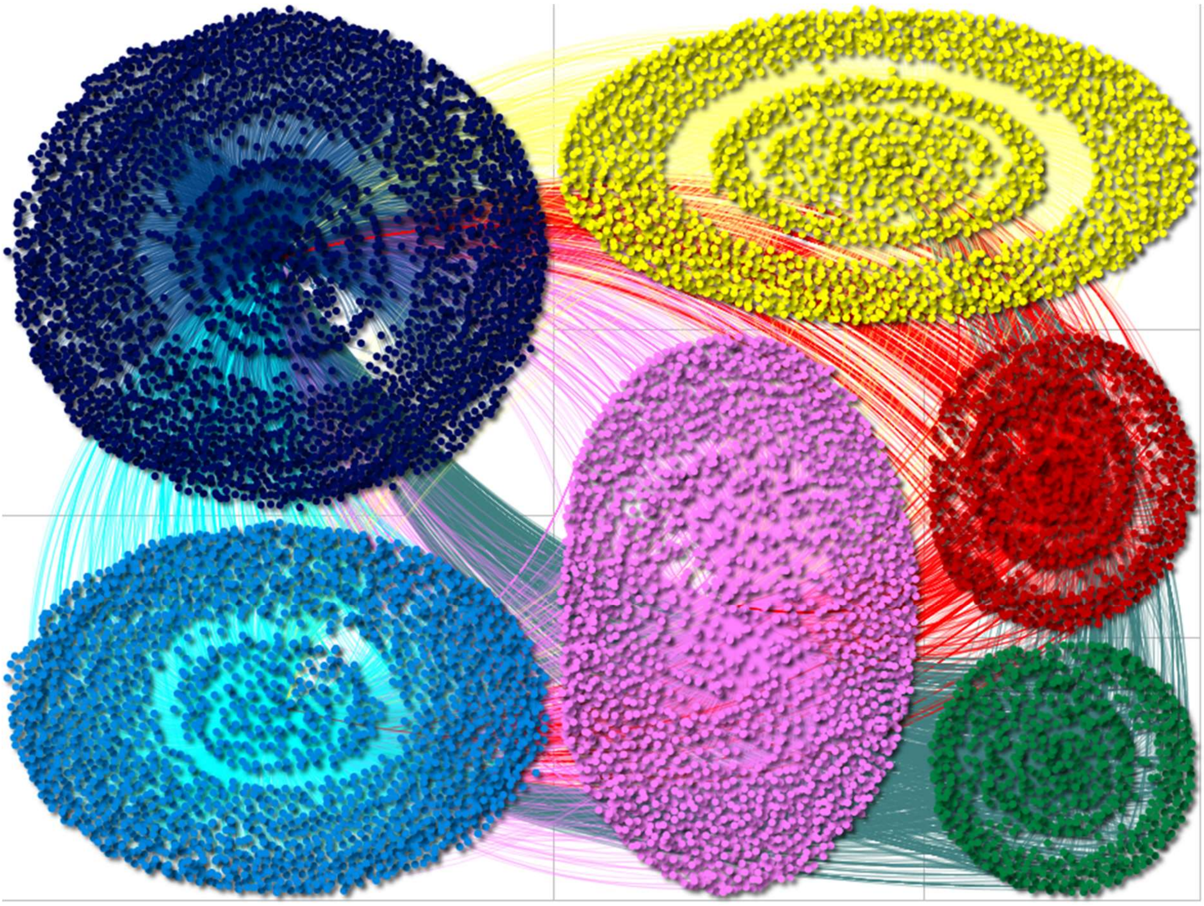


Figure 37 - Final visualisation of participants' Twitter networks

Perhaps even simply looking at this plot as a picture shows that we have something meaningful, that interpretation infused the quantitative analysis. Each of the six coloured circles in Figure 37 represents one of the participants’ Twitter accounts, with a very clear inner network and more distant network. Again for the purpose of preserving anonymity, no identifying details are given, however, closer inspection of these networks appeared to confirm what the interview analysis had suggested.

1. There is a sense of belonging within the autistic community, and this is reflected in the outer circle in each case. For the pink user where there is a less clear inner circle, there is still some divide between personal interests and autism-related accounts
2. Each user has a less dense inner circle, which strongly appears to comprise of personal friends, hobby-related accounts, and similar

I absolutely acknowledge that it may seem obvious that many Twitter users has an inner circle of close contacts and a wider circle of accounts in which they are interested. What I find particularly interesting in this case is that the networks reflect not only what the participants said about themselves, but also what they did not explicitly say, but became evident following interview analysis through the lens of an autistic researcher, with similar lived experience.

Having conducted this research as an autistic and otherwise neurodivergent person, one of the most personally satisfying outcomes of the social network analysis was the visualisation showing that autism is not the entirety of an autistic person's life, personality, and interests. This, too, would be impossible if I did not frame the quantitative method in an interpretivist philosophical framework.

4.5 Interviewing Others About My Own Liminal Journey

Once I had started working through the interview transcripts, attempted the coding, and begun reflecting upon the experiences, it struck me that there was more to explore in my own lived experience too. My own account of this is, of course, undeniably true and valid. I may misremember and entirely forget some aspects, but this is part of the subjectivity which makes autoethnography meaningful while studying lived experiences (Ellis, 2004; Haynes, 2017). It had been in the back of my mind for some time that threshold concept literature highlighted the importance of individual experiences and the individual nature of mastering a threshold concept, but was almost entirely written from the perspective of an external researcher. This prompted me to wonder if how I saw my own transformational learning journey was comparable with how those who were close to me saw it.

Exploring the validity and depth of a teacher's account of their students mastering a threshold concept, when compared to that which may be offered by the student themselves, is beyond the scope of this research (although remains something I would be interested in exploring further), but I was curious, and so asked two close friends to provide their account of how I had changed over the course of the several years preceding.

Another point which I found interesting at this juncture was that there does not appear to be an adequate phenomenological term for this process. My own account of my lived experience is autoethnography, and I am the researcher who interviewed the participants about their lived experience, but I have yet to find an adequate term for triangulating my own account with how it appeared externally. The closest which I could find was the Johari Window (Luft and Ingham, 1955), a model developed to illustrate interpersonal relationships, and an individual's awareness, or lack thereof, of the aspects of themselves that can be observed by others. In the Johari Window (see Figure 38), there are four quadrants, each of which is known to the self, known to others, both, or neither. Not all of our own behaviour is visible to ourselves, nor are the motivations behind it. Through inviting these two friends to comment on my own external appearance over the previous few years – and by deliberately asking those who I knew would be honest, rather than watering down their accounts to spare my feelings – I was working towards making myself aware of what was previously invisible to me.

Figure 38 - Johari Window

Through inviting these accounts, I was opening up the aspects of my own experience which were not organically available to me. These are not any more valid than my own perspective on the various events, but they were intended to serve as an additional perspective. From a personal point of view, having gone through some significant life events and the subsequent transformation, it was interesting to see how trusted individuals close to me had seen these. While it is impossible for another person to have an insider perspective on my life events, this was perhaps as close as is possible.

In general, these accounts are broadly similar to my own. Both are perhaps more positive than mine, but this is to be expected when you consider that they do not have the same emotional involvement. Nor do they have my tendency to view myself in a rather negative light, having by that point lived with the feeling of not fitting in for over three decades. These accounts do not cover the entirety of my life, but do take into account around 10 years in the case of Friend 2, and at least fifteen for Friend 1. These periods of time both incorporate the time where my own liminal journey towards self-acceptance occurred, alongside several years beforehand, where they would have known the previous version of me.

Both of the accounts have been provided below. Friend 1's account has been edited only to remove irrelevant information, as this took the format of an ongoing email conversation. Friend 2 chose to write her account and send it to me once finished; this has been included in full, having first obtained consent and ensured they were happy for their writing to be included verbatim.

The accounts written by these two friends broadly speak for themselves, although there is one key point I would like to make before moving on to the actual accounts. I do not know if this will be obvious to anyone other than myself, but one very clear point stands out to me on reading these accounts – I have people around me who understand me, and accept me. These people choose to be in my life because of who I am, not despite me being neurodivergent. Bearing in mind the points I have made earlier about the impact of being made to feel weird, or like an outsider, it is essential to understand that these relationships are a core part of my liminal journey. I could learn to accept myself for who I am because I am accepted by those around me.

4.5.1 An External Perspective on My Experience – Friend 1

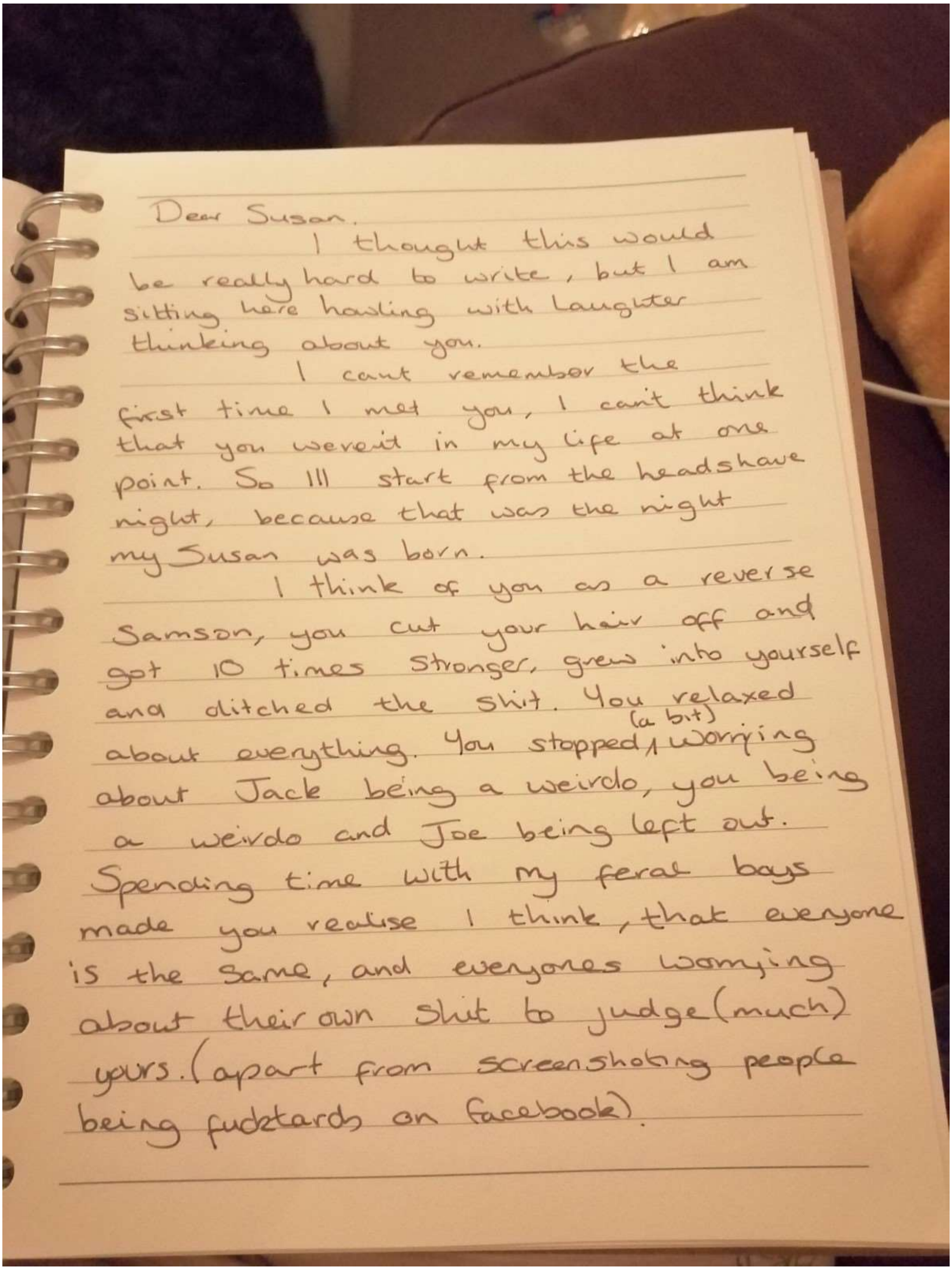
Protecting Friend 1's identity is imperative as, in addition to being a trusted friend from whom I would seek such an account, they are a participant in the research. This person engaged in some sense-checking of the ideas I had following the interviews, as can be seen in the first sentence of the excerpt. No information from the interviews was shared, but I had approached this person, and another, to discuss the broad ideas I had around self-acceptance, and around communities, to ensure that they made sense and seemed plausible to others (a form of participant validation).

> "THAT'S interesting. So, kind of, they think they have changed but then the way they talk about their experience indicates they've not? It's probably deep-seated internalised ableism. :) I think I might only be part joking there.

> Right, so I think you are more confident and more relaxed. More relaxed about being open on [group we both belong to] so something about more self-esteem, less concerned about others judging? Also, by confident, you are confident where you are a subject expert now, you don't seem to defer (but am I all that sure that you did defer before now I think about it? Maybe better expressed as happier to chuck in your opinion when previously you might not). You are def more confident about the whole PhD/uni/working thing, that shines through. You are (rightly) so chuffed about that, that's very visible.
>
> And now I've typed that, I think I am right, but also, I am not sure if I am putting thon you that I feel. I definitely feel more confident now that I have a voice that deserves to be heard as much as the next person (especially on [group]) and I've had a complete shift in my internal view of myself. I've moved from 'a bit crap, rubbish at all this compared to everyone else' to 'totally not any of those things, just different'. Whether that's visible in what I do (or say, online) I don't know. Though interestingly, I don't think R would say I have changed much BUT also, I was thinking about this the other day, he gets so little of my endless internal monologues that he wouldn't know they've changed. It's a double empathy thing as well, I think. Like the last three weeks I have felt on my last nerve with him home a lot but I don't think he's realised the extent of that because it just doesn't shine through, it's in my internal monologue."

4.5.2 An External Perspective on My Experience – Friend 2

This second account of a friend's perspective on my experience was written by a friend who is not involved in the research in any other way – albeit she will have played a role in my autoethnography through being a close friend as my own liminal journey was progressing. This friend knew me for several years prior to any of these changes taking place, so has a good perspective of me before, during, and after the various life events which were involved. I asked this friend to write her account partly because she was a part of my life throughout these experiences, and partly because I knew she would be honest, even if saying something I may not want to hear. The resulting account follows.



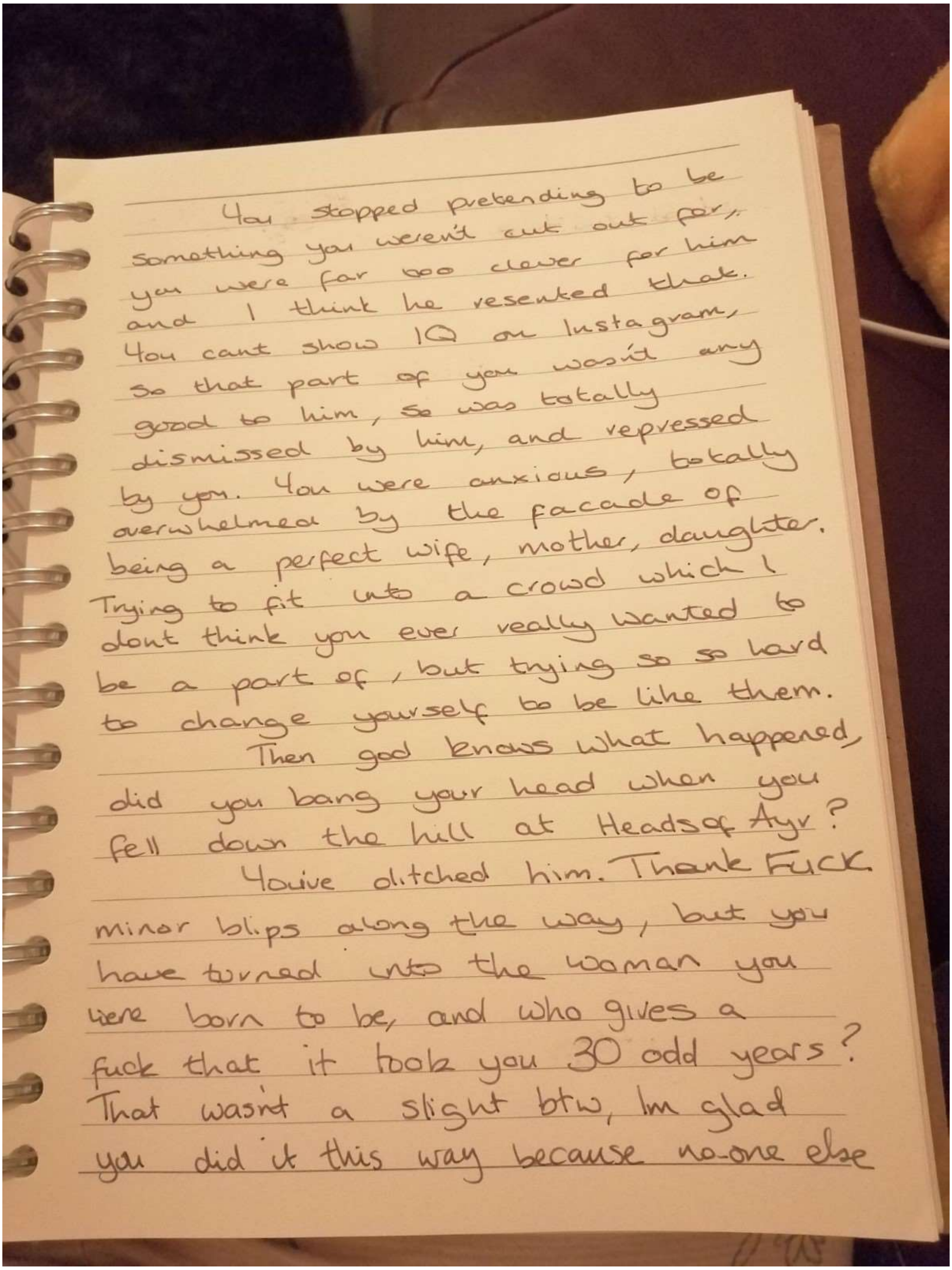
Dear Susan,

I thought this would be really hard to write, but I am sitting here howling with laughter thinking about you.

I cant remember the first time I met you, I can't think that you werent in my life at one point. So Ill start from the headshave night, because that was the night my Susan was born.

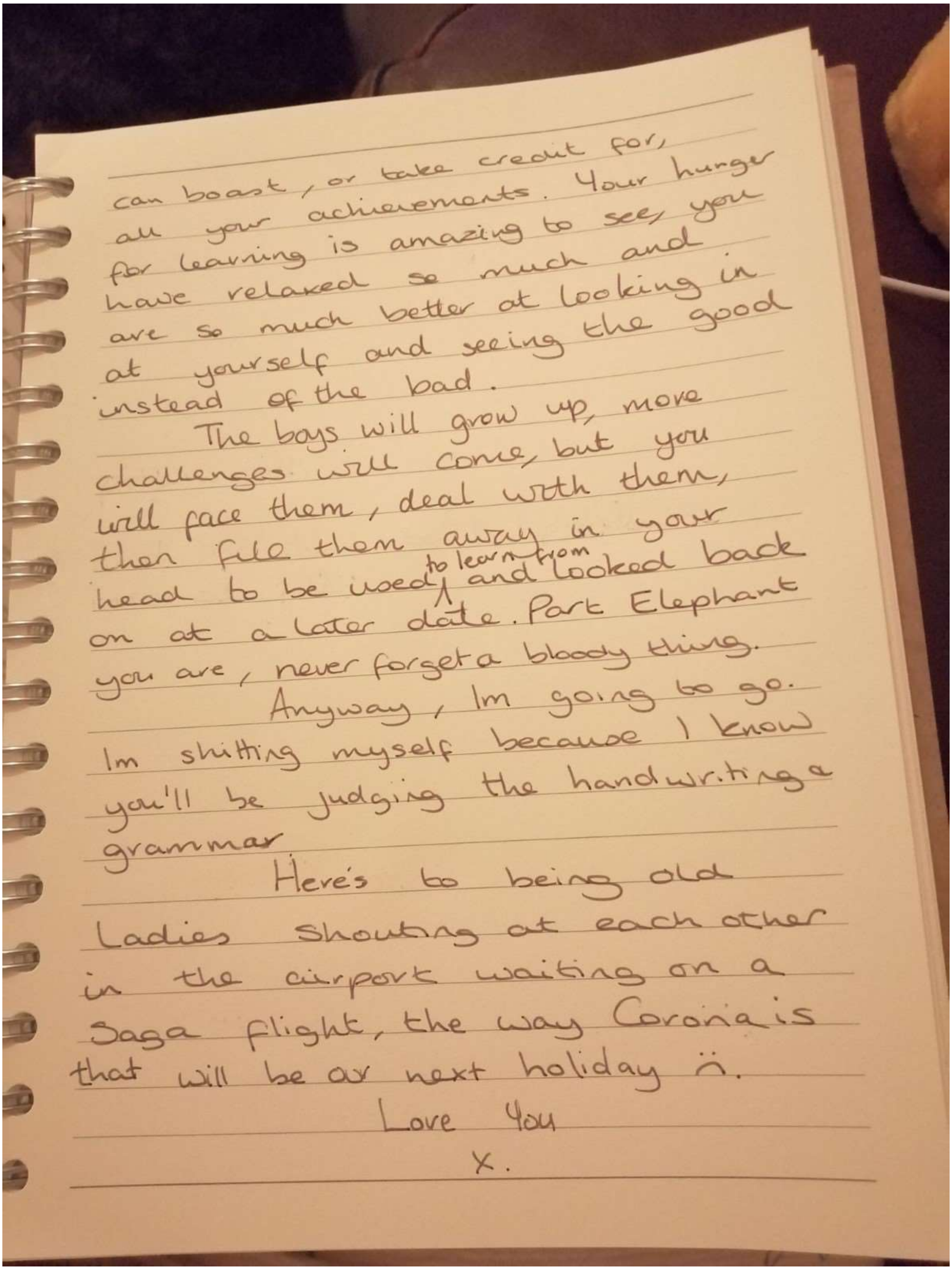
I think of you as a reverse Samson, you cut your hair off and got 10 times stronger, grew into yourself and ditched the shit. You relaxed about everything. You stopped (a bit) worrying about Jack being a weirdo, you being a weirdo and Joe being left out. Spending time with my feral boys made you realise I think, that everyone is the same, and everyones worrying about their own shit to judge (much) yours. (apart from screenshoting people being fucktards on facebook).

Figure 39 - First page of Friend 2's account



You stopped pretending to be
Something you weren't cut out for,
you were far too clever for him
and I think he resented that.
You cant show IQ on Instagram,
So that part of you wasn't any
good to him, so was totally
dismissed by him, and repressed
by you. You were anxious, totally
overwhelmed by the facade of
being a perfect wife, mother, daughter.
Trying to fit into a crowd which I
dont think you ever really wanted to
be a part of, but trying so so hard
to change yourself to be like them.
Then god knows what happened,
did you bang your head when you
fell down the hill at Heads of Ayr?
Youive ditched him. Thank Fuck
minor blips along the way, but you
have turned into the woman you
were born to be, and who gives a
fuck that it took you 30 odd years?
That wasnt a slight btw, Im glad
you did it this way because no-one else

Figure 40 - Second page of Friend 2's account



can boast, or take credit for, all your achievements. Your hunger for learning is amazing to see, you have relaxed so much and are so much better at looking in at yourself and seeing the good instead of the bad.

The boys will grow up, more challenges will come, but you will face them, deal with them, then file them away in your head to be used to learn from and looked back on at a later date. Part Elephant you are, never forget a bloody thing.

Anyway, Im going to go. Im shitting myself because I know you'll be judging the handwriting a grammar

Here's to being old Ladies shouting at each other in the airport waiting on a Saga flight, the way Corona is that will be ar next holiday ☺.

Love You

x.

Figure 41 - Third page of Friend 2's account

4.5.3 Revisiting My Autoethnography, and Becoming the Interviewee

Towards the end of this research, it was decided that I would be interviewed by my supervisor about my own experience of the process, using the letter that had been written by a close friend (Friend 2, see Figure 39 to Figure 41) as a starting point. The letter itself has already been discussed, but there were some interesting, and unexpected, findings from revisiting it in my own interview. Just as there were some clear messages in what was not said during the interviews with the other participants, there was a similar underlying sentiment evident when revisiting my initial autoethnography following the interview. In this section, I discuss how the progress I had made towards self-acceptance myself only became obvious to me at this point, despite having recognised the same in others.

Before beginning this discussion, it is important to be aware that the book chapter I wrote in 2019 was not deliberately kept vague, nor worded in a certain way to be appealing to the audience. When I wrote it, every single one of the 3,855 words was painful. I agonised over writing it and, as far as I was concerned at the time, I laid myself bare in it, giving a brutally honest account of the experience of realising I was neurodivergent. The truth is that I did exactly that, but only in so much as I was able to at that point. Just as I saw interview participants enthusiastically say they were comfortable in their own skin, and saw being diagnosed autistic as a positive experience, whilst also communicating non-verbally that this was not quite accurate, I painted a very positive image of my own realisation, which now appears quite superficial and masking a not-insignificant need for processing and coming to terms with this new sense of myself. Perhaps this is a form of defence, a self-deception that enables the process, as in contrast with the original autoethnography, while I had been slightly apprehensive prior to the interview, it was much easier although also far more honest and detailed.

in the next two sections, I use quotes from both the initial autoethnography (written in 2019) and the interview transcript from early 2021 to illustrate and discuss the changes that took place during that period, and were only noticeable with hindsight. To avoid over-complicated explanations of each, I have included the quotes, alongside a brief comment on how I now see them when revisiting.

4.5.4 Revisiting Some Key Quotes from Original Autoethnography

The first change which struck me while revisiting the earlier writing was how I described my feeling of being lost. Although it is to some extent understandable that I have attributed a lot of my thoughts to how I felt about parenting Jack – after all, I had spent over a decade parenting him and just a few months considering my own neurodivergence at that point – upon revisiting it, it appears glaringly obvious to me that I was not yet ready to fully explore my own feelings, preferring to "hide" behind glossing over any less positive aspects, and focusing on the parenting side instead of fully expressing myself.

In the following, I have highlighted certain quotes which stood out to me when revisiting the autoethnography, and colour-coded the reactions I had when re-reading.

*"I've always felt I was a bit of an outsider, that person who's not quite in a group but also not quite *not* in it, but that was just me"*

"I've been diagnosed with, and medicated for, anxiety since I was about 19. I had PND after both births. I've always felt like I don't fit in, like I'm somehow different, and I'm always, ALWAYS, tired. This world is not made for me, or people like me, and it is exhausting. But this is all ok now, because I know why it happens, and I can make sense of it."

*How I **wanted** to feel, not how I really felt

**No, it's not*

**True, but it's not everything*

"When I first became interested in threshold concepts, I was under the impression that I was neurotypical and, as such, was experiencing life and its various challenges much as everyone else could be expected to. So, although my research topic has remained the same, my perspective on it was virtually turned on its head just a short time into the project. The thing that may seem surprising to anyone who has not had such a realisation about themselves is that this was an entirely positive experience."

*Again, what I **wanted** to feel

"Although, in fact, realising that I am autistic myself has been infinitely less challenging than awaiting diagnosis for my son. After almost 8 years of very little sleep, severely delayed speech, various other missed "milestones", and a constant, overwhelming feeling of "why on earth can I not just do what everyone else seems to find so easy?" his actual diagnosis was very much welcomed. […] Worried about his future, and how his life would turn out. Worried about how people would perceive him and treat him. Worried about how he would cope when I wasn't around anymore to help. Worried about how I could make sure that he, for want of a better phrase, lived his best life.

*Absolutely not (just) about Jack

4.5.5 Speaking (More) Honestly About These Same Experiences

Although I have used the word "honestly" here, it is not that I was deliberately masking or minimising my feelings in the first autoethnography. Rather, I had not yet progressed enough along the journey of self-acceptance to be able to express myself. I have mentioned earlier that writing this book chapter had been incredibly painful. I remember feeling almost distressed by it, almost as if I was letting myself down by saying anything other than that I was fine, we were fine. This was how difficult it was even to explore these feelings and express them in writing.

When the time came to do my own interview about the experience, which involved a face-to-face conversation over Skype, where there was no opportunity to hide how I felt while talking, or to edit multiple times to make sure I was happy with how I had said something, I was nervous. I naturally tend towards making jokes as a coping mechanism, and rarely talk about anything seriously. Anytime I had tried, I had found it too emotional, and stopped. Despite that, I had a strong sense that this would be a valuable addition to my research, and worth the short-term emotional turmoil involved in having the conversation.

In reality, the conversation was fine. Yes, I did take a few very short breaks to compose myself when topics were particularly tough to talk about, but it was infinitely easier than the earlier writing had been. Here, I will include some quotes from the transcript of that conversation, which illustrate how much more open and honest I can now be.

"So basically, I never, kind of, had any kind of confidence in myself and always, kind of, thought that there was a way that my life should be and things I should do and could never, kind of, understand why I couldn't do things. Because I would be watching other people and go well, they're doing this, and this seems really easy, and I don't understand why I'm having a problem with this. Or why I feel like something's wrong. Or why I feel like I'm not fitting in. So, when I was about 18...17-18, that's when I met my ex-husband first. Yeah, and I don't know. I kind of just...I was like well this is what happens in life, you just go with it and it's a kind of...it's hard to describe because it...it...it kind of felt like I was always quite lost and always kind of looking for what should I do next and what should come...like...almost like I was following directions on how to be a person instead of just being myself, if that makes any sense."

The quotes above and directly below here show quite a contrast between this account and my earlier assertions that, yes, I did not fit in, but this was just me and it was fine…

"Yeah, and then I started not doing so well at school 'cause I got to the point where I had to do exams and I cannot do exams to save my life. Yeah. So, kind of, all the stuff I knew and all the stuff I was good at then, kind of, started to disappear and I was just like well, I don't really know what to do with myself. Maybe I wasn't really that good. Maybe they all just...I don't know, maybe they were all wrong. I, kind of, didn't really know what to do with my life…

...it just always everything felt wrong. And I always kind of thought, well, it's me because everybody else is doing this. This is what everybody wants to do your life. This is what you're supposed to do. What is my problem that I'm not dealing with this?"

Rather than insisting that I am fine and at peace with everything, I am now going so far as to admit that I still have progress to make on this. This is not a regression from my first account, but progress towards being confident and comfortable enough to admit things are not perfect (because what is?). Self-acceptance doesn't mean believing you are flawless; it means being comfortable in your own skin, warts and all.

"But yeah, I mean, we're kind of up to quite recent things right now, because it's kind of just when I was starting my PhD. And even then, I was like, what the fuck am I even doing? I'm like, I don't even know why they've accepted me. I don't know why anybody is letting me do

this, because I am just going to fuck this up. Like, I have fucked everything else up […] "I'm starting to believe that I'm okay now, I think. But yeah, I think...Yeah, it was...it was pretty much of that as soon as I started reading about autism stuff that...that I kind of realized, oh, hang on, this is probably why this has happened. And this is all kind of making a bit of sense to me. And that kind of stuff coming together, like that kind of way for me. And because I kind of think that, like people around me have always thought that I have had it together and that I have been sort...sorted and being confident and knowing how to do things. But inside of me has been totally, totally different."

4.5.6 Relating These Accounts to the Interviews

Looking back at the initial autoethnography that I wrote, having done the interview and processed how my perspective has changed, the disconnect between what is said and what is underlying it is as clear here as it was while reflecting upon the interviews with various participants. Just as they asserted that discovering that they were autistic was an entirely positive experience, while unconsciously expressing something different, I had done the same. This is not to doubt the authenticity of their accounts, nor of my earlier one, it is authentic in the moment. Self-acceptance is a process.

Relating this back to threshold concepts, it is not surprising that this was clear to me while interviewing participants, and to those around me while I was undergoing the same process myself. Somehow, it was still a surprise to me to see it in my own storytelling but, after all, threshold concepts are generally only evident to the learner with hindsight. Interestingly, the same movement towards the autistic community and then move away towards my own community is also visible with hindsight, yet also surprising despite having seen it in the interview participants, and recognised it there to the extent where I embarked upon the social network analysis.

4.6 How This Adds to What We Know About Threshold Concepts

As the core aim of this research has been to investigate how threshold concepts present in autistic people, the findings around threshold concepts form an important proportion of the overall findings. These have centred around the relationship between mastering a threshold concept and belonging within a community, as the empirical research appears to show an additional step in the journey from pre-liminal to post-liminal. Namely, it appears that the participants experienced a threshold concept in order to find that they belonged within the autistic community, and then another which enabled their progress from viewing being autistic as a defining characteristic in their lives, to recognising the importance of accepting their autistic selves, but also that they were each individual and not just autistic. This additional stage may be, at least in part, attributed to the threshold concept in question relating so strongly to personal identity rather than a specific educational or professional concept, however, it appears important regardless.

4.7 Concluding the Analysis Chapter

In this analysis chapter, I have discussed the process of and touched upon the outcomes of analysing and reflecting upon the empirical data elements of this research. I will now move on to introduce these findings in more depth. In the following findings chapter, I will discuss three findings in detail – the similarity between threshold concepts in autistic people and those which have been studied in the wider population, the role of identity and communities in threshold concept acquisition, and the suggestion that post-liminal may not be the end of the line in such transformative learning experiences.

5. Findings

In this chapter, I will introduce the findings from the analysis of the empirical data, namely, the striking similarity between threshold concepts in autistic and the (presumably) neurotypical threshold concept experiences which are discussed in extant literature, and a difference I did find when studying the liminal journey, which does not relate to the participants' neurotype, but to the threshold concepts model itself. I also outline the role which is played by identity, and those an individual is surrounded by, throughout the liminal journey. In keeping with what is posited by the seminal threshold concept literature, this research demonstrated the importance of communities, both in forming a sense of identity, and in embracing it. As I discuss in Section 5.3, this research also suggests that this role may not be as straightforward as tends to be stated.

5.1 Autistic Threshold Concepts are Threshold Concepts

As I started this research to explore how threshold concepts present in autistic people, it stands to reason to assume that I did, at least to some extent, assume that this was going to be different to how they present in non-autistic people. In reality, what transpired from this research was that the process seems to be the same (in so much as a highly individual process can be the same amongst any group of people). Just as I have learned that autistic people are just people, I have also learned that autistic threshold concepts are just threshold concepts. Rather than being a non-event, this is perhaps one of the most impactful findings from the research. The sameness of the process does not indicate that there was nothing to be found, it represents some support for the argument that autistic people are not broken or lesser humans, we are still people.

To relate this back to extant threshold concept literature, where a threshold concept is described as being "*akin to a portal, opening up a new and previously inaccessible way of thinking about something. It represents a transformed way of understanding, or interpreting, or viewing something without which the learner cannot progress. As a consequence of comprehending a threshold concept there may thus be a transformed internal view of subject matter, subject landscape, or even world view. This transformation may be sudden, or it may* *be protracted over a considerable period of time, with the transition to understanding proving troublesome. Such a transformed view or landscape may represent how people 'think' in a particular discipline, or how they perceive, apprehend, or experience particular phenomena within that discipline (or more generally)*" (Meyer and Land, 2003: 1), I will now draw some parallels between this statement and the experiences discussed by participants.

In the previous chapter of this thesis, I illustrated the journey to self-acceptance in terms of the pre-liminal, liminal, and post-liminal stages as shown in Figure 42 below.

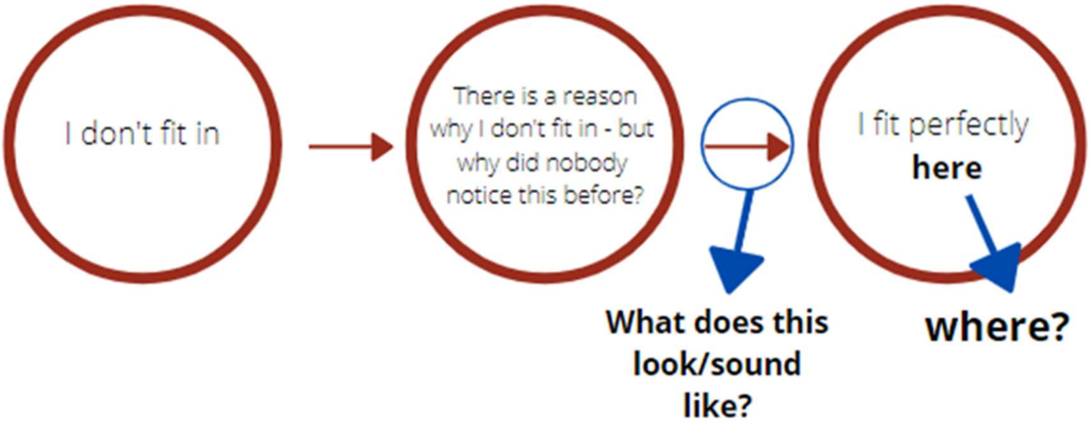


Figure 42 - Journey to self-acceptance

To further expand on how this research both draws on and adds to threshold concept literature, I will briefly discuss how the journey to self-acceptance fulfils some of the criteria for a concept to be considered a threshold concept, in so much as these criteria have to be fulfilled. As it is not necessary for all characteristics to be present, and to avoid unnecessary repetition and overlap, I discuss those which seem most evident. The quotes used in the following discussion have deliberately not been labelled according to participant, in order to protect anonymity.

5.1.1 Transformative

Once a threshold concept is understood, a learner's view of a discipline will be changed, as will their identity, to an extent

In this context, the discipline is probably best described as both a participant's sense of self, and their view of autism and neurodivergence. The journey to self-acceptance as a late-diagnosed adult is one from seeing yourself as a broken, faulty, damaged person who does not fit in and has most likely been told so, to seeing yourself as one who is exactly as you should be. Self-acceptance does not mean believing that everything about your self is perfect (in fact, that is an indication of not quite reaching self-acceptance yet, as I will discuss shortly), but rather that the process is still ongoing. Self-acceptance is more about, for want of a better term, accepting yourself warts and all, and being comfortable with being yourself. This appears to follow a pendulum-type effect, where there is extreme positivity following self-diagnosis, swinging towards negativity when past issues traumatic experiences relating to unrecognised neurodivergence come to mind, and, finally, settling in a more stable place of belonging within a community.

My own journey towards self-acceptance is recounted in detail in both the reflection and autoethnography sections of this thesis, so I do not repeat it here aside from where required for clarity. Amongst the participants, there were some explicit mentions of this transformed sense of self, for example:

> *I think discovering neurodiversity made me feel validated, like my sense of self had more worth, you know? Other people agreed that my life was worth something, and I wasn't on my own anymore. There's a big difference between parents and teachers telling you "There's nothing wrong with you, you're just different" to reading about other autistic people, and how being different is actually a GOOD thing. That's the main difference that made me understand myself better, the social model of disability. Rather than "there's something wrong with you, but that's okay" it was "there's something wrong with society, and that's not okay."*

Another quote from a different participant also expresses this change very nicely, when they say that:

> *But I started to see that, you know, maybe there was something about me. That was different to other people that have either a clinical identified reason that wasn't "you're a really shit person, who is really shit at life". I mean, one of the big things that executive dysfunction is that before I read that I have only explanation. I thought I wasn't kind. I thought I wasn't nice because I couldn't do really basic and get calls or sending an expected it to somebody or remember that birthday or remember to ask because that you know something was going on in their life and before… before detox and counselling helped with it, but in the really dark times before that, I just thought I was a horrible person also potentially a psychopath because I have alexithymia.*

One further quote covers both the "before" and "after" of self-acceptance quite succinctly, with that participant saying:

> *I've been told my whole life, especially by my mother, what a terrible, terrible person I was just constantly every day that you are a really terrible person.*
>
> *You know, maybe some of those other things are just… just not true, perhaps, or maybe… maybe I do have a sense of service, maybe, maybe that's what it is, rather than feeling like I need to try to atone for something or it is it was very strange and kind of uncomfortable, but also in the slightly longer-term sort of lightening.*

The three quotes included above represent the most explicit references to transformation from the participants. All participants mentioned transformation, and discussed how they felt they, their perspective, and their sense of self had changed. The second quote also makes reference to the unavoidably difficult aspect of the liminal journey, where the participant mentions "… the really dark times before that…". To use a common metaphor for explaining threshold concepts, and the liminal journey in particular, this appears similar in some ways to puberty. A child cannot become an adult without going through puberty, and cannot avoid the difficult, tumultuous aspects of that change. Of course, puberty is not a threshold concept in itself, it is a biological process, but serves well as a metaphor. In this case, the participants talk about how they began the liminal journey as one version of themselves – "a terrible, terrible person", "a really shit person who is really shit at life" - and progressed over time, through this liminal journey to being more comfortable with themselves.

The quotes chosen here also illustrate the coming to terms with the new sense of self – "maybe some of those other things are just not true", "I started to see that maybe there was something about me" – which was shown from the perspective of being able to shift from having a sense of self which was founded upon other people's expectations, whether explicitly communicated to the individual in question, or taking the form of societal norms, towards seeing themselves as an individual who was exactly who they were supposed to be. One point which should be noted from these quotes is that the comments and expectations of others do not necessarily need to be negative for an individual to benefit from this kind of transformed sense of self. As one participant notes, they were told "there's something wrong with you, but that's ok", which was still vastly improved by a shift in perspective to "there's something wrong with society, and that's not ok".

5.1.2 Irreversible

Threshold concepts may be difficult to unlearn, although may be altered by future learning

Self-acceptance is, by its very nature, difficult to unlearn, although it absolutely is fluid, and ever evolving. To draw upon the autoethnographic elements of the research here, self-acceptance means I have reached a point where I have a general sense of calm and comfort in who I am. It does not mean that I do not ever doubt myself, but it does mean that I do not go back to the state where I feel I am somehow broken or flawed. Of course, even when accepting yourself, you do experience normal human reactions and emotions to events and experiences, but the difference is in the depth of these. As described by one of the participants, it is as though my baseline has changed. My highs and lows are less extreme, and I am broadly comfortable with being myself, a sentiment which also came across in the interviews and informal conversations which I had with participants, and other neurodivergent adults, throughout the research process.

The other aspect of this is acceptance specifically of my/our autistic self(-ves). As autistic people, autism is a core part of who we are, but is not the entirety of who we are. This is reflected by the social network analysis, where self-acceptance seems to be indicated by moving away from a predominantly autistic group, towards personal interests, friends, colleagues, and so on. Self-acceptance, at least as it has been seen while conducting this research, appears to involve being able to embrace all the “parts” of yourself as one whole, rather than placing emphasis on one aspect.

While I feel very strongly about not revealing any potentially identifying details, so have not labelled these with the specific accounts, the sociograms showing the inner circle of contacts, and the slightly less connected autistic networks of each of the six participants illustrates this phenomenon very well.

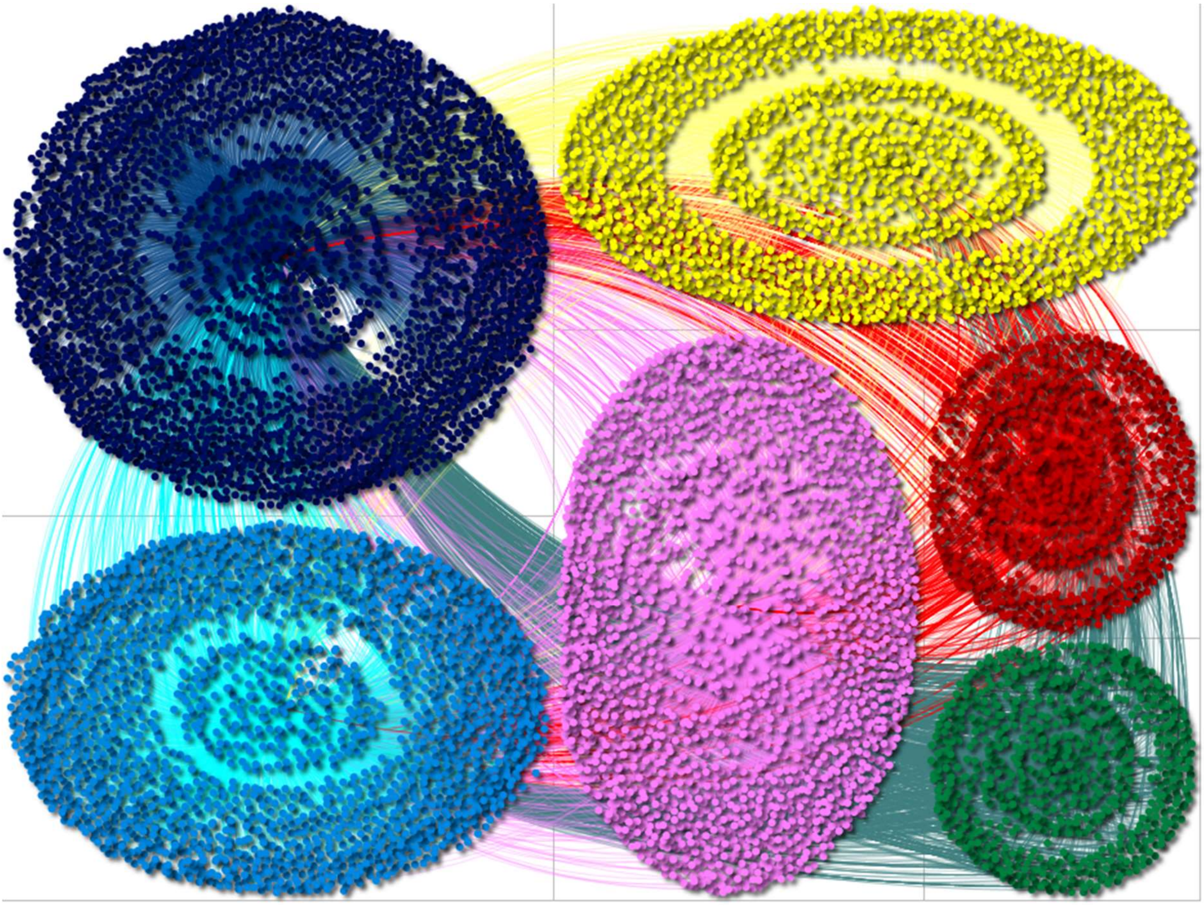


Figure 43 - Participants' Twitter networks

I discuss more specific details about the communities and networks element later in this chapter, however, Figure 43 above shows the two levels which are in each participants’ ego network. As mentioned previously, each of the coloured networks represents a separate participant, with the inner circle showing those who the person is closest to in terms of Twitter communication. These inner circles all show connections relating to friends, family in some cases, hobbies, work, and similar interests. The other circle, which represents those to whom each participant is connected but not quite so closely, is where the autism-related accounts and connections can be seen. The participants are all part of the autism community on Twitter, but it does not appear to be the main focus of their attentions. Autism, and being autistic, features significantly in each, but is not the be all and end all of what they are interested in, or what and who they are.

5.1.3 Liminal

Grasping, or mastering, a threshold concept can be considered as a rite of passage, or the journey towards the afore-mentioned portal

Whether or not self-acceptance is considered a threshold concept, and as a highly personal experience, it may be considered differently by different people, the participants in this research each confirmed it had been a transformational journey for them. Some reported positive experiences, others less so, but the journey from pre-liminal to post-liminal was undoubtedly evident, with the change in perspective associated with that also present (see Section 5.1.1). My own double-autoethnography serves as an illustration of this liminal journey towards self-acceptance, as shown in Figure 44 below.

Figure 44 - Self-acceptance as liminal journey

The autoethnography which was published relatively early in this research process serves as an account of the liminal phase in my own mastery of this threshold concept. In it, I feel I am at peace with my newfound self, but there are many aspects which are changed when it is revisited around eighteen months later. These have been outlined elsewhere (see 4.5.3 and 4.5.4) so I will not repeat in full here, but the discussion earlier in the thesis provides more information.

That which I have learned through this reflexive journey of sensemaking has prompted me to question if the threshold concept framework is overly simplified. In other words, is post-liminal really one phase? To return to what I suggested in the introduction to knowledge levels, I propose that there may be different levels of threshold concept, with varying degrees of depth of personal transformation. As such, I suggest that post-liminality is not the end of the line, but the start of the next phase.

5.2 Is Post-Liminal the End of The Line?

In terms of threshold concepts, this research was conducted from the perspective that, according to the threshold concept framework, the process of mastering a threshold concept involves encountering some new knowledge, navigating the liminal space while processing this knowledge and how it fits with existing knowledge, before exiting into the post-liminal stage having learned and transformed enough to become a member of a certain community. This is illustrated across numerous studies into threshold concepts, where mastering this threshold concept enables the learner to think like an accountant, to become a physicist, and so on. With this in mind, the assumption here was that accepting oneself as autistic following a late diagnosis would enable membership in the autistic community. To some extent, this is true – after all, the participants were recruited from the autistic Twitter community, and each expressed that becoming part of that community had been a key factor in their journey towards self-acceptance. However, it appears that joining this community was part of the liminal process, and that mastering the threshold concept – that is, achieving self-acceptance, leads to moving away from this particular community again.

The exception to this appears to be where the participant is also professionally involved in autism research or practice, and it does not seem unreasonable to assume a person's social network, Twitter or otherwise, tends to include some aspect of their professional life. My own includes plenty of contacts from past and present employment, after all. Not operating their Twitter account as part of a professional involvement with autism research or practice was one of the criteria for selecting the six participants whose Twitter networks were explored in more detail, as illustrated in Figure 37. With each of these participants, when their Twitter network is visualised in terms of their closest connections, there is a clear divide between an inner circle (those with whom the participant interacts most) and an outer circle (those with whom interactions are less frequent, or perhaps more one-sided), with the inner circles predominantly made up of non-autism-related accounts in each instance. Of course, given how much neurodivergence is undiagnosed or not recognised at all, this is not an absolute indicator that none of those close friends and contacts are autistic, but it still represents a clear divide between, for want of a better term, each participant's autistic self, and their entire self.

This is quite difficult to explain while also maintaining that autism is part of a person, and not a deficit nor something which detracts from their humanness. Of course, there is no separating the autism from the person, so therefore no separating the autistic self from the whole self. What has been seen here is perhaps more of an indication that, while autism is undoubtedly a core part of a person, and should not be disregarded, a person is far more than just their autism. Perhaps this can be explained in terms of the threshold concept and community membership generally. When an individual masters a professional threshold concept, it enables them to become members of that professional community. It is perhaps easier to understand that a person's profession is not their whole self, and then relate this back to being autistic, rather than the other way round.

Without meaning to be dismissive towards the struggles and obstacles in the way of many autistic people, nor to claim that it is not a bigger part of some people's selves than others, there is much more to a person than their neurotype. To use myself as an example once more; I am neurodivergent, but I am also a woman, a mother, a PhD student, a friend, left-handed, Irish, tall... The list goes on. I am no more likely to surround myself solely with other autistic people than I am to solely surround myself with people who have any other one of those characteristics, or even all of them. There is an individuality in people which means that they cannot be reduced to a list of characteristics, so even if we were at a point where neurodivergence was recognised and diagnosed appropriately, it wouldn't be enough to say that all autistic people are the same, or that everyone with ADHD is the same (I also have ADHD, and definitely find other ADHDers to be quite annoying, quite regularly...).

That leads on nicely to my next point. Not only do those autistic people who participated in this study not find that they fully belong amongst other autistic people, there were several mentions of actively wanting to leave the Twitter community, or feeling that they had to watch their every word to avoid inviting toxicity. In fact, at least one of the participants had deleted their Twitter account in between responding to my call for participants and the time where I revisited Twitter to conduct the social network analysis. This particular participant was the keenest to discuss the positive impact of the online autistic community in helping them to process and accept their diagnosis, so it was not a case that they did not value the online community, or feel that they had benefitted from it, it was that the negatives began to outweigh the positives once these benefits had been had. Generally, across almost all of the conversations, and on reflecting upon my own experience, it appeared that the community served a purpose rather than being the end destination (see Figure 45).

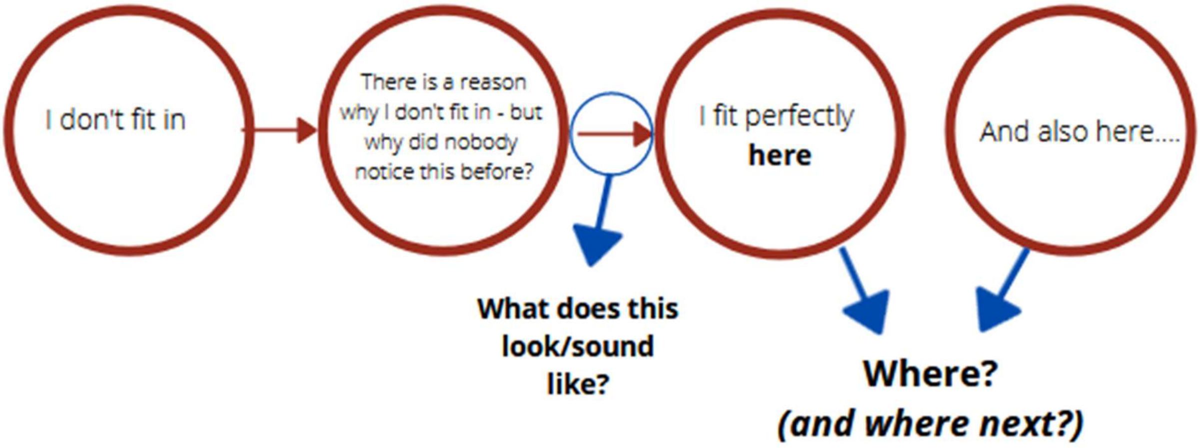


Figure 45 – Updated Journey towards belonging

This has raised the question in my mind about whether post-liminal really is the end of the line when mastering a threshold concept. There is undoubtedly a threshold concept involved in accepting oneself as something other than that which you had believed for your whole life to date (between around 25 and 50 years in the case of the participants), but it appears to open more doors than it closes. I acknowledge that this research involves a small group of participants and investigates one phenomenon but, if the autistic community is where autistic adults come to learn before mostly moving on, could this also be true for those communities to which people become members following mastery of an education or professional threshold concept? Can all accountants or physicists be counted together any more than all autistic people can? This is beyond the scope of this research, as I have explored how the threshold concept presents in autistic people, however it has certainly raised questions for future research.

Whether or not the post-liminal stage is over-simplified by the threshold concepts framework, the role of communities and networks in the liminal journey appears to be a central one. This underlying theme in each of the conversations with participants is what prompted the social network analysis, in which it seemed to be reflected. As identity, community and networks played a significant role in this research, I will move on to discuss this element in more detail, following some further speculation on post-liminality.

5.2.1 Speculating Further

And let me now reason abductively about this consideration of whether post-liminality is really the end of the line. An obvious possible explanation for people moving on from the autistic community is that as it helped them come to terms with being autistic, they did not learn more only about their autistic self, as it is part of their self, they learned about their overall self. This can mean that through their self-acceptance as autistic, they may become better at what else they are, e.g., an autistic physicist may become a better physicist having accepted their autistic self. I note that this is pure speculation, there is no evidence for it – but it can serve as a starting point for future research.

However, perhaps it is worth going even further. One of the considerations for exploring threshold concepts as they present themselves in autistic people was that there is an off-chance that due to some of their characteristics (e.g., monotropism) and thanks to the homogeneity of the participant group along these characteristics, perhaps something that is generally true about threshold concepts can be more visible when looking at the phenomenon is autistic people. Perhaps, there is a more generic significance of most autistic people moving further to other communities after they feel they are done with their self-acceptance. Is it possible, that mastering any threshold concept leads to a two-stage post-liminal phase? At first, the threshold concept changes the worldview, and then, gradually, it becomes a more ordinary ingredient of the domain knowledge. Not because new threshold concepts are arriving, simply because after the initial boom, they get their real place. There is some indication to this possibility in Pirsig’s (1992) conceptualisation of dynamic and static quality.

5.3 The Role of Identity, Communities and Networks

The role of identity and community is a core one in extant threshold concept literature. As has been mentioned throughout this thesis, it is mastering a threshold concept that enables one to become a member of a particular community. Given that this also involves being able to think as a member of that community, following an oftentimes protracted period of transformation of self and worldview, the learner's identity is inherently tied up in their mastery of the threshold concept in question, whatever that may be (Meyer and Land, 2003). Similar focus has been placed upon community, identity, and belonging in autism literature, particularly that which has been conducted from a similar participatory or emancipatory perspective. Research such as that published by Crompton et al. (2020), highlights the positive impact autistic people report occurs when they are surrounded by other autistic people, and also the establishment of a community of practice amongst autism researchers and educators.

The theme of belonging is an important one, both in the existing research, and in this study: it is the mastery of a threshold concept which facilitates belonging within a community, and it is the sense of belonging within the autistic community which is so notable and positive an experience for autistic people. Having been in the unique position of working through the very process which I was studying, I can confirm that it was feeling that I finally fit in and belonged somewhere which stands out to me as the impact of my recognising my own neurodivergence. It is a positive experience for any individual to feel like they belong, but even more so after a lifetime of not feeling quite like you fit in, and not understanding why. Figure 46 below illustrates self-acceptance in terms of belonging, following the liminal journey from pre-liminal through liminal and onto post-liminal.

Figure 46 - Self-acceptance in terms of belonging

My statement that the autistic community is not necessarily the ultimate place of belonging does not mean it is not important. There is a lot of overlap and connections in common amongst the participants (see Figure 47), and even the ease at which I could reach participants is testament to the strength of the community.

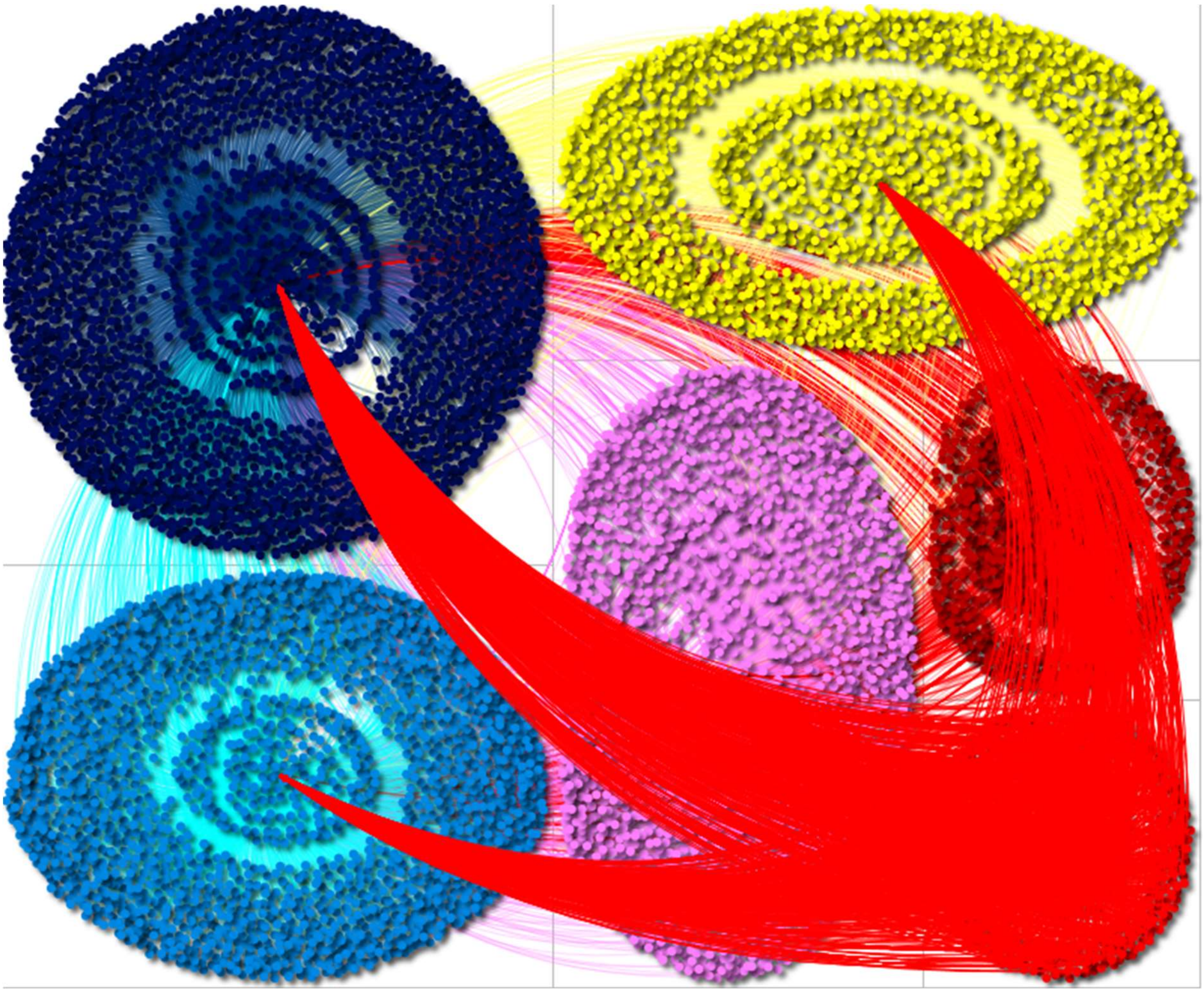


Figure 47 - Inter-connectedness of participants' Twitter networks

Across all six participants' networks, there are just four accounts who follow all, each of which are professional autism-related accounts, and 7 which we all follow in common. Again, these seven are all directly related to autism. The visualisation below, Figure 48, shows the overlap between three of the accounts. These three users interact with each other regularly, beyond just the usual Twitter interactions, but still have significant differences in their Twitter networks, with 80 followers and 20 followed accounts in common.

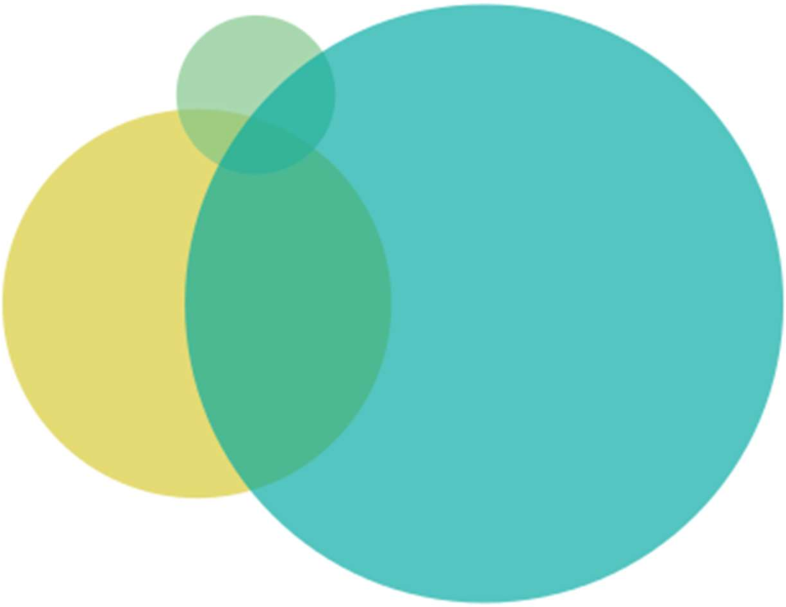


Figure 48 - Overlap in followers

This overlap is somewhat higher, when comparing accounts which have more of a professional interest in tweeting about autism (see Figure 49), which brings me back to the point about the autism community (which has been described as a community of practice (Guldberg et al., 2019) as being more of a professional one, and not a place of belonging as such for individuals.

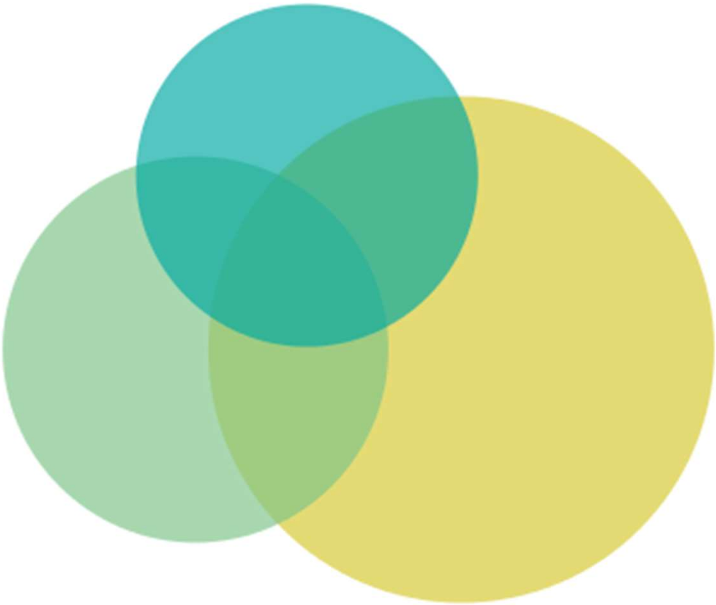


Figure 49 - Overlap in professional accounts' followers

Of course, this is my interpretation of what I have seen and experienced, and requires further research to explore into greater depth. On the face of it, it appears to support what has been expressed both implicitly and explicitly while communicating with participants – there is absolutely an autistic community (or network of communities, and communities-within-communities), but autistic people are neither all the same, nor do their identities lie solely in their autistic selves. The autistic community, using the term “community” colloquially, is incredibly important, but it is not “home”. Finding a place here appears to be more of a milestone on the way home, than the destination itself.

This is what has prompted my proposed future research into social learning into networks and communities, particularly those which are online. From this research, there seems to be a definite need for communities to act as a kind of catalyst, a safe space where people can feel comfortable enough to be themselves. However, this does raise an issue for me in terms of the characteristics of threshold concepts. To paraphrase existing threshold concept literature, mastering a threshold concept triggers a change in the self which enables membership of a community. What I have observed, and experienced, over the past three years appears more like being on the cusp of mastering a threshold concept enables membership of a community, and then the following change in identity and transformation of self enables a move away from needing this community, towards a more individual place of belonging.

There is quite clearly a link between identity, networks, and communities, but having conducted this research, this link now seems to me to be less straightforward than portrayed in existing literature. I acknowledge here that a transformative learning experience in the guide of discovering your own neurodivergence is likely to be of a different magnitude than a formal education or profession-based threshold concept, but there appears to be more here to explore in terms of what allows membership of the community, and what role the community plays in the transformation.

Now that I have introduced the findings from this research, I will move on to discuss these in the context of existing literature, as well as this particular research context.

6. Discussion

In this chapter, I discuss the findings from the various elements of this research, both in terms of what they mean in the research context, and how they relate to the existing literature in each of the fields which have been brought together. The philosophical underpinnings of this research, and the methodological approach which has been utilised within this philosophical framework, have been detailed (see Sections 3.3 and 3.6), and I will now discuss what these meant for the research in practical terms. I also discuss in more detail how my positioning as both researcher and participant offers dual perspectives on the research process and, indeed, the liminal journey which is illustrated throughout. While it is impossible to separate these, I attempt to explicitly specify the points at which I had to shift perspective to make sense of what was happening. In order to provide clarity for the reader, I will primarily speak from a researcher perspective in this discussion chapter, although my personal experience will inevitably feature. To further expand upon the relational reflexivity (Hibbert et al. 2014) which has been used throughout the research process, and how each of my roles informed and was informed by one another, I include a reflection from a personal perspective as Chapter 7. This is intended to complement and support what is included in this discussion chapter.

The main purpose of this discussion chapter is to combine both my findings and the existing literature to develop and support my argument that communities and networks play a vital role in mastering a threshold concept, and that the community to which one belongs following the liminal phase may not be the end of the journey towards belonging, but rather a catalyst enabling the final stage of finding where one belongs. Drawing upon both threshold concept and autism and neurodiversity literature, I present an illustration of how threshold concepts appear to present in the neurodivergent, that supports the neurodiversity paradigm. I will also delve further into the phenomenon which I have mentioned in various sections of this thesis, where the threshold concept framework suggests that self-acceptance as autistic should enable membership of the autistic community, but the findings appear to suggest that there is a further step to be taken. I propose that there is much to be learned from further exploration of communities, networks, and their role in transformational learning, whether or not this is labelled as a threshold concept.

The primary argument in this discussion chapter is around the role of communities and networks in learning, however, I am hopeful that the autism- and neurodiversity-specific element of this research serves to improve societal understanding and acceptance of neurodivergence.

Each element of the empirical research provides its own insight into how the liminal journey towards self-acceptance following an adult diagnosis of autism was experienced by the participants. My own lived experience has proved invaluable throughout the research process, and I discuss how working through the process of self-acceptance at the same time as researching the experience of others turned out to be a powerful resource. The discovery of my own neurodivergence changed the planned research quite significantly, and the fact that I was inevitably fully immersed in the research as a result facilitated richer findings than would otherwise have been possible. My personal involvement in the research topic meant that, as I have mentioned earlier, it became difficult to find research methods which adequately reflected what I was seeing and hearing from participants, and feeling and experiencing myself.

The combination of methods which I arrived at heavily featured sensemaking and harnessing my own emotions around both what I was experiencing and what participants were expressing, in order to build and develop an image of these experiences which was as true a reflection as possible. It may not be fully possible to understand these experiences unless you have gone through them yourself, but I have done my utmost to represent the process as clearly and thoroughly as is feasible.

As it was the original focus of the research, it makes sense to first discuss the findings on how mastering a threshold concept presents in autistic people. The short answer to this seems to be “no different than it does in the, presumably, neurotypical participants in other studies”. I have already specified that self-acceptance as autistic was the potential threshold concept which I offered as a starting point to participants, each of whom did confirm it had indeed fit with their understanding of what a threshold concept is, an assertion which was supported by their accounts of progressing through the liminal journey.

6.1 Reinforcing the Importance of an Insider Perspective

As I have referred to throughout this thesis, it was my insider perspective which enabled the richest and most meaningful insights (Brannick and Coghlan, 2007). Without this, I could not have co-created the findings with my participants, and absolutely would not have had a perspective which allowed for the tweaks and changes of direction which can only be attributed to an intuition that this was the way to go. As I have also mentioned, this insider perspective has also brought its challenges - it was an entirely unexpected element to the research, and it has been challenging both to process that I was an insider, and also to write about it in a coherent way. The back and forth of the liminal journey does not lend itself to straightforward written accounts.

> *"…Right from the start, from the time someone came up with the word "autism" [it] has been judged from the outside by its appearances, and not from the inside according to how it is experienced."* (Williams, 1996: 14)

The above quote from Donna Williams explains in a nutshell why it has been important to me to conduct this kind of participatory autoethnography. The autoethnography may have been a slightly later addition, but the inclusion of, and co-creation with, autistic people is essential when conducting autism research. Just as those who have had any experience can discuss and understand better than one who has not, who better to communicate the experiences of autistic people than those people themselves? Even with the best of intentions, it is impossible for the full picture to be seen and appreciated by someone who is viewing it from a different perspective.

This is not to suggest that all participatory research encompasses the views and experiences of all autistic people – I am aware that there will be many autistic people whose experiences do not reflect those of myself and the participants in this study, but it is infinitely better than conducting research which does not adequately reflect the lives of any autistic people. The benefits of participatory autism research have been publicised by collectives such as the Participatory Autism Research Collective, the Autonomy academic journal which publishes work by autistic scholars, the Theorising Autism project (Greenstein, 2014), the Shaping Autism Project (Fletcher-Watson et al., 2019), and Damian Milton, whose work on double empathy goes a considerable way towards explaining that the issue is not that autistic people do not understand other people, but that autistic people better understand other autistic people, just as neurotypicals better understand other neurotypicals (Milton, 2012b).

More recently, Jac den Houting (2018) made an impassioned statement about the advantages of taking a strengths-based approach to autism and other forms of neurodivergence, researching the resourcefulness and resilience of autistic people in the face of their perceived adversity by neurotypicals and partnering with the autistic community. Contemporary autism research, such as that discussed throughout this thesis, has made significant progress in terms of encouraging participatory autism research, however, there is still much room for improvement. In short, we do not need more exclusive research on autistic people for those who are non-autistic, but more inclusive research with, from and for autistic people.

While the diagnostic process is, in itself, not part of my research area, my own experience can be used to illustrate how a lack of participatory research and, in particular, participatory research which influences practise, has a negative impact on recognition, and therefore acceptance, of the strengths of autism. My own experience of the diagnostic process is reflective of the experiences widely discussed on social media by women who have sought diagnoses. We do not fit the checklist; therefore we cannot be autistic. The issue here is not so much whether or not we are autistic, it is the complete misunderstanding of an entire population which is reflected in this process. The following excerpt from some autoethnographic reflective notes which I kept during the research process illustrates why a participatory approach is needed here. While I know it is unusual to add a significant number of quotes from data into the discussion, it seemed to make sense in this case, as it illustrates this issue from the perspective from which it is experienced.

> “Personally, I did not have any idea that I had autistic traits until my mid-thirties. Of course, this is far from being ideal and there are plenty of aspects of my life which could have been easier had I known, from the perspective of a researcher, this also allows for an interesting perspective on how threshold concepts may occur in autistic people who are not recognised as being autistic. Indeed, perhaps realising one is autistic may be a threshold concept in itself.”

"The wholly inaccurate trope about autistic people being emotionless, lacking in empathy, and, perhaps, more robotic than human, continues to be used with concerning frequency. This occurs across academic publications, professional practice, autism support services, and general, everyday life type scenarios more often than one would like to think. It is one of those misconceptions that simply refuses to go away, despite being one that, as an autistic person, I can categorically state is simply not true. I have empathy – often too much, as is reported by plenty of other autistics, just perhaps not in a way which is understood and acceptable to neurotypicals."

"Having come to the realisation that I very neatly fit into the category of 'undiagnosed middle-aged autistic woman' and, having been equipped with a strong sense of curiosity, I began my journey towards diagnosis. Not for any particular support need, or tangible benefit, more for my own understanding of myself. Along the way, after being fobbed off by several GPs before encountering one who was at least empathetic enough to refer me to the appropriate service, I read and listened to countless tales of how the system fails autistic women. If you're not a young boy who lines up cars for fun, you're not autistic, according to these accounts. That statement is intended to be taken with a pinch of salt although, until I attended my own diagnostic appointment, I did not fully appreciate just how painfully accurate it is."

"Following several months on a waiting list, I received a letter accompanied by a form for my parents to complete, outlining my early years. I am the eldest of four children, and my early childhood was some three decades ago, so my parents' recollection of specifics was definitely hazy. The completed form returned to the service, and I duly received a telephone call inviting me to a diagnostic appointment with a week's notice. With my, by now, considerable knowledge of autism, and several attempts at the Autism Quotient Test where I scored in the high 40s, I was almost certain that I was undoubtedly autistic. This test comprises 50 statements which should be answered on a scale of 'very much' to 'not at all,'

> and a score about the mid-20s indicates that autism assessment may be beneficial."

> "I did not doubt the experiences of those who had said the system failed them, but the reality of just how disconnected autism research and practise is from actually living as an autistic person was not fully appreciated until I experienced that diagnostic appointment for myself. The details are irrelevant at this point but, in brief, I was told that as a functioning adult who was a PhD student and a single parent, I could not be autistic. The questions asked were outdated, and the assumptions made were frankly astounding. The official report contains 'facts' about topics which were never discussed, and inaccuracies about those that were. I was told to contact local mental health services about diagnosis of a depressive personality disorder which, incidentally, is the most common misdiagnosis of autistic women. Not only that, but the appointment was concluded abruptly once I questioned their methods, and my discussion of more contemporary, participatory autism research was dismissed as autistic academics serving their own agenda. This from the main autism body in Scotland, who publicly state that they want to listen to autistic people and have them inform practice".

These misconceptions relate to autism in this research, but highlight the general need to take lived experience and insider accounts into consideration while studying any phenomenon involving human behaviour. It is impossible to separate experiences from the context in which they occurred (Dörfler and Stierand, 2021; Stierand and Dörfler, 2014), great importance can be placed on conducting research within the relevant context. Rather than being overtly biased, or limited by the involvement of insiders, research conducted in this manner is, in fact, arguably more rigorous than would be otherwise possible. Considering that some of the greatest minds in human history have been, sometimes retrospectively, identified as autistic (or at least displaying significant autistic traits), it stands to reason that it is everyone's benefit to create a world which is accommodating of the Teslas, Einsteins, Newtons and Darwins amongst us. These great minds and, indeed, all of those who are seen as lesser by society due to non-compliance with social norms, deserve to be embraced, listened to, and freed from the gaze of the researcher, and those who feel they know better.

The following quotes are included as they have resonated with me while conducting this research, particularly in terms of recognising the need to challenge the norms and recognise the value of differences.

> “Here's to the crazy ones. The misfits. The rebels. The troublemakers. The round pegs in the square holes. The ones who see things differently. They're not fond of rules. And they have no respect for the status quo. You can quote them, disagree with them, glorify or vilify them. About the only thing you can't do is ignore them. Because they change things. They push the human race forward. And while some may see them as the crazy ones, we see genius. Because the people who are crazy enough to think they can change the world, are the ones who do.” (Anonymous)

> “The reasonable man adapts himself to the world: the unreasonable one persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man.” (Shaw, 1952)

There is good reason for the focus to switch back to autism here, when I have taken care to stress that this is not specifically autism research. The fact is that these misunderstandings of autism are key to this research, although not from the perspective of trying to dispel any of these myths. These misunderstandings form the basis of much of the struggles which each of the participants had faced and, therefore, influenced their journey towards self-acceptance. Indeed, these myths and misconceptions are perhaps exactly why the journey had been so painful and protracted. They might also be why I have felt the need to stress that this is not specifically autism research. They are absolutely why I could not have obtained such rich insights had I not been autistic myself.

6.2 Relating This Research to Existing Literature

Throughout this thesis, I have discussed how this research relates to existing work on autism and threshold concepts. There are also several other areas which contributed to my research, and have been included in the literature review, namely knowledge levels, sensemaking, and communities of practice. Each of these has been touched upon at various points, and now I will discuss how this research relates.

6.2.1 Knowledge Levels

As mentioned early in this thesis, knowledge levels (Dörfler et al., 2009) featured heavily in the background to this research, but did not play a significant role in the research itself. This has been included in the literature review, and is referred to when discussing earlier stages of the research, as understanding this model of learning and competence contributed to the initial research into threshold concepts which I had conducted at undergraduate level. As such, just as some other areas of research were brought in as this study evolved and my reflexive approach took me in an unexpected direction, I recognised that this was not the most appropriate model of learning and existing for this context. When the discovery of my own neurodivergence triggered a shift away from the initial intention to look at transformational learning amongst well-known autistic people, such as Temple Grandin, and towards a participatory approach, this model became less relevant. Despite this, it is important to include knowledge levels in this thesis, even if briefly, as this prior knowledge formed the basis from which I began this research. It is also important to acknowledge that different models of understanding learning exist, aside from that with forms the main focus of this particular research.

6.2.2 Sensemaking

Sensemaking is one of the later additions to this research, as outlined while discussing the emergent research design (see Section 3.4), although was present in how I approached the research well before I explicitly identified it. My intention throughout was not just to see what was happening while an autistic person progressed along a liminal journey, but to understand this, why it was happening, and what it meant. As mentioned earlier, the interviews and interactions with participants provided insight into their liminal journeys towards the threshold concept of self-acceptance, but I was not satisfied that I had a full understanding. Of course, I probably still do not have a full understanding, given how complex and ever evolving a phenomenon this is, but I am now satisfied that I have engaged in a process which uncovered as deep and meaningful an understanding as possible.

Sensemaking featured from several different perspectives over the course of this research:

i. Amongst late-diagnosed autistic people as they came to terms with new, unexpected truths about themselves, and sought others with similar experiences
ii. My sensemaking around my own neurodivergence, which is essentially the same as that in point (i), but with the added complexity of researching as I processed
iii. The role of community in forging identities
iv. Sensemaking as part of the research methods (see Figure 20)

The role of sensemaking did not become evident until the later stages of the research, where I had the findings from the interviews, the initial Twitter text analysis, my own autoethnography, and had started exploring the participants' Twitter networks. I knew at this point that these were all related, and had been continually revisiting each in addition to being informed by each as it happened. I could see that the participants had spoken about their liminal journey, their involvement in the Twitter community, and the importance of the people they surrounded themselves with in helping them to accept their updated identities. I could also see that each participant had the inner and outer circles in their social networks, as shown in Figure 37. On the face of it, this nicely illustrated the sense of belonging which comes along with mastering a threshold concept, but the model of preliminal to liminal to post-liminal did not appear to adequately convey what I was seeing, and experiencing.

As the analysis had been ongoing, I had spoken to some of the participants again with some follow-up questions about the online community, and generally feeling that they fit somewhere. These conversations yielded some insight into the impact of community and belonging, and helped to add some validity and trustworthiness to the findings through sense-checking and co-creation. However, there was still something that did not seem to be coming together – a sense that there was more to be learned from the synergy between the various components of the findings. The deliberate choice to use sensemaking as a research method was made following an interviewing-the-researcher exercise with my first supervisor.

During this interview, I recounted my experience of this liminal journey just as I had asked the participants to do while I was the interviewer. This was lengthier than the other interviews, at two hours long, but was as open as they had been, allowing me to explore my own thoughts as I spoke, and go into detail which I had not actively considered before. As a result, the transcript of this interview was very similar to those from the participant interviews, and much rawer than the written account which I had published previously. Of course, it was also not edited, and my words were not deliberately chosen for a specific audience. My discussion on the comparison between the two can be found in Section 4.5.4.

This comparison was then the catalyst in changing how I was approaching the findings, and the perspective I took while considering them. While I had taken care to remain reflexive and open-minded throughout, as I have already discussed, conducting this comparison, and the sensemaking which was involved in doing so, proved to be the key to quite an important finding – that which has raised the question of whether the post-liminal phase is the end of the line.

Throughout the research, I was engaged in a process of becoming, where I strove to come to terms with my own new identity as a neurodivergent adult. The research topic involved me exploring this same process of becoming in others, with each new perspective enabling me to see the phenomenon through an updated lens. I had been aware of this to some extent, but taking a step back and deliberately considering the findings in terms of the seven properties of sensemaking (Weick, 1995) enabled the final insight into the meaning of what I had found. The findings from this research did fit with the liminal journey associated with threshold concepts acquisition, but also indicated a further step beyond simply post-liminal. As my aim here was to explore how a threshold concept presented in autistic adults, this is beyond the scope of the current research, and forms part of planned later work.

6.2.3 Communities of Practice

As has been discussed earlier in this thesis, communities of practice literature has been included to aid with understanding the role of communities and networks in threshold concept acquisition, once the interviews revealed this as a common theme. Communities of practice are referred to in extant autism (Guldberg et al., 2019; Fletcher-Watson et al., 2019) and threshold concepts literature (cf. Walker, 2012), but did not feature in my initial literature review. Instead, the inclusion of this area of research was an addition enabled by the emergent research design at a later stage of the study. In this context, communities of practice, in particular the differentiation between communities and networks, contributed to the interpretation of the Twitter social network analysis. Being able to differentiate between communities and networks was essential when moving from the overall #ActuallyAutistic to the participants' own personal networks.

In brief, while communities of practice was not a core element of this research, some knowledge and understanding of this area of literature was key to identifying the communities within communities – or constellation – which made up what is colloquially referred to as the community around #ActuallyAutistic. Communities of practice, therefore, may not have directly contributed to the findings from this research, but did form an essential part of my own sensemaking process while analysing and reflecting upon what I had seen and heard. I also anticipate that this aspect, communities of practice and social learning, will play a more significant role in my planned future research.

6.3 Further Questions Raised by This Research

In addition to the insight into the communities and networks surrounding each of the participants, which was the aim of this research, further questions have been raised while conducting the exploration into, in particular, the Twitter networks. Some of these questions relate to the autistic community(-ies) specifically, while others are more general musings around communities, networks, and how this type of approach could be used to retrieve more meaningful insights.

As mentioned earlier, there has been some earlier research into the autistic community as a community of practice, both in terms of education and research (Guldberg et al., 2019; Fletcher-Watson et al., 2019). The Twitter community centred around the #ActuallyAutistic hashtag was used as the basis for the social network analysis component of this research and, while there was undoubtedly value to be had from connecting with others with a similar lived experience, or at least elements of experience in common, this exploratory analysis of the network appears to suggest that it is a network, as defined by Wenger in communities of practice literature, and not actually a community (Wenger et al., 2011), at least not for individual members. With that said, there are elements of both the common interests of a network, and the shared identity of a community present.

While this is not to suggest that these professional communities of practice within the autistic community are not incredibly important and impactful, it appears that there is still a risk of applying too homogenous a label to autistic people by considering this a community. From what I have found while conducting this research, the Twitter community seems to be an important stepping stone in the liminal phase of autistic self-acceptance, but tends to be a temporary place of belonging which enables an individual to progress towards where they truly belong. Of course, this will not be true for everyone, but those participants who shared their experiences with me either explicitly stated or strongly implied this was the case. The exceptions to this were those who had a career, either academic or otherwise, which centred around autism. With this in mind, future research into how the community, or constellation of communities, on Twitter actually works for autistic individuals is planned.

Assuming that the Twitter community does function as a community of practice, questions can be asked about how this both relates to the lack of inclusion and acceptance in general society, and how it can be used to improve both. It is unsurprising that a marginalised group such as this comes together as a result of feeling less different and less impaired when surrounded by other autistic people (Crompton et al., 2020), but could these positive elements be harnessed and focused more positively to support autistic people (and, indeed, other neurodivergent individuals)? One of the common complaints amongst neurodivergent people, myself included, is that any support or other services and resources offered after diagnosis have a definite air of taking a one-size-fits-all approach, that does not account for the heterogeneity of the population. Given that so much more of our lives are online now, it would be interesting to explore how communities and networks could be established and developed in a more inclusive manner, which reflects the fact that autistic people are still people, with all the differences and variety that this entails. As the communities of practice literature states, it is impossible to enforce an effective community on demand, but encouraging the existing connections to flourish and expand could have a significant benefit on several levels.

Moving away from the neurodiversity element and towards networks and communities in general, this research has also inspired some questions around how other communities may appear when explored using a similar approach. Just as the assumption here was that the

#ActuallyAutistic network would represent a place of belonging at the conclusion of a journey of becoming, so taking a different perspective on other communities could uncover a more meaningful insight into both how members benefit from membership, and how this could be improved. My main concern here relates to the learning which takes place within communities and networks, which is currently in a state of flux given the recent enforced move to online and virtual communications.

With so much information and network data available, it may be beneficial to explore how these networks and communities impact upon, and are impacted by, their members’ learning and development. Moving away from this personal context, using a similar approach to explore collaborative learning and knowledge sharing (cf. Yström et al., 2018; Coghlan and Coughlan, 2014) may prove fruitful. Working and learning effectively online can involve an entirely different skillset to that which was required before the COVID-19 pandemic, particularly when it comes to sharing tacit knowledge. Could it be that the experts in a field are now different people, and the balance of power, for want of a better term, is shifted by a move online? The change in our working and learning patterns has been significant; has this disrupted the hierarchy within organisations and communities, to the point where there is perhaps less of a hierarchy as communication across levels is enabled by virtual communications? Perhaps there is still hierarchy, but with a different structure.

In future research, while I may not focus on threshold concepts explicitly, I intend to conduct further exploration into liminality (see Section 5.2.1). It appears to me that there is much to be learned from these periods of great change, both on a personal level, and an organisational one (Söderlund and Borg, 2018). While neurodivergence is a personal characteristic, improved understanding of it impacts on an organisational and societal level.

This final section has discussed the research process, and the insight into the liminal journey experienced by participants which was obtained through applying a selection of methods. I have also discussed how some of the methods which were used at various stages were not conducive to meaningful findings in this instance due to the nature of the topic being studied, but may be put to use more fruitfully while exploring less personal, deeply individual, transformation learning experience. Finally, I have outlined some of the further questions which have been raised while conducting this research. Next, I will reflect upon the research experience, which also formed part of my own liminal phase.

7. A Reflective and Reflexive Narrative

If I was to use one phrase to describe my PhD process, it would be “absolutely not what I expected”. In this chapter, I will reflect upon my three years’ studies, the impact of conducting this research, and the various changes which have taken place over that period of time. Some of this has already been discussed throughout the thesis, as I described the research itself, my reasoning for adapting and discarding certain methods and approaches, and the discoveries about myself which came as an unexpected package deal with research involving neurodiversity. While my own experience is not the most important component of the research by any means, it is inextricably intertwined, and so feels important to reflect upon as a way of concluding at least this stage. In the spirit of sensemaking, the actions which I have taken have been impacted by, and impacted upon my own experiences and learning along the way. As such, I am now uniquely placed to provide a first-hand account of the very learning experience which I was studying, and here it is. Some of this will undoubtedly be a near repeat of what I have said elsewhere, but it is all essential while reflecting upon the past several years.

From the start, I had a very personal involvement in the research topic. My eldest son, as I have stated earlier, was diagnosed autistic at the age of 8 in 2003. I am deliberately not going into too much detail about him, as I am fiercely protective of his autonomy and his ownership of his own story, as it were. There is a tendency amongst parents of autistic children to engage in a form of martyrdom, where the focus is on how difficult they find it to parent this child whose needs they did not foresee, with little consideration for how these needs impact the person who is most affected by them – the child themselves. This generally takes one of two forms, either lamenting the difficulties they face, or overtly seeking praise for being such a hero and doing the best they possibly can by their child. I will admit that I did this. Not to a very great or public extent, but I did, for a time, make his autism about me, feeling I was being very inclusive and accepting by sharing pieces such as “Welcome to Holland” below.

> *“I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......*

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place.

It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

> *But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland."* (Kingsley, 1987)

With hindsight, I can now see that there are several issues with this. It seems like an excellent indication that you are embracing your child's needs and celebrating their differences when you first look at it. However, the focus is very much on the parent's perspective – where is the support for the child, rather than the parents' emotions? Secondly, pretending that everything about neurodiversity or another disability is positive is just as toxic as ignoring the positives. Again, where is the support for the child, who is navigating a world which was not designed for them? Thirdly, there is a strong assumption that parenting in "Italy" is the same for everyone, and only this pesky curveball of a disability is making it different. Absolutely not true. Parenting is difficult, we are all individuals regardless of any labels or diagnoses we may or may not have, and this kind of societally enforced expectation of a standard normal is ridiculous and dangerous.

I will hold my hands up and admit that I have posted things like "autism won today" on Facebook when talking about my son. I truly believed I was being supportive and recognising that it wasn't his fault that whatever had happened that day happened but, of course, in expressing how much I hated his autism, I was essentially saying how much I hated a part of my son. Of course, this was not true from my 'then' perspective, as I regarded autism as an undesired add-on to my son, not as one of his traits. However, if I consider it from his 'then' perspective, it was part of him.

I will not expand on this much more as it is not, for the most part, relevant to the research or indeed my reflection, but it is important to have context for where I started before the journey to where I have ended up, or at least am resting for now before progressing further, can be understood. When I started this PhD research, I knew I had an interest in knowledge and how people learn, and I knew there was not enough information on how people like my son learned. This is what I wanted to explore.

As this reflection comes towards the end of my thesis, I have already explained, discussed, and unpacked the main points of my own transformational learning from a research perspective, but not necessarily from a personal perspective. It is this personal experience and perspective that has enabled my research to go where it did, and it is the research which has enabled me to explore and develop myself. While I am careful to take pains to explain that this is not autism research, it is threshold concept research where autistic adults are the group of people forming the context, the reality is that just as there is no separating the autism from the child, there is no separating the learning about self-acceptance, communities and networks from the learning about autism and my autistic self, my ADHD self, my neurodivergent self, or whatever other terms I may want to use to describe myself on a given day. Regardless of what I was researching, it would and can only ever be done from a neurodivergent perspective, as that is the mind which I have and, for better or for worse, it is me, and I am embedded in the research which I do.

Once I started to suspect my own autism quite early in the research, my attitude shifted. I realised that my comments about my son’s autism were not quite as benign and helpful as they were intended to be, and I started to understand why I had found certain aspects of parenting, and life in general, difficult. On the face of it, I felt that I was happy knowing why I do what I do, and why I think how I think, and set about being very vocal about how harmful autism research and practice can be, and focusing almost entirely on learning more about autism, how the narrow criteria which were formed based on a relatively small demographic missed just about everyone who was not a young, middle-class white boy who lined up trains and had poor social skills, and how many people had chronic mental health issues purely because the actual root cause was not being recognised. I was angry.

I was angry that I had gotten to my mid-30s without knowing this pretty important thing about myself. I was angry that I had been medicated for anxiety and depression since my late teens and no medical professional had ever though to look into why that might be, beyond “how is your marriage?” (miserable, we’re now divorced) and “it’s postnatal depression, it will get easier when your sons are older” (not reassuring when you have a toddler and a new-born and are struggling to face every day and feeling deep, deep dread every time one of them cried). Very, very unfairly, I was angry at my parents, and my teachers, and everyone else who had commented on how sensitive I was, how shy I was, how clearly intelligent I was yet could not do well in exams… and none of them thought there might be something else going on. Of course, none of them could have known this because, while it might be picked up upon now, it was not ever going to be noticed in the 1990s because we just did not know what we know now about neurodivergence. I was, above all, absolutely livid at the diagnostic team who told me I could not possibly be autistic because I was doing a PhD and was a single parent. It does not take too much research to see just how patently untrue that one is.

This anger was useful, because I channelled it into my research. The Twitter network or community of autistic people which I had been introduced to by a friend became my lifeline. It was my connection to people who had been through the same as I had been through and I related fiercely to a lot of what was being said. As I've discussed already, this Twitter community was where my participants were recruited from and, aside from the great research benefits of having this insider perspective, it felt amazing and incredibly validating to have such a positive response to my call for participants, and to have been recognised as one of their own, despite the protestations of the diagnosticians. As an aside, Twitter, and presumably just about everywhere else, is bursting at the seams with clearly autistic or otherwise neurodivergent adults who cannot get the help or support they need because of these heinously unfit for purpose processes. I am far from alone.

It was my own experience of discovering my own neurodivergence that told me that self-acceptance in a similar situation was quite likely to have been a threshold concept in the lives of those who I now knew are my peers. The responses I got strongly supported this, at least amongst the subset of autistic people with whom my research resonated. It was the same intuition, based upon what I was feeling myself, that told me that social network analysis of some kind was an avenue I should explore. At this point, I was slightly calmer and more reasonable about the whole thing, and had remembered that I was not really supposed to be spending my time on working out what autism is, and nor did I want to, I was interested in how this level of learning happened, and how it looked when it did. Of course, I am very interested in the autism and neurodiversity aspect, but that is a personal interest and not a professional one, as such. These people had opened their hearts to me, and shared unbelievably personal and touching stories with me, and underneath what they were telling me about how great it was to know that they are autistic and how they can now enjoy being their true selves, there was an underlying note of…something. Not quite sadness, not quite anger, although we had discussed both of those at length. It was something that I could not quite put my finger on.

By this point, after having these rewarding conversations with people who were kind and generous enough to share their experiences with me, I had a good picture of how this particular threshold concept presented in autistic people and, as that was the aim of my research, I could technically have stopped at that point and had something valuable to share. People had been faced with challenges throughout their lives, they found out that they were autistic, they found the autistic community and felt like they belonged. Mastering a threshold concept enables membership of a community, they had found their community, and that was that. Except it wasn't.

I knew there was more to it. I could not, in good conscience, say that I had explored this phenomenon when I had this persistent niggle telling me constantly that was more to be found. What I had discovered and uncovered was valid, and did represent the experiences of the participants. It was fine, but as I said while presenting at a EURAM conference recently (see Harrington et al., 2021), I was not happy with fine. I wanted to keep going. Not only did I know that I hadn't yet gotten the full picture, but I also knew that I would be doing a disservice to myself and to the participants by not at least attempting to delve a little deeper into working out exactly what that niggling something was.

I did. And it was fantastic.

I had started using methods such as text analysis on Twitter, on blogs and websites participants and other autistic Twitter users had pointed me towards, and on threshold concept literature, in an attempt to see how these accounts matched up in a way that let me explore a bit further how threshold concepts presented in autistic people. Not much meaningful came from these, but until this point, I had not realised why.

The Twitter posts, the blogs, the academic publications – they were all written for other people's eyes. The interviews, the underlying unsaid words which I could see while reflecting upon the interview process, the intuition I had about there being more – they were there because I am an insider. In trying to tease out how this learning could be found in the various sources I was missing that the real value lay in what I knew without anyone having to tell me, or without having to read more about how to analysis transcripts, texts, and social network data. These people had spoken to me as a peer, as one of their community, and in doing so had expressed things in a different way and been more open, honest, and blunt than they would have been while writing a blog or a Twitter post which could be read by anyone. Twitter was valuable, but not when used in the way Twitter content normally is. The networks and communities around each participant only meant anything about their selves when armed with the knowledge I now had from speaking to each of them, and from being able to interpret what they had said and what they had communicated non-verbally through the lens of a peer.

After a lifetime of constantly struggling to do what I “should” as a neurotypical person in the society where I was brought up, I was still unconsciously trying to do what I should in research terms, and missing what was right in front of me.

What the Twitter networks showed was that there was a strong autistic presence in each of the participants’ networks and that being autistic was a significant part of their identity, but it was not all there was. Basically, when autistic people are in an environment and a headspace where they can be comfortable with being themselves, their autism becomes less important. These people all had different interests and different themes to the people they were closest to in their social networks, just like neurotypical people do. Based on the people I spoke to, and the networks I looked at, autistic people are just people. People who think differently, but are still human. This is the best thing I could possibly have found.

Seeing as this reflection is about me and my experiences, I should clarify that, while this was obvious to me looking at the participants’ networks, I did not realise it about myself until a while later when my supervisor interviewed me about my own “journey”. There was a lot said during that conversation that I do not want to repeat here, but it was cathartic, it helped me to realise just how far I had come, and how much I had changed. It also triggered my realisation that, just as the participants had, I had moved into the autistic community, anchored myself firmly in there, and then slowly and unconsciously moved away again, towards, well, myself.

It was the embodiment of sensemaking – "*how can I know what I think until I see what I say?*" (Weick, 1979: 5).

Throughout the past three years, this research and my own sense of self and acceptance of who I am have very much gone hand in hand. Even after writing up my autoethnography in the form of the book chapter included earlier, I was not fully aware of just how much I was informing the research, and the research was informing my own progress towards being content and accepting of myself. It was not until now, at the end of the study, that I can see this, and even that is only because of the final interview. My thoughts while looking back at how the research unfolded, and how and why I chose the combinations of methods that I did, are full of what-ifs. I am reasonably comfortable in myself and with my neurodivergence at the moment, and am incredibly aware that a lot of this is down to chance.

If I had not decided to attend university as a mature student, I would probably not have had some of the life experiences which have led me to this place. Even this reflective and reflexive account has been very surface-level in terms of just how distressing the various discoveries and changes over the past few years have been, mainly because most of it is not relevant. In short, if I did not return to education, I most likely would never have discovered my neurodivergence and been able to make peace with myself. I am, for the first time in my adult life, not being treated for mental health issues because they were never really the problem – my undiagnosed ADHD was.

That same ADHD is what has allowed me to make connections between certain cues and prompts that may not be immediately evident, and made me impulsive and stubborn enough to decide I was including quantitative methods in an Interpretivist study because I knew that was what was right, so was determined to pursue it. There are absolutely downsides to being neurodivergent, but I am conscious not to forget to recognise the strengths too, particularly as I force my dopamine-seeking ADHD mind to sit and finish writing this thesis…

While autism is what made me part of the community I have been studying, and ADHD is what makes me creative and determined to follow my ideas, I am also aware that I will not always be an insider when conducting future research. I am confident that the insights I have had as an insider, and the courage this gave me to pursue a less standard approach to my research, are in themselves an invaluable tool for future research. I may not be an insider, but I do know how important it is to recognise the nuances and peculiarities of a group, and to be faithful to maintaining these while choosing methods and approaching a research problem, not to mention being aware of how research impacts upon the participants, as well as the other way round. I also feel very strongly that recognising my own neurodiversity contributes to making me a good teacher, which I am passionate about.

Overall, as this comes to a close, I am grateful to have had this opportunity. I am lucky both to have been able to discover and explore this part of myself, and to have used this experience to gain more insight and understanding into a marginalised group. I am particularly grateful to have “discovered” that neurodivergent people are, despite popular opinion, still just people…

These past few years have had their ups and downs, and have certainly not been easy but, as the saying goes, if it was easy, it wouldn’t be worth doing.

8. Conclusions

Now that I have discussed the findings from this research, and how they compare to the existing research in each of the fields which have been brought together here, I conclude this thesis by expanding a little more on what the implications of these are. I also outline my proposed future research, and how I intend to progress from this PhD. I outline in turn how this research contributes to understanding and embracing neurodiversity, how it adds to existing threshold concept literature, and what this research means in terms of the proposed inclusion of more quantitative methods in interpretivist research (or at least a move away from an almost automatic discounting of any quantitative data or methods). It is important to note once more that this research was not intended to provide a definite answer on how best to study threshold concepts, or what constitutes a threshold concept, but to illustrate how this journey appeared in a specific group. The following discussion relates to the main findings from this research, namely:

- The similarity between the autistic threshold concept experience, and that described in extant literature relating to presumably neurotypical people
- The potential for a further step in the liminal journey, beyond initial post-liminality
- The role of identity, communities, and networks in fostering a sense of self-acceptance and belonging

8.1 Implications for Understanding and Embracing Neurodiversity

While this research has not looked at what autism "is", it has provided a different perspective on what becoming an autistic person is. I do not mean becoming in the sense that one is not autistic until a certain point, but becoming in the context of progressing from a misunderstood, seemingly defective neurotypical person to self-acceptance as an autistic adult. Much of the current misunderstanding appears to stem from continuing reliance upon outdated and misinformed research, where those who think differently were othered and decreed as defective and somehow lesser. As such, research which has been conducted from an autistic perspective, particularly one which illustrates a strong similarity between how a phenomenon is experienced by autistic people and how it is experienced by neurotypicals, has the potential to contribute towards better understanding of this natural human diversity.

Illustrating as it does that even the small subset of autistic people who participated in this research are heterogeneous as people in general, although they are similar in terms of neurodivergence, it has shown that looking for a difference in how threshold concepts present in fact resulted in demonstrating there appears to be no difference. The journey may be different, because the thinking and experiences are different, but autistic people are not flawed people, we are just people. As I have spoken about at a recent neurodiversity celebration event hosted by the University of Glasgow and University of Strathclyde, what is said to be "wrong" with us is exactly what is right (Neurodiversity Strathclyde, 2021). Embracing this natural variation in being human could have a positive impact which reaches far beyond simply making life a little less difficult for those who do not fit perfectly with social norms.

8.2 Implications for Threshold Concept Research

Threshold concepts are the framework for transformational learning experiences which formed the basis for this research, evolving as it did from my undergraduate research projects. Having conducted the interviews with participants who had each experienced a specific threshold concept in the guise of self-acceptance as autistic, and found clear indications that the transformational learning did not stop with finding a place of belonging in that specific community, I would suggest there is potential value in future threshold concept research which focuses on the learning which happens within these communities. It could be fruitful to explore whether there is further transformational learning within the post-liminal period of other disciplines where threshold concepts have been identified (see Section 5.2.1).

What I have taken from this research is that much of the interesting and meaningful insights were related to the liminality. It was the changes which the participants underwent which communicated the impact of their surroundings, context, and knowledge. The continual changing and evolving which the participants described, and which was reflected in the social network analysis, is perhaps more important to bear in mind for future research than considering post-liminal as a destination. To this end, I also propose considering recognition of liminality and temporality (Söderlund and Borg, 2018) as an essential component of related research.

8.3 Quantitative Methods in Interpretivist Research

This exploratory research was conducted with the intention of studying how mastering threshold concepts, and the preceding liminal journey, present amongst autistic adults. I do not believe that the insights which were gained would have been possible had I maintained a purely qualitative approach, under the misconception that interpretivist research must be qualitative in nature. I firmly believe that the combination of methodological approaches which were used at various stages of the research facilitated a more holistic view of these transformational experiences than could possibly have been obtained using just one method. Using this particular combination of methods enabled me to explore a little further than I may have been able to otherwise. Indeed, it is unlikely that without the autoethnographic element of my insider experience, I would have realised that the interviews suggested that it would be prudent to explore the participants' social networks. Extant threshold concepts literature stresses the role of community once the threshold concept has been mastered, for example (Meyer and Land, 2003), but the transformation enabled by the community was unexpected, even with an, admittedly also unexpected, insider perspective.

While extant threshold concept literature often mentions the threshold concept as being the key to belonging within a given community or discipline (Meyer and Land, 2003; Walker, 2012; Davies and Mangan, 2005), there appears to be a tendency to assess this either fully from the outside, or using mastery of professional terms or educational topics as a proxy measurement. In this thesis, I am proposing that using a combination of methods beyond those which are perhaps expected to be used enables a far richer insight into the phenomenon being studied – in this case, looking beyond identification as an autistic person, towards the community in which the individual themselves feel they belong. Of course, this may not be necessary for each threshold concept, but in order to understand an experience which is highly personal, and involves a dramatic shift in sense of self, it is important to consider the person themselves.

I do, of course, recognise that self-acceptance as autistic is vastly different to measuring a professional or educational threshold concept, but propose that using a combination of methods could provide a much richer image, with those methods tailored to suit the context in question. In this instance, I have used insider lived experience, interviews with those who identify with a potential threshold concept, and social network analysis to complement one another as part of an emergent research design (Tom, 1996; Martin, 2008). I would suggest that a similar combination could prove fruitful while exploring other threshold concepts, with the willingness to embrace the unexpected being of more importance than the specific methods used. As this is based on one exploratory study, further research is required to explore the potential of this combination of methods.

Finally, that this successful study serves to illustrate why I am strongly opposed to the seemingly common view that interpretivists cannot, or should not, use quantitative methods. As indicated earlier, I have been unable to find existing quantitative interpretivist work in our field, however, had we followed this tendency, I would almost certainly have missed valuable insights. It was only through combining the qualitative and quantitative, and viewing both through an interpretivist lens, that I was able to find what I did. As such, I would urge others to reconsider the view that interpretivist research is solely qualitative.

Of course, I am not suggesting that all interpretivist research must include both, merely that we, as researchers, should be open-minded when exploring an avenue that may contribute to good research, and gaining a holistic and contextual understanding. As interpretivists, what is important for us is that all data and information (meaning processed data) is interpreted in the context of the research, not the form in which that data is presented. While I do not profess that a combination of quantitative and qualitative is always useful, I do believe there is much value to be had from open-mindedness. I fully intend to take this approach, and develop it future, during future research.

8.4 Proposed Future Research

Having conducted this research into threshold concepts and transformational learning, I am keen to build upon this with future research. At this stage, there appears to be much to be uncovered about learning within communities through adopting an interpretivist approach which allows for the inclusion of quantitative methods as appropriate to the given scenario.

As more and more of our formal education and professional interactions move online, so too do the communities and networks in which we work and learn, and the format in which that learning takes place. These online interactions, and the virtual settings in which they occur, provide a new perspective on social learning, which could be relevant across a number of fields. I propose to develop my approach further, with the objective of gaining deeper, more meaningful insights into this process. Perhaps finding ways to improve online ways of mastering threshold concepts, supporting this process and/or the associated communities. I also believe that future research into the learning which happens within these communities which are accessed through mastering a threshold concept could yield useful insights.

I also intend to conduct further research into the post-liminal phase and, more specifically, whether it is indeed the end of the line in terms of transformational learning. As discussed earlier in this thesis, the findings from this research indicated that post-liminality is part of the journey, rather than its end. I would tentatively suggest that classifying post-liminality as the end point of a journey towards mastering a threshold concept may be applicable where the threshold concept in question affords membership to a professional or discipline-specific community. To refer back to some common examples used in threshold concept literature, if one masters a threshold concept and becomes accepted as, and thinks and acts as, an accountant or physicist, any development within this membership may be largely irrelevant. Conversely, where the threshold concept is a deeply personal one, such as achieving self-acceptance as an autistic adult, the autism-related community being something of a setting for further development towards the place where an individual truly belongs becomes more important.

In terms of the quantitative interpretivist approach to this research, there is much further exploration to be done which is beyond the scope of this study, however I propose that its successful inclusion in this research speaks for its potential. Social network analysis in particular has been used here to explore and illustrate how a threshold concept presents in a particular demographic, and my future research plans involve expanding this further, through exploring learning in other settings with a similarly open-minded approach to the methods used. Although the use of quantitative methods in interpretivist research is not unique to this study, it is an unusual approach in the context. I intend to utilise such an emergent approach in my future research, with the objective of championing the use of the most appropriate methods in a given situation, rather than simply conforming to what is expected under a particular philosophical framing. While the context of my future research may change significantly, my dedication to conducting *good* research will not.

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Appendices

Appendix 1: Participant Information Sheet

Participant Information Sheet for Interview Participants

Name of department: Management Science

Title of the study: A Bayesian Interpretivist Approach to Exploring Threshold Concepts

Introduction

My name is Susan Harrington, and I am a PhD researcher within the Department of Management Science at the University of Strathclyde. I am conducting research into how threshold concepts present in individuals. As an autistic researcher, and parent to an autistic teenager, I have decided to focus on self-acceptance as autistic following late diagnosis.

What is the purpose of this research?

My research explores the ways in threshold concepts, or transformation learning, present. The focus in this instance will be on self-acceptance following late diagnosis as autistic, although threshold concepts can occur across a variety of educational and personal setting.

Through identifying these moments, and exploring how they may appear, I intend to contribute to a current movement towards increasing understanding of autism, through exploring both my own experiences, and those disclosed to me by participants.

Do you have to take part?

I am keen to hear your views, and to learn more about your experiences, but participation in this research is entirely voluntary. None of your personal information will be disclosed, and anything we discuss will be anonymised, with all potentially identifying factors removed.

You may also withdraw your consent at any time, and any data already collected from you will be destroyed.

What will you do in the project?

Due to current COVID-19 restrictions, this interview will be conducted in compliance with current University ethics policy. That is, via Zoom, telephone, or email conversation. The specific mode of communication can be determined to suit your personal preference. I would like to hear your experience of self-acceptance following a late autism diagnosis, and how you feel this changed (or did not change) you as an individual, and your sense of self. You are also free to discuss any other transformative learning experiences you may feel are relevant.

Why have you been invited to take part?

You have been invited to take part as someone who is potentially interested in contributing to participatory autism research.

The research I am conducting has a dual purpose. Firstly, I aim to develop a novel method for exploring learning theories. Secondly, I aim to contribute to the discussion in participatory autism research. It is my belief that this context is the ideal environment to generate such new methods, and further that this is an environment that would benefit greatly from them and the insight they will bring.

What information is being collected in the project?

I will ask you some open questions about your lived experience as an autistic person, and you are free to answer these in as much, or as little, detail as you feel comfortable with. All data will be anonymised to protect your identity at all times.

Who will have access to the information?

Only I and my supervisors will have access to the information.

Where will the information be stored and how long will it be kept for?

All information will be stored on the University's secure systems, and will be anonymised. The information will be stored for the duration of this project, upon which point it will be destroyed.

If any aspect of this research is submitted for publication, any identifying characteristics will be removed, and only anonymised information will be used.

What happens next?

If you would like any more information about this project, or would like to participate, please contact me using the details below.

If you do not wish to participate, thank you for your time and for reading this so far.

If you would like to be kept informed of any findings from this research, please do let me know.

Researcher contact details:

Susan Harrington

Dept. of Management Science, Strathclyde Business School
Level 7, Sir William Duncan Building
130 Rottenrow
Glasgow
G4 0GE

susan.harrington@strath.ac.uk

Chief Investigator details:

Dr Viktor Dörfler

Dept. of Management Science, Strathclyde Business School
Level 7, Sir William Duncan Building
130 Rottenrow
Glasgow
G4 0GE

viktor.dorfler@strath.ac.uk

This research was granted ethical approval by the Department of Management Science Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
Department of Management Science
University of Strathclyde Business School
Duncan Wing
199 Cathedral Street
Glasgow
G4 0QU

Telephone: 0141 548 4361
Email: mansci_admin@strath.ac.uk

Appendix 2: Threshold Concepts Information Sheet

A Brief Introduction to Threshold Concepts

Firstly, thank you once more for participating in my research into how threshold concepts present in autistic adults. Before proceeding, I would like to clarify that, through participating, you are confirming that you are:

- Over 18
- Diagnosed or self-diagnosed autistic (whether or not you publicly declare this)
- Happy to discuss a transformative experience in your own life. I have proposed self-acceptance as a threshold concept; however, you are free to refer to any other experience(s) should you wish. There is no obligation to disclose the experience itself, as my focus is on the change in your perspective, world view, or sense of self. However, it would be interesting to hear about the experience, if you are comfortable with discussing.

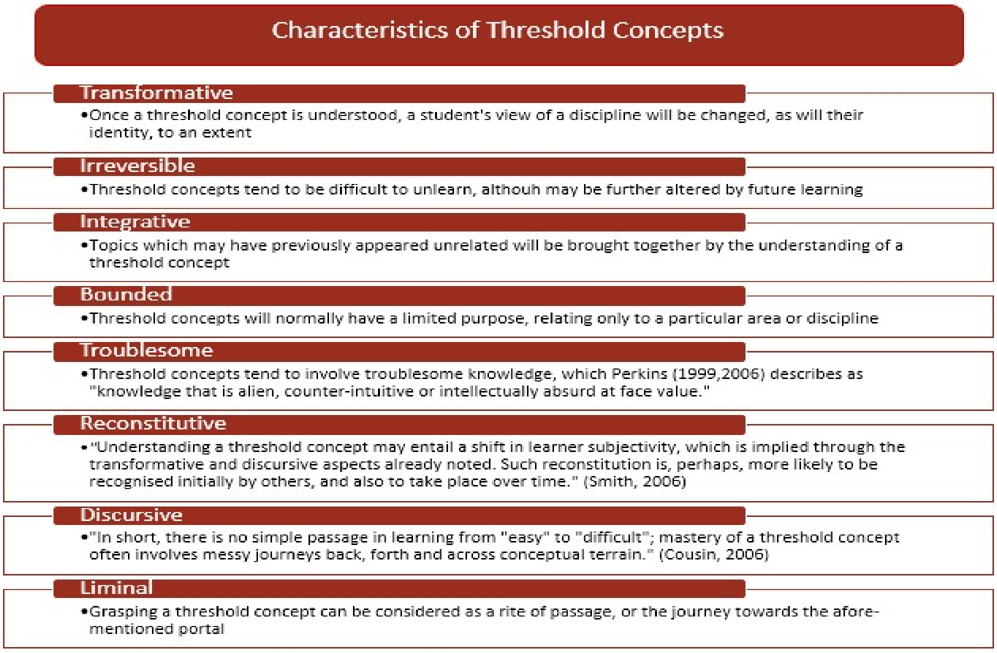
As your experience will be personal to you, and the aim of my research is to capture this as accurately as possible, the questions I ask you will be deliberately open-ended. You are, of course, free to choose what you do and do not answer. Please rest assured that you will be kept anonymous throughout if you wish.

To establish a common ground for our conversation, here is an outline of what I am thinking.

What is a threshold concept?

In short, a threshold concept is something that, once you have learned it, triggers a change in how you view yourself and/or the world around you. It is more than simply learning, there will be a transformative element to it, however, the event itself may not seem momentous at the time. It has been described as stepping through a portal, into a new dimension where you see everything in a new light.

The following diagram explains the common features of a threshold concept briefly. Please do not worry if this does not entirely make sense to you yet – I am happy to explain as much as you like before we begin.



Characteristics of Threshold Concepts

Transformative
- Once a threshold concept is understood, a student's view of a discipline will be changed, as will their identity, to an extent

Irreversible
- Threshold concepts tend to be difficult to unlearn, althouh may be further altered by future learning

Integrative
- Topics which may have previously appeared unrelated will be brought together by the understanding of a threshold concept

Bounded
- Threshold concepts will normally have a limited purpose, relating only to a particular area or discipline

Troublesome
- Threshold concepts tend to involve troublesome knowledge, which Perkins (1999,2006) describes as "knowledge that is alien, counter-intuitive or intellectually absurd at face value."

Reconstitutive
- "Understanding a threshold concept may entail a shift in learner subjectivity, which is implied through the transformative and discursive aspects already noted. Such reconstitution is, perhaps, more likely to be recognised initially by others, and also to take place over time." (Smith, 2006)

Discursive
- "In short, there is no simple passage in learning from "easy" to "difficult"; mastery of a threshold concept often involves messy journeys back, forth and across conceptual terrain." (Cousin, 2006)

Liminal
- Grasping a threshold concept can be considered as a rite of passage, or the journey towards the afore-mentioned portal

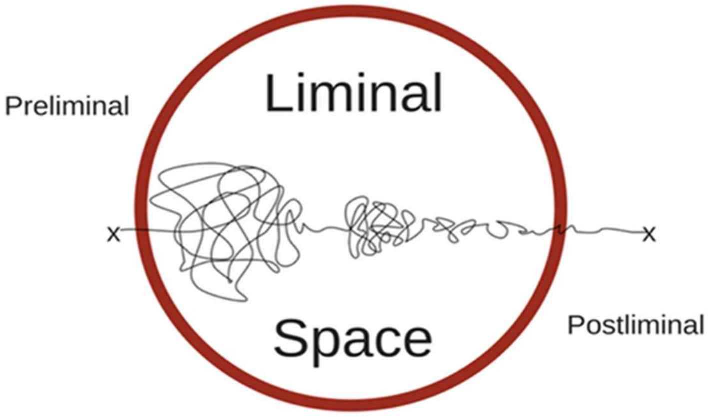
This research tentatively focuses on threshold concepts in autistic people, with self-acceptance as an autistic person identified as the first potential threshold concept. As the term “threshold concept” is not generally a common phrase, I have prepared some illustrations and examples to help you to understand what I am referring to. These are simply examples used in existing research, and are not intended to be prompts, or an exhaustive list of potential threshold concepts.

- Understanding gravity for the first time
- Realising that the world is not flat
- Transforming from being a child to an adult, through puberty

None of these may seem notable now, but are very difficult, if not impossible, to unlearn once learned -this is the key point defining an experience as a threshold concept.

When you are faced with new knowledge which contradicts your current beliefs, it is not likely to be a smooth journey from start to finish. You will, along the way to a threshold concept, travel through what is known as the "liminal space". This is an unavoidable period of turmoil and difficulty, which must be overcome before the threshold concept is experience. I feel that puberty is a good example of this – very few of us will say it was an easy experience, but it definitely changed us!

If you prefer to visualise things, the liminal phase may look something like this:



Using the example of puberty, preliminal refers to being a child, the liminal space is puberty itself, and postliminal is when you emerge as an adult at the end. Similarly, the process could be described by using the image of a caterpillar, a cocoon, and an emerging butterfly.

Why self-acceptance?

I have chosen to focus on self-acceptance as autistic, as I recognise this as something which most definitely triggered a change in my own life. For example, it has helped me to be kinder to myself, to recognise that some aspects of my self which I had previously seen as negative are not my fault, so to speak, and that I am good enough as I am. If I was to describe it in one word, it would probably be relief. As a result of this realisation, I am far more comfortable in myself and my "quirks". Of course, this is a very brief overview, and it wasn't quite as smooth a journey as that may sound.

I have also experienced other personal threshold concepts, which I do not wish to explicitly discuss, however, to demonstrate how we can discuss the transformation without touching upon any details of the experience itself, it involved a long period of being unhappy and aware that something was not quite right, a change in circumstances which gave me the confidence to change things, yet more turmoil when the changes were happening, and then a new-found sense of self. Although this experience was not pleasant, it has had a very positive effect on my life in the long-term. It certainly did not feel like that at the time, however.

At this point, I am aware that I am associating negativity with threshold concepts. This is not necessarily the case – there will be some effort involved in accepting the new knowledge, or new state, but it may well be a very positive experience. There are those of us who would feel terrified standing at a cliff edge, and those of us who are exhilarated by it!

This conversation will be entirely led by what you are comfortable with. What I am looking for is as clear a picture as you can/are willing to give about the change in yourself. Please describe events in whatever words come naturally, there is no need to use certain terminology, or feel you must use formal or polite language. Feel free to express yourself as you wish.

What next?

Once you have read this introduction, and are happy you understand the project, we will be ready to proceed. Normally, this introduction would be given at the start of a traditional interview but, due to current circumstances, our "interview" will take place via email instead. This has the advantage of allowing you to respond at your own pace and think about your answers. There will be no need to come up with an answer quickly, and no need to look back and wish you had worded your answer differently. Skype or Zoom conversations can also be arranged if you prefer.

Our conversation can take place over a short period of time – perhaps you would prefer to write a single piece about your experience – or over a couple of months, with you taking some time between each response. It is important to me that you are comfortable with this, so I am happy to proceed at your pace.

Looking forward to speaking to you,

Susan susan.harrington@strath.ac.uk