Autistic Dreaming: a phenomenological study of dreaming and well-being

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Autistic Dreaming: A phenomenological study of dreaming and well-being

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2. None of the material contained in the thesis has been used in any other submission for an academic award.

3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.

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Abstract

Whilst there have been a handful of studies into autism and dreaming, it remains a potentially under-researched area. Studies that have been carried out with autistic participants have demonstrated that there are differences in the sleep architecture that produces dreams and in the content of those dreams. Research into the dreaming experiences of other atypical groups or loosely affiliated communities have shown that this activity may indicate a change in their underlying conditions or may be used to monitor the effectiveness of any therapeutic intervention. If correlations between dreaming and the impact on well-being of autistic people can be demonstrated then this same potential for therapeutic support could be applied.

To investigate this gap in knowledge, a Thematic Analysis (TA) approach was used which was later supplemented with an Interpretative Phenomenological Analysis (IPA). Three participants were recruited using a Semi Structured Interview Questionnaire (SSIQ) and the interviews transcribed for analysis. Following a review of the feedback around this initial pilot, the data collection was moved to an on line survey based on the SSIQ. This reached a wider group of potential participants and a further 90 questionnaires were completed. These responses were prepared for a parallel analysis, all the responses were explored in the descriptive TA and 6 of these were selected for the idiopathic IPA. The data provided by the on line questionnaire offered some quantitative data which was used to highlight the qualitative findings.

Initial findings have shown an appreciation of the therapeutic benefits of dreaming and links to waking well-being in a variety of ways. An unexpected finding has been the role of dreaming in the construct of a sense of personal identity and how it is perceived in the sense of an autistic self-hood. The study will provide suggestions for further research in the area.

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In memory of absent friends.

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Preface

Like many autistic people, I don't always recognise how different my 'normal' is to that of others and dreaming has been one of those areas. Heightened levels of stress about any issue has produced dreams which are incredibly vivid and have such a level of threat or bizarreness (or both) inherent in them that an episode would leave me anxious, confused and tired, more prone to making frustrating mistakes and not wanting to engage socially. In some instances, I have been absent from work because of them and, on one rather memorable occasion, I have ripped apart a pillowcase.

The research was designed to investigate how people with autism experience dreaming and the impact that it has on their waking life, but in the process of reading around the research area I became aware of reality checks in which the dreamer is directed to try to do something in the dream such as read an analogue clock face, switch a light on or off or press the fingers of one hand onto the palm of the other, and if the dreamer can't accomplish the task then they will know that they are dreaming.

I hadn't consciously decided to try this but was in the middle of a dream and from some deep recess of my unconscious thought to try to read a clock face. When there was a blurry haze where the numbers and hands were supposed to be, I knew that I was dreaming. The threat and tension of the dream dissipated. I knew that whatever the threat had been it was not real and could do me no harm. It was as if the dream had lost its potency in that split second and I was able to just relax within it and watch the events play out knowing that they were of no consequence.

List of Abbreviations

AADE	ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ANI	Autism Network International
APPGA	All-Party Parliamentary Group on Autism
ARC	Autism Research Centre at the University of Cambridge
AS	Aspergers Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CAN	Critical Autism Network
CAP	Cyclical Alternating Pattern
CAS	Critical Autism Studies
CASP	Critical Appraisal Skills Programme
CRAE	Centre for Research in Autism and Education
DSM-5	Diagnostic and Statistical Manual of Mental Disorders Version 5
EEG	Electroencephalogram
EMDR	Eye Movement Desensitization and Reprocessing Therapy
HRQOL	Health Related Quality of Life
IADE	IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE
II	Initial Interview
IMFAR	International Meeting for Autism Research
IPA	Interpretative Phenomenological Analysis
INSAR	International Society for Autism Research
LD	Lucid dreaming
NAS	National Autistic Society
NREM	Non Rapid Eye Movement
OLQ	On Line Questionnaire
PARC	Participatory Autism Research Collective
PTSD	Post Traumatic Stress Disorder
QOL	Quality of life

REM	Rapid Eye Movement
SC PTSD	Sub Clinical Post Traumatic Stress Disorder
SSIQ	Semi Structured Interview Questionnaire
SMADE	SENSEMAKING ACTIVITY OF THE DREAMING EXPERIENCE
SWS	Slow Wave Sleep (SWS).
W-QLI	Wisconsin Quality of Life Index

Chapter 1 Introduction

1.1 Introduction

The purpose of this introductory chapter is to provide the context for the research project. The chapter will describe the early development of the area of study, autism and the potential of the study.

1.1.1 Sources used in the report

Discussion of the findings of the report will be discussed in Chapter 4 and onwards with reference to the lived experience of the participants. Throughout the report there will be references to and quotations from autobiographies and blogs (on line recounts on a subject written by an individual) from autistic people which will provide first hand perspectives of the subject under discussion. These quotations have been copied verbatim and there have been no alterations made to grammar or spelling in order to preserve their authenticity, likewise the use of ‘[sic]’ has been avoided to ensure their meaning is as the author intended.

1.1.2 Terminology

Whilst issues around the preferred use of language will be discussed later in this chapter, autism is used in this report to stand for all categories of the spectrum which may be referenced by participants and used in the wider literature review; Aspergers or Asperger’s Syndrome will be included within this generic label rather than as a sub category of its own.

1.2 The origins of the study

The origins of the study are both personal and professional. Throughout my life I have been aware that I have very vivid and intense dreams, the contents of which do not appear to have any correlates to my waking life, which leave me preoccupied and trying to make sense of the dreaming experience, in some instances for several days. These dreaming episodes become more intense during periods of heightened anxiety and, on occasion, have resulted in me taking an unplanned day off work to recover from an almost traumatic experience, although I would refer to a migraine rather than a dream when explaining my absence.

As the coordinator of a regional autism diagnostic service, I would speak to families about the challenges they were facing and, whilst sleep issues in general where often a concern, dreaming was also a theme of discussion. An internet search of a range of autism and dreaming on line communities, for example wrongplanet.net, community.autism.org and world-of-lucid-dreaming.com, continued to suggest that this was a credible area for further research. Having formulated the concept of the study from these anecdotal origins, I was able to undertake a more conscious, albeit informal, feasibility study to gauge if this was a phenomenon that is sufficiently significant to justify further investigation.

Of the 23 families and individuals that I spoke to informally, 16 reported experiencing issues with dreaming that affected them to such an extent that they referred to their experiences as a subject of concern. The terminology that they used to describe the dreaming experience reflected that which that I had read on various internet forums, with people referring to dreams in a generally negatively orientated manner using language as 'distressing', 'repeating over and over again', ‘vivid’ and 'unbelievably strange'.

The following recounts are quoted in response to a blog by Gavin Ballard in his Life with Aspergers series (2009):

> Ever since I was a little kid I've dreamt of flying in my dreams. Sometimes for the fun of it, and sometimes to get away when I feel I'm being persecuted. Often I jump from tall buildings, cliffs, mountains or precipices. I do fall for a while before my flying abilities take effect, and then I can fly and even glide like a condor through valleys and what not traveling long distances through the countryside. But here is a weird rule that's been stuck in my brain: I can only

> fly as fast as I am old. For example, if I'm 25 years old, my maximum speed is 25 miles per hour.
>
> and
>
> sometimes some intense dreams disturb my thoughts as if they gave me the idea that what happened in the dream (often related to past events that emotionally touched me a lot) after waking up the thoughts still wander in my mind and it takes time to realize that it was an event that never happened and I have to think a lot to chase that idea because it gives me fear to be trapped in a false idea to deal with outside reality... not like a psychotic idea I really realize it is wrong but would make it difficult for me to deal with reality if I get disturbed by images of an event from my dreams and not true experience... very strange and really annoying.

Taking these experiences into account and considering what the consequences of this legacy of dreaming might be, the aims of the research project began to crystalize around finding out how people with autism experience dreaming and what impact this may have upon their well-being.

1.3 Autism

If this thesis was being submitted 15 or ten years ago, the report would have commenced with a series of definitions involving the Triad of Impairments, Theory of Mind, Central Executive Function and a description of sensory processing. There is no longer such a clear or universally accepted view of what autism is; ‘there is no definitive autism theory, only a developing body of theory applied to autism’ (Chown, 2017, p8).

1.3.1 What is autism?

My interest in the study of autism originated from personal connections with the subject and my understanding has developed through my prior research and work in autism related fields, as a teacher, and more recently, coordinating a diagnostic service and offering advice and training to support parents, families and practitioners. Being in this immersive environment has enabled me to develop an appreciation of the person specific nature of autism and a practice of viewing the challenges that an individual may be facing through an autistic lens to achieve a tailored and personal response, rather than assuming that there is some global 'remedy' that might be applied to all autists.

For the purposes of this study, the following 'way of thinking about autism' will be used:

> Autism refers to a neurotype that leads to
>
> - a cognition that is qualitatively different from that of the PNT [predominant neurotype] in the way that information specific to communication, social interpretation and interaction is processed and understood;
> - and to a perceptual reality of the sensory environment that differs considerably from one individual to the next.
>
> (Beardon 2017).

1.3.2 Misconceptions about autism

1.3.2.1 Homogeneity

Autism Spectrum Conditions refers to a range of presentation and abilities. Historically the spectrum has been divided into sub groups of high and low functioning and Aspergers, With Asperger's Syndrome having no language delay and the difference between high and low functioning autism relating to an intelligence quotient measure. The distinctions are no longer encapsulated in the most up to date diagnostic criteria (the specifiers in DSM-5 relate more to categories of need) and their use is diminishing as they are considered to be stigmatizing and unhelpful, especially to the autistic person. Whilst the removal of unhelpful sub types with the spectrum has been viewed positively there remains a dyspathy in that the autistic population is now represented by one reductivist criteria which summarizes its phenomenological being in a diagnostic paragraph and allows the production of generalizations and conclusions about the population that do not take into account its heterogeneity;

in reducing autism to a single diagnosis, it could be argued that there is substance to the suggestion of homogeneity (Cameron, 2012).

single term of autism or autistic to describe a group of people does sound a unifying concept, however the autistic population is not homogeneous, like the predominant neurotypical population it is representative of a huge range of diversity:

> I want to see a world where books and TV shows and films depict autistic people of color, LGBTQIA+ autistic people, autistic women, autistic people with other disabilities, autistic people who can pass for neurotypical and who can't, autistic people who are verbal, non-verbal, partially verbal, autistic people with all kinds of special interests, autistic people who use special interests in their work and those who don't, autistic people who are hypersensitive and hyposensitive and sensory-seeking, autistic people of all ages and all occupations, autistic heroes, autistic villains, autistic geeks and autistic sports captains and everything in between, with good qualities and flaws that are related to autism and those that aren't related to autism at all—realistic, multi-dimensional autistic characters that don't feel hollow or like the butt of a joke. And until that's achieved, autistic media consumers everywhere will keep working our headcanon[1] magic.
>
> Feminist Aspie 2015 A Headcanon Named Autism: In Defense of Finding Our Own Representation

1.3.2.2 Sameness and interests

Monotropism is a concept that includes, interest and focus and sameness in the sense of perpetuating the interest, of not wanting to transition away from it and has been proposed as ‘a conceptual model that is capable of informing practice’ (Murray, Lesser & Lawson, 2005, p 140).

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[1] Headcanons are interpretation of the actions and backstories of fictional characters that are not mentioned or intentioned in the storyline itself but created by fans.

> In a nutshell, monotropism is the tendency for our interests to pull us in more strongly than most people. It rests on a model of the mind as an 'interest system': we are all interested in many things, and our interests help direct our attention. Different interests are salient at different times. In a monotropic mind, fewer interests tend to be aroused at any time, and they attract more of our processing resources, making it harder to deal with things outside of our current attention tunnel.
>
> Fergus Murray, Me and Monotropism: A unified theory of autism (August, 2019).

A preference for sameness is an attribute ascribed to autism which does have relevance (Uljarevi, Richdale, Evans, Cai & Leekam, 2017), however this needs to be viewed in the context of the anxiety of the individual (Gotham et al., 2013; Rodgers, Glod, Connolly & McConachie, 2012). Sameness, interests and the rituals that are created around them, compensate for or remove uncertainty; the greater the perception of uncertainty, the more the person with autism may focus on the perpetuating and preserving that which is with their control, the sameness and the interest (Woody & Szechtman, 2006) making the transition from one activity to another difficult (Sevin, Rieske & Matson 2015).

Interests do not have to involve complex activities, for example, some instances of sameness or repeated actions, like stroking a pet, may be linked to the pleasant sensory feedback that they provide (Alcorta & Sosis, 2006), or again as a compensation for something less pleasant or anxiety inducing (Black et al., 2017).

In conclusion a preference for sameness and the perpetuation of narrow interests will vary greatly from one autistic to another and also within the autistic person depending in anxiety levels.

1.3.2.3 *Savants*

It is estimated that around 10% of autistic people have some form of savant syndrome, and that 50% of people with savant syndrome have a diagnosis of autism which female savants representing only a small percentage of the population (Corrigan, Richards, Treffert & Dager, 2011). Savants 'have some spectacular ‘islands of genius’ that stand in jarring juxtaposition to overall limitations’ (Treffert, 2013, p564), and despite generally low cognitive abilities have an exceptional talent in some area. There are splinter skill savants who have intense preoccupations that allow the memorisation of a quantity and specificity of data around the subject, talented savants whose talents would be noticeable in a peer group of mixed abilities exceptional, and prodigious savants whose skills would be remarkable in a person with no cognitive impairment. Savantism can be acquired in later life through some form of brain injury or disruption, and skills may also be lost in the individual acquires skills to improve cognitive functioning (Selfe, 2012). The profile of autistic savants has been raised by individuals such as Kim Peek, Daniel Tammet and Stephen Wiltshire, and through fictional characters such as Raymond Babbitt in the film Rain Man (1988) which has possible led to the misconception that the link between savantism and autism is more pronounced than is the case:

> What people don’t realise though is that, just because half of Savants are autistic, that doesn’t mean that half of autists are Savants. In fact, Savants make up a minuscule amount of society and only 50% of that small segment are autistic. This makes the odds of an autist being a savant about as likely as an autist not being asked whether they are a savant at least once in our lives.
>
> James Sinclair form the article 6 Astonishing Savants from the blog Autistic and Unapologetic

1.3.2.4 *Lack of emotion*

The association of a lack of emotion and autism is one that has been almost embedded in popular culture not least through stereotypes such as Raymond Babbitt in Rain Man (1988) and Spock from the Star Trek series. These had become an archetypal shorthand for autism which has started to be challenged in recent years by other and diverse autistic portrayals in the media (for example Forest Gump, Sheldon Cooper in the Big Bang Theory, Sherlock Holmes in the Benedict Cumberbatch depiction) and through the emergence of more high-profile people who are prepared to openly discuss the diagnosis (Courtney Love, Daryl Hannah, Chris Packham, Greta Thunberg). The stereotype of Spock has quite an on line following with characteristics that are resonant or helpful to the population in other ways:

> Not only did I see in Spock somebody, like me, who couldn't help not fitting in, but he was a profoundly good soul despite his inability to fit in. It was possible, entirely possible, that my decency and compassion, which I felt so acutely but that others never seemed to see, was misunderstood, like Spock's, because I expressed it so differently. People didn't get it. And they often rejected Spock's decency and goodness, like mine, because they could not see what he saw. But that didn't make his desire to be a friend and to live a good life any less sincere or valuable. In Spock, I had a model, both intellectual and moral, that allowed me to envision myself as something other than a colossal failure as a human being.
>
> From the blog 'What I learned from Spock as a lonely kid with autism/Aspergers', Lisa Schweitzer 27.02.2015.

Given the plethora of advice and articles about autism and 'meltdowns' it would appear strange to purport that people with autism lack emotion (Ryan, 2010; Bedrossian, 2015; Smith, 2012). Regulating emotions can be complex skill to master (Conner et al., 2019) and this may be a factor in triggering a meltdown reaction, in that an individual does not recognize how distressed they are until they are in a state of extremis, or that an individual is so aware of the possibility of overreacting that they mask or camouflage emotional responses in order to attempt to manage them (Hull, 2017). Equally, the range and scope of materials on improving anxiety and low mood in autistics would suggest that the assertion that the population presents with a lack of emotion is not a credible one (Hollocks, Papadopoulos, Howlin & Simonoff, 2013: Mikita et al., 2016).

Research has suggested that autism can be neurobiologically described by the 'Intense World Theory' which suggests that 'hyper-functional microcircuits are speculated to become autonomous and memory trapped leading to the core cognitive consequences of hyper-perception, hyper-attention, hyper-memory and hyper-emotionality' (Markram & Markram, 2010), and that responses to emotions follow similar patterns to other senses, that is of being hyper or hypo; Judy Endow describes how one state can trigger the other:

> When it comes to relationships, I on purpose do not have a lot of close friends. This is because I pick up on my friend's emotions and often match them in my own body. When

> this happens the emotion my friend feels in regard to something becomes very intense and overwhelming for me to experience. It is like a way too big a dose of empathy. Once it starts I cannot shut it off, even though my friend may be able to do so. Just like my thinking automatically goes for the match, in my close relationships my neurology automatically goes for the feeling match. Because of my autistic neurology I experience empathy too deeply. Not only is this overwhelming and draining, but dangerous.
>
> Most autistics I've talked to experience this too-much-empathy magnification of other people's feelings in their own bodies. Most talk about experiencing the two extremes – the too much empathy or complete emotional shutdown.
>
> Judy Endow writing about Autism and Stuck Emotion on the blog Olibean.

Rather than lacking emotion people with autism may have amplified emotional responses which they struggle to process and control (Mazefsky et al., 2013; Samson, Hardan, Lee, Phillips & Gross, 2015).

Whilst it would be reasonable to dismiss the assertion that people with autism lack emotion as a myth, it is reasonable to suggest that people with autism have some difficulties in interpreting and sharing emotions (Lartseva, Buitelaar, Lartseva & Dijkstra, 2015; Teh, Yap & Rickard, 2018), and in emotional regulation as described above. There is also a complex relationship between alexithymia and autism, which may mean that there are some individuals who have some difficulties processing emotions but this would be an aspect of alexithymia rather than autism (Poquerusse, Pastore, Dellantonio & Esposito, 2018).

1.3.2.5 Autism ends with adulthood

Autism is a lifelong condition although how a person is affected by autism may alter across their life span and depending upon the situations they work or live in. For many people, autism becomes easier to live with in practical terms beyond school where there is more scope for adjustments in terms of what hours a person works, how many people they work with, if they are customer facing or not, although there remain difficulties for people in other areas of life. Some studies that have suggested that children can ‘grow out’ of their autism (Blumberg et al., 2015; Helt et al, 2008) and that this might be supported by a particular intervention (Scott, 2009), However the overwhelming evidence and reported experiences of autistics are that challenges, presentations and behaviours persist throughout life although they may vary in effect and intensity over time. Whilst there is a relatively low proportion of research into the life experiences of elderly autistics, this has been highlighted as an area of priority:

> I'm 70 now, and wasn't diagnosed with Asperger’s until I was 67… I have some arthritis, some forgetfulness, and a pervasive sense of an unfulfilled life and loneliness. The physical heart is fine, but my mental heart isn't happy. I feel that if I could find something fulfilling and useful to do, especially something with a technological content, it could help me with my present feeling of unfulfilled worthlessness.
>
> I definitely am feeling both loneliness and isolation. This is pretty common in elderly folk generally, but in my case it's also largely engendered by my introspective nature. I never learned how to go out and find friends because I've always been too busy and too shy to allocate time to doing that.
>
> A year after my diagnosis, when I raised the question of isolation and loneliness associated with Asperger's, my GP suggested I contact the nearest Aspie group, which I've done, but it is 170 miles away - rather a long way to go. I don’t think he understands my needs as a person with Asperger’s at all.
>
> From Freddie’s story, ttps://www.autism.org.uk/about/adult-life/stories/older-people/freddie.aspx.

Some people do not receive a diagnosis until they are adults and often describe the relief that they feel and the clarity that it can bring in understanding early life challenges, the lateness of the diagnosis does not imply that they have recently become autistic but rather that they have spent their early life masking of camouflaging, or have been given au unhelpful label (e.g. naughty) and their needs over many years may have been unrecognised and unmet; people diagnosed with autism as adults have always been autistic:

> So, I’m 45 and I only recently had it confirmed that I was autistic. This was world-changing for me, but probably not in the way it is for most people. For me, it was like I was focusing a camera lens and the world finally became clear. My entire life finally made sense. My weird behavior as a child. My awkwardness and rarely fitting in. My reactions to the world. My expectations of others. But the journey to reach this understanding was very long. And it was very short.
>
> Jenny Bristol, Landing of the spectrum: I’ve always been autistic. I just didn’t know it until now (2018).

1.3.3 Time line of autism related milestones

1.3.3.1 Introduction

The following section aims to outline the diverse developments related to autism, primarily in the UK. These are national initiatives and do not include the development of more regional charities, groups and services.

1.3.3.2 1962 - The founding of the National Autistic Society (NAS)

The NAS was founded to champion the rights and interests of those affected by autism. It hosts conferences and offers training events and programmes for parents and professionals; the NAS manages a range of educational provisions. Residential settings and support groups. The NAS promotes research and publishes the academic journal ‘Autism’. The NAS provides the secretariat that supports the work of the All-Party Parliamentary Group on Autism (Ozsivadjian, 2007).

The mission of the NAS is currently stated as:

> To transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers.
>
> To change attitudes by improving public understanding of autism and helping businesses, local authorities and

> government to provide more autism-friendly spaces, deliver better services and improve laws.
>
> (source: www.autism.org, the NAS website).

1.3.3.3 1992 - The creation of the Autism Network International

The Autism Network International (ANI) was founded in the USA in 1992 by Jim Sinclair, Kathy Grant and Donna Williams. After starting out as a correspondence group it moved to an online network (a term preferred by the founders) offering mentoring and promoting advocacy for autists.

In 1996 the group organised the first Autreat event, a residential event organised by autistic people primarily for autistic people although 'family members and professionals are welcome to attend, but the structure and content of this event will be determined by the interests and sensibilities of autistic people' (www.autismnetworkinternational.org). The conference-retreats offered workshops and socialising opportunities for autistic people of all ages, they were held annually with the exception of 2001 until the last Autreat event held in California in 2013, with the title 'Living Life the Autly Way' and served as a blueprint for future events in Europe (Sinclair, 2005).

1.3.3.4 1998 - The founding of the Autism Research Centre at the University of Cambridge (ARC)

ARC is essentially a group of researchers from across the biomedical departments of Cambridge University, collaborating on a variety of projects. As well as producing a range of academic studies the Centre has developed Quotient tests for screening for autism (Wakabayashi et al., 2006: Auyeung et al., 2009), produced a DVD to support children with emotion recognition (The Transporters DVD, 2007) and has contributed to raising awareness on the media on various issues (2016, BBC2, Employable Me). The Director of ARC, Professor Simon Baron-Cohen, is also the President of the International Society for Autism Research (INSAR).

> The mission of the ARC is to understand the biomedical causes of autism spectrum conditions, and develop new and validated methods for assessment and intervention.

> The ARC fosters collaboration between scientists in Cambridge University and outside, to accelerate this mission.

1.3.3.5 2000 - The creation of the All-Party Parliamentary Group on Autism (APPGA)

The APPGA was founded in February 2000, comprising back bench MPs and Peers with an interest in autism. Its secretariat is provided by the National Autistic Society and it has one aim which is reviewed annually:

> To raise awareness of issues affecting autistic people and Asperger syndrome, their families and carers; to raise Parliamentary awareness of autism; to campaign for changes to government policy to benefit autistic people and Asperger syndrome and improve diagnosis or, support for, autistic people and Asperger syndrome.

The APPGA has been instrumental in promoting issues around diagnosis, education and the training of a variety of front-line officials in autism awareness (The NAS, 2017).

1.3.3.6 2005 - The first annual Autscape event

The Autscape events are a mix of conference, retreat, social gathering and offer opportunities for networking in which autistic people form the majority of presenters and organisers at locations that have been specifically chosen for their ability to accommodate a range of autistic requirements. The Autscape events are a development of the Autreat events organised by Jim Sinclair (Rotella, Gold, Andriani and Scharf, 2002).

> Autscape is a conference with a difference. Rather than talking to a primarily non-autistic audience about autism, this conference is specifically *by and for* autistic people. Some of it isn't even about autism at all! Non-autistic people are also welcome, but the environment and content of the event are *centred around autistic people's needs, interests and sensitivities*.
>
> (www.autscape.org).

1.3.3.7 2004 - The founding of Autistica

Autistica was founded by Dame Stephanie Shirley. It is currently undertaking research across a variety of areas including anxiety and mental health and how adults are affected by autism. In 2018 and 2019, Autistica hosted conferences with researchers and autistic participants to develop dialogue to establish future directions for studies.

> Autistica is a leading autism research charity with the following aims
>
> - funding and promoting ground breaking medical research
> - improving understanding of autism
> - advancing new therapies and interventions (www.autistica.org.uk).

1.3.3.8 2009 - The Autism Act

The Autism Act was introduced as a Private Members Bill by Cheryl Gillan, MP, and is the only act dedicated to improving support and services for a single condition. The Act made it a duty for future Governments to produce a strategy to support the needs of autistic adults and review every three years, for government to produce statutory guidance for local authorities about implementing a local autism strategy and for these to be reviewed regularly.

The Act only applied in England; Wales and Scotland introduced their own versions through their respective legislatures in the same year. It has ensured that adult diagnostic services have been extended over the most part of the country and it was announced in 2018 that the strategy would be extended to cover children and the provision of children’s services.

1.3.3.9 2009 - Launch of the Centre for Research in Autism and Education (CRAE)

Based at the Institute of Education, University College of London, its three aims, these are:

1. we aim to conduct ground-breaking scientific research to enhance our knowledge of intervention, education and outcomes for autistic people, their families and those who support them
2. we work to ensure that this evidence-based knowledge is translated so that it can have meaningful impact and make a real difference to people's everyday lives.
3. we are committed to engaging with autistic people and their allies (e.g., families, teachers, clinicians), as well as, policy-makers and the wider public, to promote awareness - and acceptance - of autism.

   (www.crae.ioe.uk).

As well as undertaking research across a range of subjects including attention and perception, and experiences of employment, CRAE has offered a series of seminars and a toolkit to promote participatory research and is currently working with Autistica to establish a series of exemplar templates and examples of information sheets and recruitment materials that future researchers can review for ideas around best practice.

1.3.3.10 2011 - The initial Critical Autism Studies day held in Sheffield

Around 40 people attended this seminar in January 2011, intended as a space for those with autism, parents/carers and professionals to engage in a neurodiversity conversation. The aim was not only to continue to explore the discourse around challenging the 'deficit' model of autism but also reposition the 'deficit' model as being problematic in itself.

The Sheffield Hallam day did not become the inaugural event in a series, it was a one off, but did show that there was interest and appetite for discussions of ways of researching or viewing autism.

1.3.3.11 2012 - Publication of the Demonstration Edition of 'Autonomy, the Critical Journal of Interdisciplinary Autism Studies'

Whilst there are peer reviewed publications relating specifically to autism, for example 'Autism: the international journal of research and practice', and

‘Journal of Autism and Developmental Disorders’, ‘Autonomy’ had a distinctly autistic focus:

> ‘Autonomy’ has been set up by a small group of autistic academics under the auspices of the Autreach Press, an organisation formed for the purpose, which subscribes to the general principles of the Autreach group of autonomous organisations who share the common aim of promoting greater autistic autonomy, hence the title of this journal
>
> (Arnold, Editorial Volume 1, 2012).

‘Autonomy’ ceased publication in 2014 after 4 volumes, it had been an ambitious project for its time and one that could be revived in the future, but it was not able to maintain sufficient momentum in the two years that it was issued to attract the number of quality contributions to make the impact it originally intended.

1.3.3.12 2013 - Revision of the publication of DSM-5

The term Asperger’s or Asperger’s Syndrome technically and historically has referred to people with no significant language delay and a full scale Wechsler IQ of average or above average levels, however DSM-5 no longer references this sub category of the spectrum and uses the label autistic to describe all those who are deemed to meet the diagnostic criteria, offering a further 4 ‘specifiers’ to describe the level of need, at the time of diagnosis, that the person presents with. The removal of the diagnosis of Asperger’s from DSM-5 was seen by some as a challenge to identity and by others as a removal of an unhelpful comparator, as Asperger’s has traditionally referenced the more able area of the spectrum and in some ways has developed an aspirational quality. The removal of Asperger’s from the diagnostic manual and the more recent publicity around the association of Hans Asperger with the Nazi party is reducing its use in the younger population, however there are those who more readily identify with this label than that of autism, although an element of this group prefer the Attwood modified ‘Aspie’ (1999). See Appendix 10 for the suggested criteria for Aspie.

One of the key issues regarding autism is that it is a spectrum condition embracing many different levels of abilities in terms of communication and cognition and the term spectrum reflects the heterogeneity in autism, yet autism is a condition that now has a single diagnostic label.

The ‘specifiers’ of the DSM-5 are being treated with caution by diagnostic services and are often not used as there is a concern that these will ‘lock’ an individual into a particular category and even if they develop skills in later life, that they will be defined by the specifier allocated at time of diagnosis. One alternative would be to use sub types such as those used with diabetes diagnosis that could distinguish area of the spectrum (Baron-Cohen, 2019). Discussion about sub types and classifications has been further debated at events such as the Annual Meeting of the International Society for Autism Research (2018).

1.3.3.13 2014 - Publication of ‘A Future Made Together: Shaping autism research in the UK’

> ‘We are facing challenging times: there are increasing financial constraints and funding cuts; many organisations are being asked to do more for less; and there is fierce competition for limited resources. It is also a time for the autism community as a whole – autistic people, families, researchers, policy makers and others – to grasp the opportunities presented by the heightened interest in, and awareness of, autism’
>
> (Baroness Browning, foreword, ‘A future made together shaping autism research in the UK’, 2013).

The Paper, gathered the views of people with autism, their families and practitioners working with them, about funding and areas of research and the issues that the autistic population felt needed further investigation and how this would be achieved. To move away from research and strategy being something that is ‘done to’ people with autism, ‘shifting autism research away from causes and biological effects onto services and social issues will also assist autistic individuals by exploring the impact of living in Predominant Neurotype society' (Woods, 2017, p1091).

The overarching research priority reiterated in this paper by Pellicano, Dinsmore and Charman (2014) was for practical solutions to effect real change to people's lives and experiences: 'Autistic adults emphasised acquiring knowledge about helping people 'manage themselves' with whatever difficulties they have' especially dealing with sensory difficulties, multi-tasking and anxiety' (p761). Participants reported that they wanted more research into the life experiences of adults with the condition: 'There was unanimous agreement from all stakeholder groups that most research seems to focus upon children rather than older adolescents and adults' (ibid, p760). The presentation of 'A future made together' and other investigations into the research priorities selected by people with autism reflects the ontological and epidemiological position of this research project.

1.3.3.14 Groups which have emerged in recent years

The following sections relate to initiatives which have evolved without an absolutely definitive date of commencement as with the other events and affiliations in this section.

1.3.3.14.1 The Participatory Autism Research Collective (PARC):

> The Participatory Autism Research Collective (PARC) was set up to bring autistic people, including scholars and activists, together with early career researchers and practitioners who work with autistic people. Our aim is to build a community network where those who wish to see more significant involvement of autistic people in autism research can share knowledge and expertise.
>
> Quotation from PARC's website
> https://participatoryautismresearch.wordpress.com/

The structure of PARC is rather different from other groups in that it is a federation of regional meetings, each with a convenor, and uses social media to reach a wider group of potential co-researchers. It has generated an ethos which is supportive of both its members and aims:

> PARC have assembled a collection of morals, theories, ideals and perhaps most importantly, people, in order to share in what appears to be the beginnings of a paradigm shift in how we study and consider autism-related challenges. PARC have considered what does and does not work in the field of disability-related research and combined these findings to deliver a revolutionary new approach.
>
> (Beaumont, 2019 p90).

Without a budget, PARC relies on universities for venues for meetings and its meetings are open to students to promote further participatory research. In 2017, PARC was shortlisted for an NAS award for ‘Most Creative Community Project’. Future aims to extend it inclusivity have been identified as follows:

> to find ways of widening participation for those with more considerable communication or, intellectual impairments, or from autistic people who also occupy intersecting marginalised identities
> (Milton, Ridout, Kourti, Loomes and Martin, 2019, p87).

1.3.3.14.2 Critical Autism Network based within The Open University

The network is one with a membership of researchers from around the world and is a virtual community that has held four physical conferences relating to critical autism studies

The network aims to:

- develop the emerging field of critical autism studies, including documenting key issues across national contexts;
- develop theory, refine conceptual issues and generate new understandings about autism
- that are not bounded by a strictly medicalised, deficit-led approach
- develop capacity by working with doctoral students and postdoctoral fellows;

> - create opportunities for dialogue with a wider audience across the five partner countries;
> - offer significant possibilities to produce knowledge and inform practice that affect people's lives.
>
> (http://www.open.ac.uk/health-and-social-care/research/critical-autism-network/).

The three themes of the Network's discussion are' Constructing 'autistic personhoods'', 'Neurodiversity and identity' and 'Interventions and policy'. The Network continues to host debates around these areas and to form links with other groups in the field.

1.3.3.14.3 #ActuallyAutistic

Hashtags or tags are devices that enable people with similar interests to easily locate each other on social media and to follow threads and debates. #ActuallyAutistic enables autistic people to connect and discuss common issues, it was created in response to a number of other autism groupings related to hashtags, which were being used by non-autistic people – practitioners, parents and those generally interested in subjects to pass comments on issues in a way that the #ActuallyAutistic found disrespectful to their views. Rather than a physical group, this is an area of debate, a forum which consistently uses identity first language for autistic people to feel secure in making and sharing comments and experiences. It encapsulates the views of an influential online group rather than claiming to represent the population.

> Some of you might be reading this and thinking, "what the hell is it this time? Why is she getting worked up about….social media hashtags?"
>
> I agree. First World Problem and all that. Please allow me to explain…
>
> Our community is growing weary of neurotypical parents (AutismMoms(TM) or the occasional AutismDad(TM)), non-autistic researchers and authors, "official" autism spectrum "experts" (who are themselves non-autistic), and many other people who are not on the spectrum, but somehow feel entitled to barge in and take over, ransacking our terminology and diluting our social media news feeds. The #ActuallyAutistic hashtag was designed specifically to filter that shizz out, and find more of our own,

> so that we can form long-overdue, desperately-needed, and often-lifesaving connections (which the neurotypical population often takes for granted, since there’s a certain amount of privilege inherent in living in a world already in sync with the way you operate).
>
> Laina Eartharcher 2017, The #ActuallyAutistic hashtag is *only* for actually-autistic people, from the blog The Silent Wave; life through one female Asperger’s lens.

1.3.3.15 Conclusions

The above is not an exhaustive list of developments and, apart from the DSM-5, Autism Network International and #ActuallyAutistic sections, refers to developments that are mainly UK based; the creation of an international perspective has not been attempted as this would be a project in itself.

As can be seen from the timeline, the pace and scope of autism initiatives has increased over the last 2 decades and now the various groups are forming collaborations and networks to facilitate the matching of resources to needs, not only in the sense of research into autism but also with social and community programmes aiming to inform and educate. Following on from the initiatives of ‘Autonomy’ and the Sheffield Hallam Event (2011), the emergence of networks within and between PARC, the Critical Autism Network and the Centre for Autism Research, have provided sustainable and developing forums for discussion which is participatory for people with autism, and may lead to a reinvigoration of the concepts of the Sheffield Autism Day or a journal publication with similar aims and objectives to ‘Autonomy’.

Diagnostic rates have increased in the period covered by the time line, however this is more attributable to a growing awareness of the condition and the establishment of diagnostic pathways , than an increase in rates of autism per se; autism has been present over generations, its prevalence is now being more accurately recognised through the improvements in awareness and diagnosis (Taylor, Jick & Maclaughlin, 2013; Russell, Golding, Kelly & Ford, 2015; Idring et al., 2015).

1.3.4 Major themes of current autistic discourse

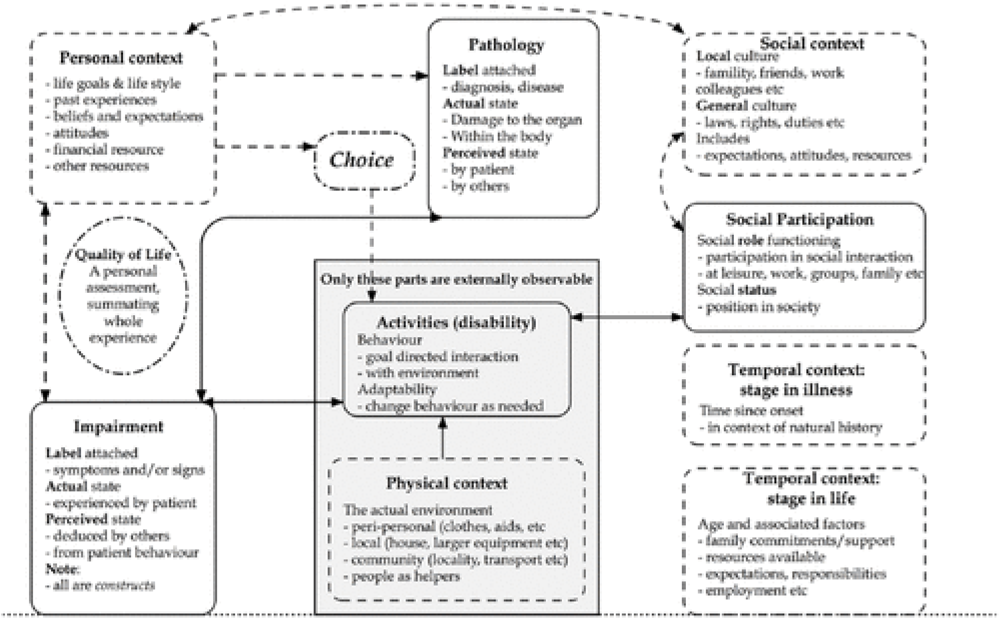
1.3.4.1 The social model of disability

Traditionally concepts of autism have been based on the deficit orientated medical model, more recently through the developments and groups described in the preceding time line an alternative view, that of the social model has emerged:

> The social model states that a person is disabled by *society*. The person might have an impairment (e.g., a paralysed leg). But that impairment only becomes a disability when society fails to accommodate them (e.g., not having a wheelchair-accessible entrance). An example of the social model in action is short- or long-sightedness. These impairments are not considered disabling, because glasses are so readily available and accepted.
>
> The social model states that the way to improve a disability is to improve the way society treats a person's impairment. Note that it doesn't say people's impairments *must* not be cured, simply that cure is not the only option and should not be forced or expected.
>
> Autisticality from the blog Neurodiversity, language, and the social model 27.10.2014

Where an individual experiences some form of challenge relating to their condition, for example having high levels of anxiety, in terms of the social model this would be as a result of the societal demands place upon that person that were exacerbating the impairment; that it is the expectations of the predominantly neuro typical society that are disabling and that it is living in their world without accommodation being made for an individual's preferences that are creating the perceived state of disability.

A further model that of the biopsychosocial model of illness, has been developed by the World Health Organisation and it seen as a more holistic model reflecting the impact of social, cultural and psychological factors when considering illness (Chown & Beardon, 2017; Wade & Halligan. 2017)



From Wade & Halligan (2017).

Using a biopsychosocial model will enable the construction of person cantered profiles reflecting the diversity of the individual and their preferences.

1.3.4.2 Autism language

The language used to describe autism spectrum conditions is a contested territory. Terminology is highly subjective, personal and also politically charged; it introduces and sets an immediate context for the individual or group, by encapsulating a range of presentations in a taxonomic shorthand. Some people may find it difficult to accept that someone who is quite erudite as autistic but would be able to recognise them as Aspergian (Attwood, 2006), especially if they did not have knowledge of the neurodiversity of the spectrum. At the time of writing there are a number of developments which are continuing to shape the debate around the language that should or should not be used.

> I use "***autistic***" rather than "person with autism" throughout. This is intentional. The basic idea is that my being is autistic- the patterns my brain form thoughts in, the essentials of the way I perceive and learn from the world are autistic. Autisticness is, for me and many others, an essential part of what makes me, me. Saying I am "with" autism denies this reality.
>
> Savannah Logsdon-Breakstone 2013 – Cracked Mirror in Shallot blog.

Researchers have adopted a more neutral stance:

> We use the term ‘Autism Spectrum Condition’ (ASC) when referring to a diagnosis of Autism Spectrum Disorder, to be respectful to those on the spectrum who feel that the term ‘disorder’ is stigmatising, whereas ASC is compatible with the presence of both the strengths and difficulties of people on the spectrum.
>
> (Hull et al., 2017, footnote 1, p2519)

> In this paper, we use this term as well as person-first language (such as ‘‘person with autism’’) in an attempt to respect the wishes of all individuals on the spectrum. (Pellicano & Stears, 2011).

As a counterpoint to the debate about autism language and terminology, Andrew Main (2003) posted an article about the condition ‘allism’, referring to non autistics or the predominant neurotype as allistic or allists and this has become a popular alternative in the blogging community.

> The word “allism”, invented for this article, is intended to precisely complement “autism”. It is based on the Greek word “allos”, meaning “other”, just as “autos” (in “autism”) means “self”.
>
> www.fysh .org/~zefram/allism.

> But I also feel that scholars should take more note of the wishes of the autism community when taking about members of that community. In deliberately using person-first language, scholars appear to suggest that their preference outranks the preference of so many autistic people. To deliberately avoid using terms in general use within a community seems to imply that the members of that community have less right to their way of expressing themselves than do scholars (Chown, 2017, p24).

In the context of this project the decision has been made to use person first and identity first language interchangeably, in concurrence with Chown and Pellicano and Stears that there is an albeit unknown, proportion of the population that may prefer person first language.

1.3.4.3 Neurodiversity

> The Neurodiversity Paradigm is an emergent paradigm in which neurodiversity is understood to be a form of human diversity that is subject to the same social dynamics as other forms of diversity (including dynamics of power and oppression).
>
> Nick Walker The Neurodiversity Paradigm
>
> http://neurocosmopolitanism.com.

Neurodiversity is the term introduced by Judy Singer, an autistic Australian sociologist, essentially it is a recognition that there are brain differences for many reasons that are simply brain differences. It is in keeping with the social and biopsychosocial models of autism in that it is a difference rather than deficit or disability that makes a person unique. Whilst the term was originally applied to autism other groups have adopted it as an enabling concept and it is one that is seeping into common use for all groups, in the same way that there is sexual diversity has developed over recent years (Radziwill, 2016).

It is estimated that over 25% of the autistic population have some form of significant comorbidity or other condition and that these conditions can largely be grouped into ‘physical conditions, mental health issues, challenging behaviours, and intellectual disabilities’ (Matson and Goldin, 2013; Gadke, McKinney & Oliveros, 2016). Baron-Cohen has proposed neurodiversity as a way to reconcile the medical model of autism with neurodiversity framework.

> The other source of the huge heterogeneity is that autism is frequently accompanied by co-occurring conditions. I mentioned gastrointestinal pain or epilepsy (both examples of disorders and sometimes diseases), dyspraxia, ADHD and dyslexia (all examples of disabilities), and anxiety and depression (both examples of mental health conditions). This is just a partial list. A recent study shows that 50 percent of autistic people have at least four such co-occurring conditions (including language disorder or learning difficulties), and more than 95 percent of autistic children have at least one condition in addition to autism.

> The relevance of this for the neurodiversity debate is that if we dip into the wide range of features that are seen in autism, we will find differences and disabilities (both compatible with the neurodiversity framework), and we will find examples of disorders and even diseases, which are more compatible with a medical than a neurodiversity model
>
> Simon Baron-Cohen 31.04.2019 from the blog The Concept of Neurodiversity Is Dividing the Autism Community: it remains controversial—but it doesn't have to be. published in the Scientific American.

1.3.4.5 Conclusions

Pellicano and Stears (2011) identified the main areas of autism research as being 'Social and Ethical Concerns', 'The New Translational Sciences of Autism', 'From Disability to Diversity' and 'Participation, Voice and Influence' and these remain prominent areas of debate to date. This section of the introduction has set these in the context of more current issues in the ongoing discussions about the nature of autism. The further theme of discourse, that relating to the medical or social model of autism, highlights that these are debates which will not easily be resolved and remain very pertinent in any discussion about the nature of autism, giving rise to the assertion that 'It is argued that autism is not a thing, but a debate about a thing' (Woods et al., 2018).

The design and delivery of this research project was made in the context of these on-going debates and in a sense, this supported the rigour of the decisions made in that there was a consciousness that any given rational could be scrutinised from one perspective or another.

1.4 Quality of life for people with autism

Autism, anxiety and stress disorders and their impact upon quality of life will be discussed specifically and in more detail in the following chapter, the Literature Review.

Quality of life measures are a composite view of key factors across a range of 8 domains (Morrise et al., 2013) The scores that are produced from the various questionnaires can then be used to assess improvements or otherwise after some form of intervention (European Commission, 2000), or to compare the quality of life between different groups. Quality of life (QOL) is understood to be different from Health Related Quality of Life (HRQOL) (Gelert, 1993, Bainch, 2012);

> The construct of quality of life represents a more comprehensive, multidimensional outcome measure, that also takes into account subjective variables such as satisfaction and subjective wellbeing. Internationally, there is a broad consensus about the fact that the term ‘quality of life’ refers to a set of factors comprising personal wellbeing. Eight quality of life domains are distinguished: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and rights.
>
> Renty & Roeyers (2006, p512).

There are a number of questionnaires that have been developed to assess an individual’s quality of life, such as the World Health Organisation (WHOQOL-BREF,2004) and the Wisconsin Quality of Life Index (W-QLI) developed in 2010 by Becker, Shaw and Reib. These can help to develop an overview rather than a holistic appreciation of how autism presents throughout an individual’s life and of how this permeates existence and well being.

The QOL measures reflect a current appraisal of life across the domains, however, it may be that a view of QOL in the future is also affected and that there is no mechanism to record how an individual perceives their future QOL in comparison to others; there have been no studies to investigate the impact on an individual’s future view in the context of knowing from some assessment that their QOL is compromised or lower than that of others:

> I have found that everything seems to have a delayed reaction. Maybe this is my Asperger’s syndrome or maybe it is just me, but whatever the reason, sometimes it really upsets me. I seems as though all my friends are advancing to bigger and better places whereas I am trailing behind at a sluggish pace, missing out on everything. I realise this isn’t actually the case, that it’s just a depression-induced perception.
>
> (Jackson, 2002, p 64).

A study by Mason, McConachie, Garland, Petrou, Rodger and Parr (2018) concluded that ‘using the World Health Organization quality of life measure, we found that autistic people (370) in the UK reported their quality of life to be lower than that of the general population’. Other studies have confirmed that there is a lower quality of life throughout the life span of autistic people (Potvim Snider, Prelock, Wood-Dauphinee & Kehayia, 2015; van Heijst & Geurts, 2015; Lin, 2014).

Whilst QOL tools are a concise way of reducing an individual to a series of composite scores there have been some concerns that they remove any person centeredness from the process (Carr & Higginson, 2001), whilst Boyer, Baumstarck, Guedj and Auquier (2014) and Cella (1995) have expressed more generalised concerns about their use. However, behind these composite, rather sterile scales, are many more statistics that may be used to highlight the often reduced quality of life that is a reality for many with autism.

Statistically, autistic people are more vulnerable to experiencing limited outcomes across a range of indicators:

- Only 15 – 21% have current or recent full-time employment (Redman et al., 2009)
- Are more likely not to experience independent living – 17% of young people in the 21 – 25 age group (Shattuck et al., 2011)
- Whilst autism is not a mental health issue in itself, 1 in 3 autistic adults experience severe mental health problems (Rosenblatt, 2008)
- Are less likely to continue into further education (Shattuck et al., 2014)
- 17% of autistic children have been suspended from school; 48% of these has been suspended three or more times; 4% had been expelled from one or more schools (Reid, 2011)
- There is a higher divorce rate amongst parents of children with autism than neurotypical children or children with other Special Educational Needs and Disabilities (Hartley et al., 2014)
- Are more susceptible to premature mortality than the general population due to a higher rate of epilepsy, heart disease and suicide (Hirvikoski et al., 2016)

- In an American study, Shattuck et al. (2012) suggest that postsecondary education opportunities for young adults with autism are 'substantially lower than the general population with previous studies indicating 40% or fewer ever attend college' (p1043)
- The same author also co-researched a longitudinal study which demonstrated that the social activities of adolescents on the spectrum where far more restricted than neurotypical control group (Shattuck, Osmond, Wagner & Cooper, 2011)
- an article in the Times Educational Supplement (2009) suggested that 6000 of the 20000 under 25s with autism had 'been lost in the system' in the UK (Lee, 2009).

Access to employment has been difficult for people with autism, and the current statistics from the National Autistic Society suggest that only 13% of people on the spectrum are in full time employment. This is a key indicator of quality of life from which other benefits flow such as a sense of purpose, economic benefits, independence, social opportunities and the mental well-being that a rewarding career can bring. Even with legislation to protect individuals from disability discrimination once in the work place, the process of negotiating the application process can be fraught:

> Access to any employment opportunity requires candidates to navigate the social encounter of the interview, while even getting to the stage of an interview in the first place requires the ability to build social capital and network with others…. A lack of eye contact, or a silence that lasts too long can have very negative consequences for rapport. Yet autistic people may give off these signals unintentionally, which is why employers need to look past small-scale social cues to take a broader perspective on what is meaningful interaction.
>
> Brett Heasma ‘Employers may discriminate against autism without realising. The LSE Business Review Blog 2017.

Recent research has used a rather different approach to reviewing the quality of life measures and how they can be degraded for people with autism, rather seeking to establish a Vulnerability Experience Quotient, ’to measure the frequency of negative life experiences in autistic adults s and explore how these are associated with current anxiety and depression symptoms and life satisfaction' (Griffiths, Allison, Kenny, Holt, Smith & Baron-Cohen, 2019), with 'victimisation' being explored as a source of anxiety and depression.

The above is not an exhaustive list but provides an indication of the range of areas in which autistic people can have restricted outcomes. Whilst these statistics refer to studies from up to 10 years ago and may have been subject to change in the intervening period there are some more current publications and figures that suggest that the autistic population is still one that is very vulnerable. The two examples that will be discussed in the following section in more detail, homelessness and the justice system in relation to people with autism, have been selected as they are issues around which a breakdown in several areas can crystallise to produce a more generalised failure through more or all of the 8 domains of wellbeing; they are both a statistic in their own right and also indicative of a failure across many areas included in the QOL measures.

Recently autism has been linked to homelessness and it is suggested in the paper 'Autism and Homelessness: briefing for frontline staff' (2015), that research in Wales has 'found that 12% of people diagnosed with autism had experienced homelessness at some time' (p3) and that in Devon in a cohort of 14 long term rough sleepers, 9 'could be classified as falling onto the autistic spectrum' (p3). The reasons for this homelessness are difficulties in social communications which give rise to relationship breakdowns and lack of support networks, and also the failure of agencies to tailor services to make them accessible:

> there are people with autism sleeping rough over a long time who have been regarded as 'hard to reach'. This is because the way that homelessness services are delivered typically doesn't allow for the different needs of people with autism.
>
> (ibid, p3).

Ultimately, the lack of response to the depressing statistics above are not as a result of something that it intrinsic to the autistic population, but rather it is in the lack of committed response from society to the differences of that population.

Kate Ross makes the following link between sleeping issues and the potential it has to introduce instability into a person's life:

> From chatting with other autistic adults, I found that I am far from the only one who has sleep difficulties. Keeping an erratic sleep schedule can have significant impact on one's ability to hold down a job (for example being late, overly tired and performing poorly), which in turn could affect maintaining payment on rent or a mortgage and household bills. Worst case scenario this may lead to homelessness and rough sleeping. [Now, before anyone presumes that I'm suggesting poor sleep leads to homelessness, I'm merely pointing out the linear deterioration and possible consequences].
>
> Kate Ross 07.09.2018 Autism and sleep: a personal perspective
> https://network.autism.org.uk/knowledge/insight-opinion/autism-and-sleep-personal-perspective.

A recently published study by Churchard, Ryder, Greenhill and Mandy (2019), suggested that over 12% of participants in a regional homelessness service had traits of autism which were congruent with the diagnostic criteria of DSM-5, if this is a stable statistic across the 5000 people estimated to be rough sleepers at any one time (Ministry of Housing, Communities and Local Governments (2017), then this is a numerically significant cohort, however as Churchard et al., (ibid) comment, when these are grouped with the 'hidden homeless', which is a larger group experiencing intermittent or disrupted housing placements, 'there may therefore be a considerable number of homeless autistic adults who are not having their needs met and who are in an extremely vulnerable position' (ibid, p 674).

Dr Andrew Greenhill, one of the collaborators on this project made the following quote in a feature about this study on the National Autistic Society's web site (2018)

> One person that stands out for me is an older man who had lived on the street for 45 years, in an inner city.
>
> "He ran away from his family home because his relationship with his father was so poor and physically abusive. He then survived by following a regular routine and sleeping in the same place every night, relying on the

> food made available at day-centres and drop ins. He refused all professional help or contact, and existed in a 'bubble' whereby he refused all attempts to engage. It was clear that he found social engagement of any kind very distressing and was highly motivated to avoid this.
>
> (https://www.autism.org.uk/get-involved/media-centre/news/2018-06-12-autism-and-homelessness-study.aspx).

Autism is also linked with criminal offending in the sense that autistic people are more likely to be witnesses to and victims of crime than other populations and also that once an individual comes into contact with the criminal justice system the more likely they are to be convicted (Cheely, Carpenter, Letoureau, Nicholas, Charles and King: 2012; Rava, Shattuck, Rast & Roux, 2017). Autism is disproportionally present on offender populations such as those in secure facilities (King & Murphy, 2014; Rutten, Vermeiren & Van Nieuwenhuizen, 2017).

Whilst having autism does not increase the risk of sexual offending behaviour, there is a recognised association between the two (Higgs & Carter; Mogavero, 2016; Allely & Creaby-Attwood, 2016).

> Such deviant and sexual offending behaviours include inappropriate courtship scripts, exposing one's genitals and/or masturbating in public, touching others in a sexual manner, and downloading child pornography…. that compared to neurotypicals, individuals with ASD had higher percentages of stalking (8.5 vs 2.8 percent) and non-contact sexual offenses (42.6 vs 33.7 percent). Such behaviour could lead to an arrest and further involvement in the criminal justice system (CJS).
>
> Mogavero (2016, p116).

These examples of offending behaviours involve activities that may be more acceptable in a slightly different context, for example the downloading of adult pornography or masturbating in private; these have become offenses because the individual had made an incorrect judgement about the context of the activity. Eustacia Cutler in the blog 'Why autistic men are viewing child pornography—and being labelled sex offenders' (2017) suggests that emotional immaturity and unsupervised internet access exacerbates this. Discussing sexual topics with adolescents who present with emotional immaturities may be judged as being inopportunity, however without some basic guidance and with access to the internet, a sexual offense of downloading child pornography is only clicks away.

The publication of the briefing paper ‘Behaviour that challenges: Planning services for people with learning disabilities and/or autism who sexually offend’ (Kolomitz, Talbot, Gordon, Hughes & Harling, 2018) acknowledged that sexual offending by autistics was a complex issue and very much influenced by presentations associated with autism, such as specific interests, literality and sensory issues;

> Peter (not his real name) is an individual with circumscribed interest in, and sensory need for, children’s garments, their dimensions and fabrics. As a child Peter lived in a children’s home and he used to take the other children’s clothes and collected them. He used this as a coping strategy and it became his special interest. As he became a young adult and no longer lived with children, he started to become captivated by children in public wearing specific coloured, textured and sized clothing. As he did not have the money to buy such clothes, he decided to stop children with their parents and ask them for their clothes …. The parents understandably reacted very strongly to this and threatened to call the police. Peter therefore decided to seek children on their own to ask for their clothes. They would run away or struggle away when he tried to pull their clothing. He then decided to abduct children and hit them until they stopped struggling, in order to take their clothes. Each step in the escalation was a practical step further to literally overcome the last hurdle (2018, p6).

Problems with diagnostic pathways compound issues with the justice system as many are not identified as being autistic until after they have entered its sphere of influence. At that point the individual may be included on the Sex Offenders Register or have a custodial sentence, possibility in a setting with a low level of knowledge around autism (after challenges by the APPGA in 2016, 7 of the 122 prisons in the UK had commenced the process of gaining autism accreditation by 2017).

> Proactive and preventative approaches to service provision can greatly reduce the likelihood of an offence occurring and help keep our communities safe. However, should a person come to the attention of the police, liaison and diversion services are a good example of an early intervention model that can help coalesce support around the individual and help to inform criminal justice decision making.
>
> The RT Hon Lord Bradley in the forward to ‘Behaviour that Challenges’ (2018).

The examples given above of the high incidence of homeless autistic people and autistic population involved with the criminal justice system and not reflected in the scope and number of studies into these issues and it is unknown of these trends are established or new and rising.

Having some sort of settled home and legal security or transparency in the sense of the justice system can be viewed as being the fundamentals required for any quality of life, without them existence is precarious to say the least. These issues have been reflected upon in some detail in the section on the quality of life for autistic people to provide the context that it is often the way in which people with autism are routinely, intuitionally, treated by society in general that it that this so often to cause of the reduced quality of life for this group.

1.5 The role of autism research

Autism research in its most essential form is the study of issues that affect and are affected by autism. Research has a role to play in education, shaping future research and in representing the population. The following sections will discuss these roles further.

1.5.1 In providing training and education

Research has led to the creation of educational pathways for those interested in the condition. According to a recent on line search, there are now 16 Masters in Autism courses in the UK and rather more universities offering a range of under graduate and post graduate certificate courses. The availability of quality academic provision should enable the dissemination of accurate information throughout the wider population and enable students to be able to draw upon their knowledge to support autistic people when they qualify or to continue as career researchers in autism. Post and under graduate researchers will be completing small scale studies which will add to the stock of knowledge on autism. A more controversial role for students is suggested as 'supporting the next generation of neurodivergent activist-academics adding to CAS literature are often master's and doctorate students' (Woods, Milton, Arnold and Graby, 2018). It would be interesting to know what the percentage is of autistic students are on autism related courses.

Research also benefits the development of training programmes to support people with autism or those supporting them, such as the NAS EarlyBird programme (Shields, 2001), the Picture Exchange Communication System (Bondy & Frost, 2001) and a variety of apps for mobile devices have been created through research projects (McGrath, 2013).

1.5.2 In enabling the shaping of future research

At the inaugural Autistica Autism Conference in 2018, tickets were allocated on an equal basis between researchers and community members (people with and families of people with autism), to promote representation of the autistic voice in the debate into what areas of research are viewed as priorities. The 2019 conference followed the same principals in promoting attendance by community members and conference materials were available to stream on line.

There are now many conference opportunities for interested parties to network and share idea, but also with the advent of social media there are opportunities to access and have further discussion about the conference agenda without actually attending. For example, in 2018, coinciding with the International Society for Autism Research there was a Twitter discussion using the tag #AutINSAR about research priorities, this was both an on line and an in-person discussion with the conversations taking place directly between autistic and/or autism researchers. The following are a selection of quotes in response to the question about research priorities, they have been quoted from # AutINSAR 2018: What Do Autistic People Want from Autism Research? on the online Magazine The Thinking Person’s Guide to Autism (2018). They have been chosen to reflect the diversity of the comments (quotations have been made exactly, with amendments to reflect the authenticity of the views of their authors):

> other theories that need looking into like monotropism and ecological theories of self/experience. Other stuff - sound scaping design/tech eh @theblub? Also peer support, social well-being.
>
> Often topics related to our daily lives—especially as adults—are missing or under-researched.
>
> What does autism look like in adults across the lifespan? How can we best support every autistic person to access effective communication?
>
> top research priorities: anything that helps Autistics better access healthcare, housing, employment, and other life necessities. Anything that directly improves quality of life.
>
> perception of autistic women in various countries and it's influence on their camouflage.

Participants were also asked how research should be carried out:

> Autism research is often normed off of 4 year old white, autistic boys. That means research is missing the experiences of the rest of the autistic community
>
> The disconnect starts with deciding what to research. Most research priorities center biomedical info, while the autistic community wants information that can be useful in our day to day lives.
>
> Discuss mismatch between research that is conducted and what is wanted, disappointment in the research process, lack of follow-up info from researchers/studies, constantly disclosing very personal info.

1.5.3 In representing the autistic population

Currently, if there is an autistic phenomenon that is of some interest to the media, for example a news item, rather than trying to speak with someone directly affected by the issue, a journalist will question someone who has undertaken research in the area with autistic people. The is not a phenomenon that is unique to the autistic population, for example Sir Cary Cooper's opinion is frequently sought on features related to stress, and there are now a number of agencies advertising services of connecting experts and journalists (for example Blue Boo Media and Igniyte). However, the extent to which the opinions of people with autism are relayed by an expert witness is notable. In providing illustrative examples of lived experience of events researchers can provide a more informed commentary on a particular issue than just relating to an academic position. The example cited by Dr Andrew Greenhill in the previous section of quality of life, relating the history of the homeless man, is a more powerful narration of those affected by the issue than simply quoting statistics.

1.6 The potential for the study

The potential for this study lies in exploring what might be different for autistic people in terms of dreaming, how they experience it, the impact it has upon waking well-being and in the wider sense of available support to mitigate its negative effects. In investigating an area of common behaviour and becoming aware of any differences or issues that autistic people may be experiencing, and to raise awareness that whilst it might be normal for the individual to have these experiences they may need support or adaptations to manage them more effectively.

The research project seeks to position the autistic participants as primary sources of narrative and data. Data will not be collected from parents, carers or professionals working with autistic individuals, although there will be some representation of these groups within the relevant areas of the literature review. This integration of an authentic autistic voice in the process is another area of contribution that this study will make to the stock knowledge that already exists.

This research will, through its acculturation of methodological approaches reflect the diversity of community that shares a diagnosis of autism. Whilst I refer to the autistic community as a notional shorthand it is stressed that, as discussed earlier in this introduction, this is not a heterogeneous population but one as diverse as the non-autistic population is assumed to be.

1.7 Aims and Research Questions

The aims of the research are:

1. to explore an area of lived experience and to assess the ways, if any, that this impacts upon the quality of life as perceived by the individual

2. to reflect critically upon these accounts and how they can be used to contribute to discussions around the subject; how they might inform directions for future research or shape further interventions

and from these aims the following questions have been formulated:

1 How do people with autism perceive their dreaming experience?

2 How do people with autism think that dreaming affects their well-being?

3 What adaptations have people with autism made to their dreaming

experiences?

1.8 Outline of the thesis

In order to provide greater context, there will be quotations from publicly available blogs which will provide an individual perspective of a particular issue.

Quotations to highlight other conditions such as individuals with ADHD will be used and also some narratives from parents and carers to at least give a pertinent and hopefully insightful view of the different aspects of the report.

These quotations have been chosen for their relatedness to the subject under discussion and the descriptions of first hand experiences that they convey.

Chapter 2 - Literature Review

2.1 Introduction

The purpose of this chapter is to review academic literature connected to autism and dreaming and how this is related to this project. As with other chapters, greater context will be given by providing illustrations of the experiences of autistic individuals to the topics under discussion.

2.2 Developing the Literature Review

Humanity has been intrigued by the process and interpretation of dreaming since time immemorial (Askitopoulou, 2015) and the study of dreaming per se has at different times in history been viewed as a rigorous science or a folk lore diversion (Kramer, 2012). The literature review for this project has focussed on demonstrating where the gap is between a series of connected areas; it was not so much about defining an area of research as defining the areas surrounding and suggesting the gap in knowledge, about providing context to 'frame' the study area:

> Both in art and in literature, the function of the frame is fundamental. It is the frame that makes the boundary between the picture and what is outside. It allows the picture to exist… through its detachment from the general continuum, while it retains a kind of glint of that unlimited vastness'
>
> (Calvino, 1993, p86).

The components of the frame demonstrate where the existing knowledge about the effect of dreaming on waking well being is and its corresponding absence or paucity in relation to autism.

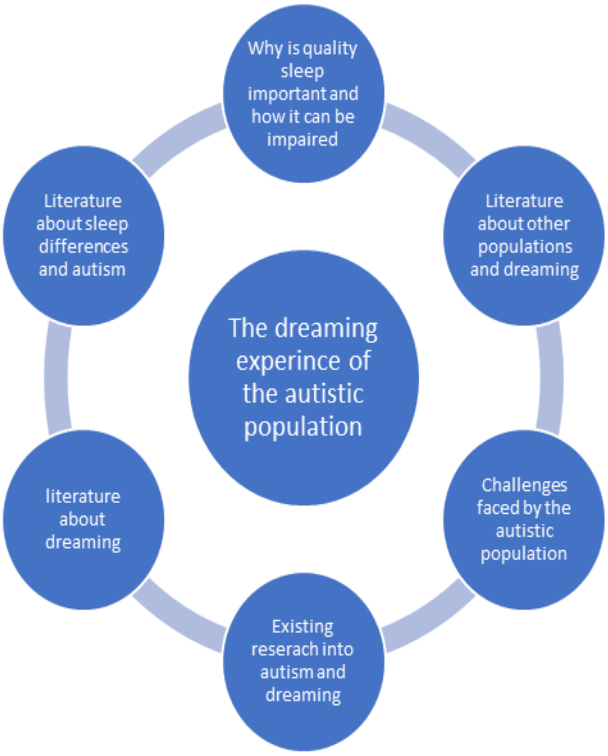
The research questions for the project have been established as:

1 How do people with autism perceive their dreaming experience?

2 How do people with autism think that dreaming affects their well-being?

3 What adaptations have people with autism made as a result of their dreaming experiences?

Due to the extensive and varied literature pertaining to dreaming, it was necessary to have a structured approach to the literature review; to create the frame within which a response to the research questions might be formulated. The following diagram shows out the themes of the literature review, or the frame which surrounds and suggests the area for study.



2.3 Why is quality sleep universally important?

Quality sleep is essential for the health of the population as a whole and has an impact across three broad domains, namely physical, mental and performance, although these are interrelated rather than discrete areas.

Quality sleep is a prerequisite for overall health and well-being (Rogers, Dorrian & Dinges, 2003), promoting specific functions such as growth (Redwine, Hauger, Gillian & Irwin, 2000). Sleep inefficiency has been shown to be a contributing factor in a range of difficulties from compromising immunity functionality (Lam & Ip, 2010; Michael, 2002) to weight management (Ding, Lim, Xu & Kong, 2018).

Degraded sleep and weight gain or obesity have been linked for several years (Beccuti & Pannain, 2011; Spivey, 2010; Chaput & Dutil, 2016). People who are good sleepers tend to eat fewer calories and produce more of the hormones that influence appetite management (ghrelin and leptin, specifically) whereas even those on a diet will struggle to maintain a healthy weight if they have degraded sleep patterns (Markwald et al., 2013). The quality and quantity of sleep over time can be used to predict the onset of type 2 diabetes (Cappuccio, D'Elia, Strazzullo & Miller, 2010) and is a significant factor in predicting other obesity related issues such as cardiovascular outcomes and stroke (Cappuccio D'Elia, Strazzullo & Miller, 2011).

Moderate sleep deprivation can have an adverse impact upon the management of inflammatory conditions in the body, such as irritable bowel syndrome and Crohn's disease (Tang, Preuss, Turek, Jakate & Keshavarzian, 2009; Kinnucan, Rubin & Tauseef, 2013).

In terms of mental performance, memory consolidation (Siegal, 2001) and psychological rehabilitation (Stores, 2001) are both severely impaired by reduced sleep as is general mental health (Levin & Fireman, 2002). Unimpaired sleep has been shown to improve concentration and memory which promotes effectiveness in activities and the satisfaction derived when individuals complete those activities (Walker, Brakefield, Morgan, Hobson & Stickgold, 2002; Mednick, Makovski, Cai & Jiang, 2009).

Sleep deprivation is strongly linked to depression (Tsuno, Besset & Richie, 2005) and suicide (Bernert, Kim, Iwata & Perlis, 2014). Emotional empathy and social interaction may be limited in cases of brief sleep duration as studies have shown a lowering in facial recognition skills (Guadagni, Burles, Ferrara & Iaria, 2014; Schwarz, Popp, Haas, Geisler, Alpers, Osterheider & Eisennarth, 2013).

Links to physical as well as mental performance have been demonstrated as being sleep dependant. As well as maximising athletic performance, Mah, Mah, Kezirian and Dement's study of collegiate basketball players (2011) showed that speed, accuracy and reaction times where significantly improved following periods of long sleep. An individual's ability to succeed in the workplace which may be associated with absenteeism, use of sick leave and lower performance (Linton & Bryngelsson, 2000) has also been shown to be negatively affected by impaired sleep

Sleep quality has an impact upon an individual's attitude to risk (Killgore, 2015), which might impair decisions around apparently straightforward tasks such as crossing the road or decisions taken whilst driving.

The reduction in sleeping duration that has been shown in these studies to produce the more life limiting outcomes is not one of 50%, but anything less than 7 to 8 hours per night consistently (Chaput, Dutil & Sampasa-Kanyinga, 2018) and it is recognised that there is a chasm of difference between the huge positives of 7 plus hours sleep and the corrosive impacts of less than 6 hours sleep (Hirshkowitz et al., 2015). However, in England, 61% (of those questioned by The Sleep Council in 2017) reported that their usual sleep duration was between 5 and 7 hours per night, showing that sleep is perhaps not routinely prioritised as an area of health concern in the UK at least.

Whilst this might be an issue of lack of awareness of guidelines for optimum benefit for health and well-being, a further major reason is that many sleep disruptors are often beyond the individual's control or influence. These include dyssomnias, which disrupt gaining a state of sleep such as sleep latency, apnea and insomnia, and parasomnias, which disrupt the sleep state including enuresis, sleep walking and dreaming. Anxiety can be a major influence in producing these sleep disruptors, and can further trigger a pattern that might not be apparent to the individual who is dealing with a range of consequences of impaired sleep as outlined earlier in the chapter.

Mind (2018)

The social environment may have an impact on diagnosing sleep difficulties, for example, people who sleep alone may not be aware of the extent of their sleep apnea or other sleep disturbance, others may be habituated to insomnia or issues around dreaming and may not realise that there may be training and techniques that might improve these (Schredl, 2013),

In terms of the context of this project, the literature review has shown that sleep is vitally important across a range of measures for physical and mental well-being and performance and, that degradation in the quality of sleep will have an adverse impact in these areas. For the autistic population, with a limited range of positive outcomes, it is crucial that any residual quality of life is not further compromised by issues of sleep impairment, and that further research is undertaken to promote greater understand of and support for these issues.

2.4 Sleep and the autistic population and why the dreaming experiences of this group requires further investigation

As discussed in chapter 1, the quality of life for the autistic population can be seen to be challenged against a variety of measures and it is important that these challenges are explored so that support can be offered to secure improved outcomes and quality of life.

Sleep difficulties are part of a series of issues adversely affecting people with autism and have been recognised for some time as an area for further research to promote well-being:

> In fact, a recent special interest group meeting at the 2011 (IMFA) concluded that while sleep disturbances remain prevalent and significant in ASD, more research must be concluded to determine the impact of sleep disturbance on cognition and daily functioning in the population
>
> (Taylor, Schreck & Mulick, 2012, p1410).

This research will focus particularly on if and how the well-being of people with autism is affected by the parasomnia of dreaming. The results may indicate that the impact is minor or insignificant, and this result in itself would be meaningful as further investigation into this field might be redundant. Alternatively, if the project detects that there may be a link between the phenomena and its impact on well-being, has been found to be the case with other atypical groups as will be explored in the following section of the review, then the project will have highlighted need for further investigation into the subject area (Mannion & Leader, 2014).

The history of study about other groups discussed in the Literature Review often seem to follow a similar pathway, in that there is a period of gathering anecdotal evidence or establishing what the thing is, and then to study how it functions on a day to day basis and beyond. The aims of these various studies have been to find further ways and alternative methods to support these groups, sometimes groups of people whose well-being might not be optimal or who face challenges functioning in society:

> For me, poor sleep has a day to day impact on my quality of life. A particularly bad night leads a 'bad autism day'. These are days when my balance is poor, where sensory issues have a more extreme effect than usual and where I can only tolerate other people for a limited time before my stress levels rocket and I’m desperate to go home. Concentration becomes difficult and I cannot manage day to day jobs, because the effort is too much. These are the days when I cannot control overeating.
>
> Cos Michael’s blog on Sleep (19.10.2017)
> http://www.autismage.com/blog.

Research has shown that a higher percentage of people with autism experience sleep difficulties than the general population, with studies placing prevalence rates between 45 - 83% (Richdale & Prior, 1995). A higher prevalence rate of inefficient or poor-quality sleep within this population correlates to a greater susceptibility to debilitating conditions produced by impaired sleep, particularly in relation to behaviour and mental health. Studies have linked sleep problems in children with autism with challenging behaviours in waking life (Russell & Sofronoff, 2005), with a correlation between the severity sleep problems and the extent of the challenging behaviours presented behaviours that they produced (Tudor, Hoffman & Sweeney, 2012).

Disrupted sleep can impair the day to day well-being of people with autism and may result in a lack of functionality which may restrict the quality of life for those affected and their families by reducing engagement with education, employment and social activities (Shreck, 2004; Smedjie, Larsson & Allik 2006). 'Sleep deprivation can have a range of negative impacts on children including impairments in memory, learning, vigilance, creative through, verbal abilities and attention ...These may impact on academic performance and would be particularly detrimental to children who already have difficulties in these areas'. (Rzepecka, McKenzie, Mcclure & Murphy, 2011, p2759).

Whilst there have been few studies on autistic adults, studies of children show that parasomnias are experienced by a greater percentage of autistic children than typically developing children or children with other developmental disorders (Gianotti, Cortesi, Cerquiglini, Vagnoni & Valente, 2011; Goldman, McGrew, Johnson, Richdale, Clemons & Marlow, 2011). Quine (2001) investigated the different effects of dyssomnias and parasomnias in primary aged children in mainstream and special schools and in this study, she describes the 'nocturnal fears', 'the child is afraid to go to bed or wakes complaining of robbers, monsters or frightening dreams. The child appears fearful and anxious. Settling problems; night waking; anxiety' (p205).

As with the non-autistic population, the vast majority and range of everyday stressors cannot be comprehensively and universally mitigated against (Bogdashina, 2003; Jacobsen, 2005), there will always be some interruption, change in programme or unexpected event which needs to be accommodated.

An inability to filter out background noise or subtle changes in temperature might disrupt an autistic person’s ability to drift off into settled sleep, fear of the darkness, separation anxiety and environmental noise from the wind in the trees or distant traffic may disrupt sleep: ‘Many Auties have the most acute hearing and may be kept awake or distressed by sounds most people simply reason about and tune out (Williams, 2006, p40). Sleep problems may be seen as possible indicators of ‘intensified symptoms of autism’ (Schreck, Mulick & Smith, 2004 p64), these may escalate sensitivities and difficulties in coping with everyday situations which would in turn make it more problematic to de-activate to productive sleep (Wiggs & Stores, 1996).

Whilst there are known issues around sleep and the autistic population there are also factors which may limit this population developing more resilience around sleep difficulties. For example, exercise and improving fitness are in the top recommendations for improving sleep quality however issues around co-ordination and poor proprioception and balance can have an impact upon an individual’s proclivity to take up exercise (Sainsbury, 2000). Likewise, a restricted or idiosyncratic diet may give rise to nutritional deficiencies in some areas; tryptophan, which is an essential amino acid producing serotonin in the body and so supportive of sleep, may be an area of concern for someone with a limited diet (Zimmer et al., 2012). A gluten or casein free dietetic intervention may be a therapeutic necessity but may equally produce a nutritional imbalance affecting sleep, amongst other areas of well-being (Graf-Myles et al., 2014).

The uncertainties that these impairments produce can result in heightened states of anxiety for many people with autism and this has been described as both profound and debilitating by writers with the condition (Grandin, 1996; Williams, 2006):

> excessive stress or anxiety can alter the brain in ways that promote hyper vigilance and abnormal behaviour, exaggerate fearfulness, disturb sleep, impair memory, and cause shift in attention - all characteristics of autism. These behaviours, in return, can exacerbate feelings of anxiety so that the entire cascade becomes one of constant emotional distress and arousal spiralling out of control (Morgan, 2006: p159).

Other factors that may connect autism with a propensity to dream will be discussed later in the chapter, but it can be concluded from general literature on sleep and the autistic population that there is an established link between a range of sleep difficulties and autism, although there is a recognised lack of research into this parasomnia of dreaming (Daoust et al., 2008).

2.5 The impact of sleep difficulties upon families

The impact of poor sleep quality in the wider context of the family a partner's well-being and the health of the relationship have been researched in recent years as there has been more of a focus on the impact of sleep on general health (Troxel, Robles, Hall & Buysse, 2007; Wilson et al., 2017).

The following recount is taken from a post by Lynn Vigo on the autism blog (2013):

> I used to take sleep for granted until I had kids. Now it is one my most favorite things in the world, in large part because it is a precious commodity in our home due to the disrupted sleep patterns of our child with autism. Typically between two and four in the morning, I hear the familiar click of her light switch and then her door open as she heads down the stairs to place her order for an early bird breakfast. All these years of broken sleep and hypervigilance have turned me into an extra-light sleeper, ready to bounce out of bed after her.

If a family member experiences disruption to their sleep patterns then it is most likely that other members of the family will be similarly disrupted, Younger children may seek comfort from a parent's presence which may develop into patterns of co-sleeping (Devnani & Hegde, 2015; Cotton & Richdale, 2006). In cases were the waking is more habitual it may be that the parents still wakes to ensure that the child is not putting themselves at risk with accessing inappropriate content on the tv or internet and that they are not trying potentially dangerous tasks such as trying to make a hot drink or cooking. Moving around the house may trigger alarms or may disturb others through switching on lights and in the silence of the early hours any noise may appear several decibels louder.

Any one co sleeping with someone with disturbed sleep is more likely to be disturbed themselves, especially if the disruption is accompanied by some form of noise or physical movement (Strawbridge, Shema & Roberts, 2004; Parish & Lyng, 2003). In cases of dreaming, this may be lashing out in response to a perceived threat or period limb movement from activity within the dream (Henin, Allen, Earley, Kushida, Picchietti & Siber, 1999; Ondo, 2018).

Pets may be disturbed which in turn may go on to disturb other members of the household (Pigeon, 2010). Depending on the physical structure of the building it may be that neighbours are impacted upon, for example in a block of flats (Park & Lee, 2018).

Whilst the situation may be manageable in the domestic setting where people may be able to find other sleep arrangements (spare rooms, sofas) to remove themselves from the disturbance, in the context of holidays this may not be possible without making some potentially costly contingency plans ie booking a second hotel room. Having visitors to stay or visiting others can be equally fraught, and so it might be that almost imperceptibly the family or the individuals become more socially isolated, not wanting to move beyond a comfort zone in which the disruption can at least be managed (Dhal & El-Sheikh, 2007; Meltzer & Montogmery-Downs, 2011).

In the same way that parenting children with additional needs such as autism can place increased demands upon families (Seymour, Wood, Giallo & Jellet, 2013), disturbed sleep can compound these demands (Schreck & Mulick, 2000), in that the caregiver or surrounding family members may have their own sleeping patterns interrupted or reduced (Rzepecka, Mckenzie, Mcclure, & Murphy, 2011), which over time can have pervasively negative effects, ‘they describe a sense of total exhaustion that contributed to experiencing loss of control, cognitive deterioration at work and home, an increased stress’ (Seymour et al.,2013, p1548).

These states can lead to stress and depression amongst parents and carers of people with autism, and can jeopardize family stability (Benson & Karlof, 2009).

According to figures published in 2006, half a million people in the UK had some form of autistic spectrum condition (Baird et al, 2006), which would indicate a prevalence of 1 in 100; the Adult Psychiatric Morbidity Survey published in 2016 confirmed this rate of prevalence in the UK, however the number of people affected by autism will run into millions when family members are taken into account.

The literature review has shown that the autistic population is susceptible to a variety of sleep issues that have a negative impact upon quality of life and more specific outcomes. There has been research which has demonstrated that sleeping difficulties can affect the wider family, so there emerges the double-bind of families trying to integrate an autistic narrative into a struggle with sleep deprivation, and then the way that the autists in these circumstances view their contribution to family life:

> “But I ask you, those of you who are with us all day, not to stress yourselves out because of us. When you do this, it feels as if you're denying any value at all that our lives may have--and that saps the spirit we need to soldier on. The hardest ordeal for us is the idea that we are causing grief for other people. We can put up with our own hardships okay, but the thought that our lives are the source of other people's unhappiness, that's plain unbearable.”
> (Higashida, 2013).

2.6 Review of studies of other populations and communities and dreaming

There are studies which have focussed on the impact of dreaming upon the well-being of various national and ethnic groups to examine the cultural response to this phenomena and regional differences of prevalence rates and distribution. For example, Schredl has investigated the nightmare topic and frequency in a German sample, concluding that ‘additional large-scale studies are necessary to determine the effect of socio-demographic variables on nightmare frequency’ (2010, p567). Sandman et al. (2015) have researched predictors of nightmares within a Finnish cohort and Munezawa et al. (2011) has conducted nationwide research into 'Nightmare and sleep paralysis among Japanese adolescents'.

There are numerous studies about the dreaming experiences of a variety of communities defined by psychological and biological factors rather than geographical location. Groups experiencing other forms of sleep impairment have been found to have greater disturbed sleep due to dreaming activity, these include narcoleptics, with and without cataplexy (Pisko, Pastorek, Buskova, Sonka & Nevsimalova, 2014).

Schredl, Schafer, Weber and Heuser (1998), studied the dreaming patterns of insomniacs with an aim of exploring the susceptibility for comorbid depression within the population. The links between dreaming, insomnia and depression and suicide have been demonstrated through studies across many years (Karia, Mehtra, Harshe, De Sousa & Shah, 2016).

Schredl, commenting on the study by Perusse, De Koninck, Perneault-Drolet, Ellis and Bastien (2016), suggests that further investigation into the dreaming experiences of insomniacs would raise awareness of the links between the two and may be supportive of more tailored therapeutic interventions, for clinicians, ‘it would be advisable to ask insomnia patients about nightmares, and – if present – treat the co-morbid nightmare disorder with Imagery Rehearsal Therapy’ (2016, p146).

Dreaming activities have been suggested as an indicator of a first major episode of bipolar II disorder (Skjelstadm Malt & Holte, 2011) and that the period of dream recall within the bi polar population may be of longer duration (Mota, Furtado, Maia, Copelli & Ribeiro, 2014).

> Personally, as someone with Bipolar Disorder, I can remember most of my dreams. I’ve written them down in my journals and have even used them in plots for my fiction books. I have written pages and pages of detail about my past dreams, and can even recall them days, months, or even years later.
>
> Bipolar Disorder And Dreaming
>
> By: Vicki M. Taylor https://ibpf.org/blog/bipolar-disorder-and-dreaming (2015).

The relationship of food and dreaming is diverse; it has been established that different types of food stimulate greater vividness in dreams (Neilsen & Power, 2015), dietary preferences have also been shown to affect dream content. In 2007, Kroth, Cummings, Rodriguez and Martin, reported differences in the dream content of participants who expressed and preference for fast food compared with those expressing a preference for organic food. In terms of this review it is perhaps the psychological relationships with food and their affect upon dreaming presentations that are more pertinent.

Kirov and Brand (2011) demonstrated a link between childhood nightmares and the development of psychiatric difficulties such as anorexia in adolescence, developing ideas from an earlier study by Claridge, Davis, Bellhouse and Kaptein (1998). Zanasi et al., (2010) investigated the dream reports of 252 anorexic patients and a control group of 252 and found significant differences in measured parameters such as Place, Characters and Emotivity. Research was also realising more practical ways to support the anorexic populations (Schredl & Montasser,1997) and it has been proposed that dreaming could be an indicator of the severity of anorexic states (Lauer & Krieg, 2004). Knudson proposed using a phenomenological approach to dreaming as a way to scaffold psychotherapy for the support of anorexics (2006).

Schredl and Sartorius (2010) investigating dreaming in children with ADHD found that the dreams of this population were more negatively toned, including 'more misfortunes/threats, negative endings, and physical aggression toward the dreamer' than the control group, commenting that 'the dreams seem to reflect the inner world of the child with ADHD' (p230). Research into adults with ADHD have confirmed that dreaming remains an issue into later life (Schredl, Bumb, Alm & Sobanski, 2017).

> Maybe what’s most interesting to me about recurring ADHD dreams is that they show how deeply embedded ADHD anxieties can become in your psyche. Living with ADHD isn’t just about the first-order effects that symptoms have on your life, but about the second-order effects of how experiencing those first-order effects changes your outlook, and the third-order effects of how you respond to those second-order effects, and so on. That’s why it’s so complicated.

> Neil Petersen, Recurring ADHD Dreams from The ADHD Millennial blog (12.03.2016).

Bakou, Margiotoudi, Kouroupa and Vatakis (2014) has investigated the dreaming experiences of a congenitally blind group of adults and found that whilst they still perceived themselves to experience dreaming, the sensory emphasis of their dreams was around sound, smell, touch and taste. Reports of dream content of sighted studies, for example Bulkeley, (2009) concluded that these are mainly visual. Meaidi, Jennum, Ptito and Kupers (2014) reported that experience of nightmares or dreams with aggressive interactions were significantly more in the congenitally blind group than in the late blind group who had experienced some vision in early life.

Other populations whose dreaming activity has been studied include asthmatics (Shapiro, 1989); people with Parkinson's (Valli et al., 2015); schizophrenics (Pavia et al., 2011); and those taking antidepressants (Tribl et al., 2013) and dreaming has been proposed as being an indicator of progression or improvement in Multiple Sclerosis (Moghadasi & Owji, 2013).

Research has shown that patterns of dreaming activity may be used more proactively in certain populations to signal developments in their conditions. For example, dreaming has been used as an indicator for post-natal depression in pregnant women (Kron & Brosh, 2003), with theories emerging that dream narration may be an indicator for healthy and at-risk pregnancies in some groups (Margheritam Garguilo & Martino, 2015).

There have been a variety of studies into the dreaming activities of children and adults with various types of epilepsy (Bentes, Costa, Peralta, Pires, Sousa & Paiva, 2011; Bentes, Costa, Pires, Pereira & Paiva, 2010; Bonanni, Cipolli, Iudice, Mazetti & Murri, 2002; Schlarb, Christen, Classen & Bien, 2016), and from these studies a theory that dreaming activity might be used as an indicator or a predictor of epileptic seizures (Chiesa et al., 2011). If this was found to be the case this could lead to more proactive treatment and management of the condition.

The above is not a definitive list, there are many other studies about the dreaming activities of other groups, however it is more problematic to find any studies on the impact of dreaming on people with autism. There has been a very short editorial piece by Dijk (2012) relating to dreaming in a population some with Parkinson's disease and some with an autism spectrum condition but nothing on a similar scale to studies of other populations.

Whilst there have been studies to correlate sleep disturbances with autism (Liu et al., 2006) and prevalence rates for general parasomnias amongst autistics (Ming et al., 2009), the subjects of these studies have been children, which has perhaps limited the assessment upon the well-being of the participant as the effects of disruption may be masked or more easily accommodated in a very young population, than, for example, a working age group of participants with other responsibilities. These autism specific studies about dreaming are few in number and the effects of dreaming on the well-being of both adults and children with autism remains largely untested.

These studies have investigated the ways in which these populations have experienced dreaming and the effects that these experiences have upon their well-being, sometimes informing clinical practice. The research into other groups dreaming experiences has explored the impact on waking well-being per se, but also the use of dreaming activity as an indication in change of the individual’s condition which might be used to initiate or to assess a course of therapeutic intervention. If populations with complex presentations are aware that dreaming has a relevance beyond that of an in-sleep activity, then they can use this to independently monitor their own well-being, or in conjunction with a range of other checks to develop a tailored, person centred quality of life assessment tool effectively unique to that individual.

If this diverse range of groups is experiencing altered states of dreaming that are generated by or indicative of the underlying condition and its development, then it may be that the suggestion that the dreaming experiences are different for the autistic population are more than just anecdotal, and rather, as with epilepsy and adhd, conditions often associated with autism (Dharmadhikari et al., 2012), there are connections between the condition and dreaming which are more than coincidental.

2.7 Factors that may connect autism and a propensity to experience vivid dreaming

Within the literature exploring models of dream production, there are indications that there are some areas, particularly those relating to neurobiological models, that may have particular connections to autism. These phenomena may be associated with presentations that can be seen in autistic people that are reflected in various diagnostic criteria such as ‘motor stereotypies’, or with other conditions that are often associated with autism such as synaesthesia and state anxiety and these will be discussed in the following section.

2.7.1 Sensory processing

The link between sensory processing and dreaming activity has been demonstrated in studies using high-density electroencephalography, to show how dream imagery was linked to increased activity in those areas of the brain governing the corresponding senses, for example dreams featuring faces were linked to heightened activity on the region associated with facial recognition and the same for other senses (Siclari et al., 2017).

Sensory issues are often associated with autism and in 2013 the American Psychiatric Association added sensory sensitivities to the diagnostic criteria DSM-5 (Repetto et al. (2017) and it is estimated that between 45 and 95% of children with autism have some form of sensory features that impacts upon their daily functioning; Crane, Goddard and Pring (2009) suggested that around 85% of autistic adults reported some form of sensory difficulties in everyday life, with the implication being that these difficulties persist into adulthood.

The traditional model of sensory difficulties refers to hypo and hyper reactions, to stimuli to the traditional senses of vision, taste, hearing, smell, touch proprioception and vestibular (Lane, Young, Baker & Angley, 2010), However is more recent years a much wider view of sensory issues has been proposed to include synaesthesia, issues with labelling and understanding emotions and of intolerance of uncertainty (South & Rodgers, 2017). The link between these sensory issues and anxiety have been demonstrated (South & Rodgers, 2017b) and this has been linked with an intolerance of uncertainty, or insistence on sameness and a reluctance to accept change, which is often associated with autistic behaviour (Wigham, Rodgers, South, McConachie & Freeston, 2015). Whilst these sensory areas are not exclusive, the impact of more traditional sensory activities upon dreaming will be considered below and those of synaesthesia and anxiety in the following sections.

2.7.1.1 Vestibular processing and dreaming

Kern et al. (2008) investigated 103 children and young people with autism and found that they had quite different sensory profiles for vestibular processing than the community controls. Ornitz (1970) linked vestibular dysfunction with a range of stereotypical behaviours associated with autistic children:

> seeking out vestibular stimulation and paradoxically the fearful and agitated states which may be induced by antigravity play and acceleration and deceleration. The autistic children may receive optokinetic stimulation from the preoccupation with tops and other spinning objects and they induce labyrinthine stimulations by whirling, body rocking and head rolling. Those autistic children who whirl themselves frequents fail to become dizzy and do not show a loss of balance associated with vertigo
>
> (p161).

Leslie and Ogilvie (1996) demonstrated that vestibular rocking during early morning REM phases increased the lucid mentations of participants in their study. Participants in this study also reported that the rocking motion emerged in the imagery of their dreams and that there was a higher incidence of dream bizarreness in dreams that were elucidated by vestibular movement. There were increased reports relating to vestibular imagery which is often a feature of Lucid Dreaming such as flying, falling and floating (Mavromatis, 1987). Other studies have shown that vestibular waking rocking can also increase the intensity of the dreaming experience and that modifying these vestibular movements has also been shown to affect a reduction in the vividness of dreams. For example, a study of the effects of Tai Chi Chuan training on the dream patterns of the group, showed that when the classes were focussed on the traditional rocking movements, the class reported greater intensity and frequency of dreaming, after stretching exercises were introduced to the class' routine the vividness of the class' dreaming activity reduced as a result of the modification to the programme (Slater & Hunt, 1997).

2.7.1.2 'Autistic Burnout' due to sensory overload and masking

Sensory processing and anxiety overlap in the sense that alterations in the levels of anxiety can affect an individual's sensory resilience (Green and Ben-Sasson, 2010) and alterations in levels of sensory resilience will impact upon levels of anxiety (Kong, 2017; Gerstenberg, 2012). Sensory processing difficulties can be anxiety inducing for the individual and exhausting, resulting in 'Autistic Burnout' especially if the sensitivity relates to environmental factors to which an individual is routinely exposed:

> A day of talking and socialising—Conversations with adults and children, timetabled and spontaneous. Running the conversational scripts in my head to full capacity all day long.
>
> Surrounded by noise; screaming children in the playground, shouting children, singing children, musical instruments, banging and clashing, the general commotion of the classroom; and over the top, the dumpf-dumpf-dumpf of my heart in my ears and in my chest.
>
> The strip lights overhead, flickering constantly in pulsing waves, each one shooting through my eyes and down through my body; I can physically feel each pulse humming and vibrating.
>
> Kieran Rose 'An Autistic Burnout' from the blog The Autistic Advocate 29.05.2018.

Sensory processing and anxiety can be further exacerbated by the impact of masking or camouflaging; 'camouflaging of autistic characteristics in social situations is hypothesised as a common social coping strategy for adults with autism spectrum conditions (ASC). Camouflaging may impact diagnosis, quality of life, and long-term outcomes, but little is known about it' (Hull et al., 2017, p

2519), although first hand narratives describing the condition are appearing in online blogs:

> I’ve experienced several moments of burnout in my life and career. Being something that I neurologically am not is exhausting. Wearing the mask of neurotypicality drains my batteries and melts my spoons. For a long time, for decades, I didn’t fully understand what was going on with me. I didn’t understand the root causes of my cycles of burnout. Finding the #ActuallyAutistic community online woke me to the concept of autistic burnout. When I found the community writing excerpted below, I finally understood an important part of myself. Looking back on my life, I recognized those periods when coping mechanisms had stopped working and crumbled. I recognized my phases and changes as continuous fluid adaptation.
>
> These periods of burnout caused problems at school and work. I would lose executive function and self-care skills. My capacity for sensory and social overload dwindled to near nothing. I avoided speaking and retreated from socializing. I was spent. I couldn’t maintain the facade anymore. I had to stop and pay the price.
>
> Boren (2017).

Sensory processing atypicalities in the autistic population may influence the production and content of dreams directly and, as Boren describes above the additional demands that sensory processing can place on autistic people can be a further source of anxiety and stress.

2.7.2 Anxiety and stress -related models of dream production

Anxiety is estimated to affect at least 40% of autistic individuals at any particular time (van Steensel et al. 2011) and is a state intrinsically linked with autism across the lifespan of the individual (Zaboski & Storch, 2018; Bejerot, Eriksson & Mortberg, 2014; Ollendick & White, 2012). Anxiety and stress can be affected by sensory responses to situations (Bogdashina, 2016; Robertson & Simmons, 2015)), social stress (Lanni, Schupp, Simon & Corbett, 2012), masking (Hull et al., 2019) and a myriad of other issues including those outlined in section 1.4 of this report.

Autism has been termed an anxiety disorder (Baron et al., 2006) and it is problematic to nominate an aspect of autism that is not associated with a state of anxiety or does not give rise to such. Social difficulties involved in constantly reinterpreting situations and interactions or the constancy of sensory issues can be sustained sources of anxiety:

> You've been told that your eccentricities were bad, that your special interests were weird, that your nonconformist behaviours were problematic, and if you only tried harder, you would do better. You have probably viewed yourself as being defective. Weird, nerdy and some other negative adjectives. You have most likely viewed others as powerful and yourself as powerless.
>
> (Dubin, 2009, p43).

Whilst there are more positive presentations of autism emerging which will be discussed later in this chapter (particularly section 2.13), for many with the condition the narratives have been around the dis-abling concepts associated with the medical view of being autistic. The process of receiving a diagnosis at any age, treatment at school, both by peers and professionals, exposure to programmes and interventions, living with family members who may themselves be anxious about various outcomes for the individual and themselves as a result of the condition, can all contribute to a level of pervasive state anxiety to which the individual can become habitualised but still remain susceptible to its adverse effects (Jones, 2013).

Anxiety is a major contributor to the production of vivid dreams (Kilborne, 2013) and so it would follow that the elevated anxiety levels of the autistic population may suggest that this group may experience more dreaming activity than others. As well as being a major cause of dream production (Nadorff, 2014), anxiety is a key concept in the continuity and Freudian models of dreaming (Lee & Kuiken, 2015; Schredl, 2017). The continuity model of dreaming is that our dreams are reflections of waking life as well as having an impact upon them. Schredl (2003) lists the waking life elements that might influence dreams as including events that have happed recently, or anniversaries of traumatic events, emotional involvement and personality types. Personality types or traits can be described as 'stable characteristics different for each person explaining individual predispositions to certain patterns of behaviour, cognitions and emotions' (Khalil, 2016, p599).

In the activation-synthesis model of dream production the prevailing emotional disposition of the cerebral cortex will have a great influence over the 'narrative' that is produced around the random items of information that it is processing (Ciconga & Bosinelli, 2001), so from the perspective of that model of dream production someone with an anxious or stressed disposition would tend to unconsciously produce dreams that are more negatively toned than someone with a more optimistic approach to life (Williams, Mertitt, Rittenhouse & Hobson, 1992).

There was some anecdotal evidence from those families that were consulted before formulating the research questions to suggest that some people find the prospect of experiencing a reoccurring dream so unsettling that they try to suppress the distressing thought or themes of the dream during waking hours. Bryant, Wyzenbeek & Weinstein (2011) found in their study that this practice led to more distressing and longer dreaming experiences around the subject that participants were trying to suppress, hence the term ironic control theory. Ironic control theory or ironic rebound is particularly distressing in cases of post traumatic stress disorder (Malinowski, 2015) in which the understandable aim of the individual is not to think about the root cause to the PTSD (Kroner-Borowski et al., 2013).

2.7.2.1 Social anxiety and issues around post traumatic stress disorder

Social anxiety has been reported as a factor that might increase dream frequency as in this report from the blog Musings of An Aspie (24.11.2012):

> The trigger for each of the types is specific, too. The violent nightmares usually follow a day where I've had a frustrating social encounter with a stranger or acquaintance–something that's left me feeling tongue-tied, inadequate or embarrassed. The rage-filled nightmares usually follow an unpleasant interaction with someone I know. Often that person will be the target of the rage in the dream.

Post Traumatic Stress Disorder (PTSD)

> PTSD develops after exposure to a potentially traumatic event. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM; [2]), the traumatic event must involve exposure to actual or threatened death, serious injury, or sexual violence. Exposure is defined as directly experiencing or witnessing a traumatic event, or learning that a trauma occurred to a close family member or friend.
>
> Lancaster, Teeter, Gros & Back, 2016).

Some people with autism will have been affected by events featuring these clinical definitions of death, injury or sexual violence, but there are levels of subclinical PTSD (SCPTSD) emerging which are seen as being as harmful in their effects and impacts as the clinical cases (McCubbin et al., 2016; Wessa, Karl & Flor, 2005).

Lancee and Schrijnemaekers (2013) have established a link between nightmares and prevailing daily distress in a cohort representative of a SC PTSD group, ie excluding those with PTSD, depression and suicidal ideation, concluding that the impact is not only distress around the experience the following day but also in terms of generating anxiety about dreaming before falling asleep as ‘people with frequent nightmares may have the presupposition that nightmares negatively impact their functioning the next day (ibid, p18). This comment by Lancee and Schrijnemaekers that once a person suffers from frequent nightmares, the expectation of the nightmare legacy the following day will increase the very anxiety that will trigger the negative dreaming experience, will have implications for those suffering from frequent dreaming episodes.

For some the trauma of diagnosis might be a trigger for SCPTSD. The length of time taken to secure an assessment can be many years assuming that the pathway can be accessed in the first place. Frequently access to other services and resources such as CAMHS or an Education Health and Care Plan or place in a specialist provision may not be possible until the diagnostic position has been clarified. In the intervening period young people and families are often left unsupported as in some regions of the country access to parenting courses such as the NAS EarlyBird or the Barnardo's Cygnet training or other support is dependent upon a diagnosis.

For women and girls with suspected autism, the route to a diagnosis can be made more complex by the issue of masking, which can complicate the presentation, and is thought the be a major contributing factor to the apparent gender gap in diagnostic rates, the following statistic differentiates between the male to female ratio of people accessing services where a diagnosis is not a criteria with accessing specialist schools :where a diagnosis is required:

> In 2015, the ratio of men to women supported by The National Autistic Society's adult services was approximately 3:1, and the ratio of boys to girls in our charity's schools was approximately 5:1
>
> The National Autistic Society
>
> https://www.autism.org.uk/about/what-is/gender.aspx

Research by Loomes, Hull, Polmear and Locke (2017) referred to 54 studies of over 53 000 young people with autism and concluded that:

> Of children meeting criteria for ASD, the true male-to-female ratio is not 4:1, as is often assumed; rather, it is closer to 3:1. There appears to be a diagnostic gender bias, meaning that girls who meet criteria for ASD are at disproportionate risk of not receiving a clinical diagnosis.

Emily Swaitek describes her masking profile and why she thinks her autistic presentation was missed and not confirmed as autism through several assessments:

> "I'm not a part of that traditional profile of autism… It never even occurred to anyone who was assessing me that somebody who looks like me, somebody who presents like me, could be autistic because I'm smiley, I'm eloquent, I can probably make eye contact if I have to, even though I don't like it. I'm a very strong mimicker and that masking and mimicking profile is true for me. I think I very much fit that 'well behaved little girl' image—very intelligent, liked reading, very quiet, maybe they'd say I was shy."

> Emily Swaitek, quoted in the blog ‘Misdiagnosis all too common for women with autism’ by Robert Muller 27.07.2018, in ‘The trauma & mental health report; sharing knowledge on trauma and mental health with the community’.

Other sources of exceptional stress for autistic people may be inherent in the prevailing mainstream model for education with large schools and classes and rigid time tables and curriculum (Rance, Chisari, Saunders & Rault, 2017; Hees, Roeyers & Mol, 2018; Wei, Wagner, Christiano, Shattuck & Yu, 2014), and the trauma of these early life experiences may persist into adulthood. Alternative specialist settings may require long journeys to access them or may need to be in the form of a residential placement. Specific interventions may have uncertain legacies with Applied Behaviour Therapy, which aims to improve outcomes for autistic children, now controversially being cited as being a cause of PTSD in later life (Kupferstein, 2018).

The impact of sleep difficulties on the wider family has been discussed previously but the stresses that can accompany parenting or being the sibling of a child with conditions such as autism are well researched (McStay, Trembath & Dissanayake, 2014; Brad, 2014; Hall & Graff, 2012). These stressors can arise from the behaviours of the autistic person, or from managing the challenges of educational systems and accessing support, however the net result is that families can become totally immersed in stress and anxiety from a wide range of sources, some may be temporary such as applying for an Education Health and Care Plan, others, such as the worry about what the future might bring, may persist over many years.

> When autistic children don’t seem to be engaging with the world, their parents often worry that they’ll get left behind: that they’ll never find a job, or marry, or raise a family of their own, and when they then experience the perfectly understandable feelings of loss that follow, they’re overcome with a terrible sense of shame. They convince themselves that feeling this way means they don’t like or accept their child for who they are, and beat themselves up for being the worst kind of pushy parents.

> From the blog The secret to successfully parenting autistic children from the series The Ring Master's Tale Helen Wallace-Iles.

As with the factors affecting the quality of life for the autistic person, these stressors can range from large events such as starting a new job with which a degree of anxiety would be expected or they may be triggered by even the most apparently mundane of activities:

> Whenever I wrote, I pored over every letter and word and full stop. If I noticed a smudge or error, I would rub everything out and start over. This streak of perfectionism meant that I sometimes worked at a snail's pace, finishing a lesson in a state of near exhaustion, yet with little to show for it
>
> (Tammet, 2007, p54).

Managing anxiety and related issues are potentially the greatest challenge for the autistic population as a whole, As research promotes understanding of specific triggers for anxiety in autists across a range of different domains including, sensory issues (Shulamite & Ben-Sasson, 2010), social interaction (Gillott & Standen, 2007), and masking (Cook, Ogden & Winstone, 2018), then the emergent picture is one of a quality of life that is hugely compromised by anxiety and related conditions.

2.7.3 Synaesthesia

> Synaesthetes see letters and numbers wreathed in fixed, seemingly idiosyncratic colours. Grapheme-colour synaesthesia, the term for this variety, is the most common sub-type of synaesthesia, occurring among four people in 100. It's also the most widely studied. Other common varieties are chromaesthesia, in which tones or notes set off flashes of colour and a symphonic wall of sound can summon a three-dimensional landscape, and spatial-sequence synaesthesia, in which seconds, weekdays, months or years encircle those who experience it, like planetary rings. Some have lexical-gustatory synaesthesia, which lends every word or name a strong, specific taste, making some delicious, and others too bitter to utter. Still other synaesthetes report ordinal-linguistic personification,

> in which they ascribe distinct genders, colours or personality types to letters and numbers: ‘4’ might be an ill-tempered, ungenerous man, constantly heckling his wife, while ‘6’ turns out to be a dignified, genteel woman with exquisite manners.
>
> (Ravindran, 2015).

Synaesthesia is a sensory processing condition in which a sensory stimuli manifests or creates a response in a different sensory area, for example a sound may be perceived as a smell or a colour (Sagiv et al., 2011). The Synaesthesia Project, located at Boston University (USA), suggested that there may be more that 35 sub types of the condition with the more frequently occurring ones being around colour-grapheme and colour-auditory.

Different forms of synaesthesia are being recognised, extending the coverage of its terms to include concepts such as loci memorisation (Tammet, 2006) and involuntary methods of loci memorisation, rather than just being a sensory experience (Simner, 2007). These inclusions refer to scene-concept synaesthesia which can be used to support memory function (Wright, 2011) and may be linked to the higher prevalence rates of synaesthesia in savants.

Autistic blogger Hayley Morgan whose nom de plume is the Cold Tea Connoisseur posted this excerpt on her perceptions of ‘Tickertape Synaesthesia and my autistic brain’:

> We're at the point of technological advances where I probably have to explain what a tickertape is to some people. A rolling tickertape is also what live news reports have, scrolling from right to left with new information. And that's the most simplified way of explaining what I see in my mind's eye. The picture above looks like me searching for information I've once heard, read through synesthesia and stored away on a script like a mental microfiche.
>
> (2017).

Synaesthesia occurs when there are alterations in the serotonergic system which produces an area of hyper connectivity in the structure of the location of the brain which leads to disinhibition (Kadosh et al., 2009). Recent studies have linked hyper connected brain function with autism (Orekhova et al., 2014) and have suggested that the greater the functional connectivity within the brain, the more severe social impairments are likely to be presented (Superkar et al., 2013). Studies have suggested that there may be a genetic link between synaesthesia and autism (Asher et al., 2009) and there is a strong familial clustering of cases. Whilst it has not yet been demonstrated that there is a functional relationship between autism and synaesthesia there is a positive statistical correlation; the prevalence rates for synaesthesia within the autistic population have been reported as being around 20%, three times higher than those of the neurotypical population (Baron-Cohen et al., 2013; Neufeld et al., 2013).

Brogaard (2013) links compensatory lateralising of serotonin levels between the brain's hemispheres as a factor which might account for the relatively high incidence (10%) of savant syndrome within the autistic population, with a significant number of this group experiencing both serotonin imbalances and synaesthesia (Rothern et al., 2012).

The academic research and literature on synaesthesia is emerging and links between synaesthesia and dreaming, especially lucid dreaming in which the participant can control the direction of the dreaming narrative, are mainly anecdotal in nature (for examples see www.world.of-lucid-dreaming.com; www.lucidity.com), The Oxford Handbook of Synaesthesia (Ed. Simner & Hubbard, 2013) found that form a group of 100 synesthetes surveyed ‘Eighty-two per cent of the synesthetes described clearly the experiences to lucid dreaming' (P470). More recent research into synaesthesia is suggesting a tendency to dream in a way that is more notable or different to that of the general population (Casini, 2017; Seth 2014).

In the context of this project, it can be seen that there is higher incidence of synaesthesia in the autistic population than in the predominantly neurotypical population, and that within the synesthetic population there is a greater tendency to experience dreaming in a more vivid if not lucid form, These links or associations may confirm the suggestion that there may be a connection between autism and a number of other conditions or states in which vivid or more frequent dreaming occurs.

2.7.4 Medication

The link between serotonin imbalance and the autistic population has become an established fact in recent years, with serotonin being elevated in the blood supply whist being significantly lower throughout the brain (Nakamura, 2010; Daly et al., 2014; Gabriele et al., 2014). The serotonin function may vary between the brain hemispheres to the extent that one hemisphere may de-activate before the other, this maybe for the briefest of moments but may be sufficient to allow the creation of vivid dreams (De Gennaro, Marzano & Cipolli, 2012). This serotonin imbalance is a contributing factor to sleeping difficulties in the population (Tordjman et al., 2013) with melatonin now being widely recognised as a treatment for sleep latency and to maintain sleep compromised by insomnia within the autistic population (Wright et al., 2011).

Melatonin may have a role in increasing vivid and disturbing dreams; there are considerable references to this phenomenon anecdotally on the internet, however a study by Kahan et al. (2000) to measure the impact on reported dream bizarreness in a mixed cohort of college students, concluded that the impact that melatonin has in increasing the REM waves of sleep also increased the potential duration for dreaming.

A variety of other medications which may be prescribed for a range of issues can produce more vivid dreams for example, many antidepressants, beta blockers, blood pressure medications, Parkinson's disease drugs, and drugs to stop smoking (Goyal, Kaushal, Gupt & Verma, 2013), and some vitamin complexes have been shown to promote dreaming (Aspy, Madden & Delfabbro, 2018).

Whilst melatonin is prescribed to support people with autism with sleep issues, other medication and vitamins are perhaps not as connected with autism as melatonin, although, for example the increased rates of mental illness in the population may mean that the prescribing rate for anti-depressants is higher than that of the general population (Leclerc & Easley, 2015).

Although there are no published figures for prescribing rates, melatonin is frequently prescribed for children with sleeping disorders. In recent years the UK approved prescription brand has changed to Circadin, which is a prolonged release tablet and more suitable as a treatment for those struggling with maintaining sleep than the rather larger number that struggles with sleep latency (Baker & Richdale 2014; Baker & Richdale, 2015). Non-time release melatonin is available on line at prices that are less than prescription charges although these supplies can be of variable quality (Grigg-Damberger & Ianakieva, 2017). Prescribing rates for melatonin have risen by 25% between 2015 and 2018 (The Guardian, 2.11.2018), however sales figures for over the counter sales are not available to provide a more accurate picture of melatonin use in the UK.

Whilst the autistic population is perhaps more likely to access melatonin to support sleep, it is unclear what other medication and supplements might be consumed that may have an impact upon dreaming. However, the link between melatonin and more intense dreaming has been established (de Gennaro et al., 2012) and this is a further factor which may lead to people with autism being more prone to experiencing more vivid dreaming experiences.

2.7.5 Chronobiology

Chronobiology is the study of the effect of circadian, infradian and ultradian rhythms on living systems. When these biological rhythms are disturbed there can be a deterioration in quality of sleep, health and mental well-being and these disruptions occur when 'an individual's biological clock is no longer in phase with its environment' (Botbol, Cabon, Kermarrec & Tordjman, 2013, p300).

Tordjman et al. (2015) suggested that circadian rhythms are irregular in autists and adversely affect levels of melatonin and cortisol production precluding the synchronization of rhythms inter-uterinaly and in very early stages of life

> The synchronization of rhythms allows tuning and adaptation to the external environment. The role of melatonin in the ontogenetic establishment of circadian rhythms and the synchronization of the circadian clocks network suggests that this hormone might be also involved in the synchrony of motor, emotional, and interpersonal rhythms. Autism provides a challenging model of physiological and behavioral rhythm disturbances and their possible effects on the development of social communication impairments and repetitive behaviors and interests.
>
> (Tordjman et al., 2015).

These temporal cycles, especially the circadian ones have been shown to affect a variety of physiological issues including migraine (Fox & Davis, 1998), obesity (Garaulet et al., 2010) and a range of mood disorders (Wirz-Justice, 2003). Circadian preferences are associated with emotional and affective temperaments, with the ‘morningness’ chronotypes having a more positive range of attributes and outcomes than the ‘eveningness’ types (Wirz-Justice, 2003).

Chronobiological preferences have been linked to specific populations, for example people with ADHD have been found to have a prevailing evening preference (Caci et al., 2009; Voinescu et al., 2012). Tore (2010) investigating chronotypes found that those with the ‘eveningness’ type are more likely to experience vivid dream states. Limoges et al. (2005) reports that whilst there was no discernible pattern of difference between the chrono typical preferences of autistic/non autistic groups, within the autistic group these were apparent: 'Persons with HFA were found to lie on the 'morning side' of the intermediate zone and persons with Asperger syndrome were found to lie on the 'evening side of the intermediate zone' (p1056), this may infer that a group within the autistic population has more of a proclivity toward vivid dream states than other groups on the spectrum.

Not all autistics view a sleep-wake cycle that is independent of environmental and social cues as being a problem. Michelle Dawson commented on ‘The circadian prison’ (2010) in a blog from the series ‘the autism crisis science and ethics in the era of autism advocacy’:

> My form of freerunning is extreme. I can sleep whenever I want--a few hours here, twelve hours there, as necessary, no matter the time of day or night. I enjoy sunlight but its absence has no effect on my mood, or on my sleep. I can work through nights, no problem, and shift to days in a blink. I've never suffered through jet lag. And so on. Until I ran into Bourgeron I had no idea this was considered pathological, at least in an autistic.

In the context of this project there is research to show that that group of autistics who may have been diagnosed with Asperger’s Syndrome when that diagnostic category was available, that is before the introduction of DSM-5, are more disposed to the eveningness chronotype which suffer from increased nightmares (Nielsen, 2010).

2.7.6 REM and NREM differences found in autistic participants

Non-rapid eye movement and rapid eye movement are a particular areas of sleep architecture involving the cyclical pattern of sleep, with phases including rapid eye movement (REM) and non-rapid eye movement (NREM) featuring slower wave sleep patterns ranging from N1 to N4 (Deatherage et al., 2009). Dreaming that takes place within REM phases is more likely to be recalled and to feature more recent memories than NREM sleep (Mcnamara, Mclaren & Durson, 2007).

It was originally believed for dreaming to be rare in phases of NREM sleep however more recent research has discovered that this is not the case and that there is probably an equal potential to dream in either phase and that it is the density of sleep spindles that is the difference between recalling a dream or having a lesser memory of the episode (Suzuki et al., 2004).

A study by Simor, Horvath, Gombos, Takacs and Bodizs (2012) concluded that people with autism have atypical sleep architecture in terms of the duration of the different phases of sleep, with a tendency towards shorter NREM and longer REM sleep which would suggest that autistic people are more exposed to longer phases of sleep in which dreaming occurs and is more likely to be recalled.

2.7.7 Sleep spindles and autism

A further aspect of sleep architecture which may support the view that the autistic experience of dreaming is technically different to that of the general population relates to sleep spindles. Sleep spindles occur though NREM and Slow Wave Sleep (SWS). Sleep spindles are electroencephalographic rhythms that occur periodically during NREM sleep waves and they constrain the communication between the thalamus and the cortex through the discharge of neurons throughout the thalamocortical region. During periods of SWS, they are understood to be a key factor in the consolidation of declarative memory as their oscillatory pattern suppresses new information from brain activity and allows the brain to process recently acquired memories (Deatherage et al., 2009).

When sleep spindles become less dense in stages of NREM sleep the communication between thalamus and cortex, the sensory transmission cognitive processing is enabled and so the ability of the brain to engage in dreaming activities that it is more likely to recall is increased. Where there are fewer sleep spindles the suppression of current brain activity is reduced leading to greater dream re-call and less memory consolidation (Merikanto et al., 2019).

A study by Bruni, et al. (2007) found that there was a lower density of sleep spindles for children with Asperger's Syndrome. As people with autism have a sleep architecture with fewer sleep spindles (Limoges et al., 2005) it can be demonstrated that there is the potential for greater dream frequency and clarity of dream recall in this population.

2.8 Conclusions

Any interruption to sleep for whatever reason will increase the potential for dreaming, simply because there will be a disruption to the complex cycles produced by a person’s sleep architecture and that resetting these by regaining a state of sleep will re-start and repeat these cycles (Soffer-Dudek, 2017). Disturbances to quality sleep have an increased potential to produce further disturbances and degrade sleep because the individual will not experience the full cycle of progressive inter-cycles of REM sleep and sleep spindles, meaning that the re-captured state of sleep has the potential to be further disturbed and it may be a relatively short period of time before the individual is roused from sleep again due to the increased brain activity of the re-set sleep architecture (Bing, Moller, Jennum, Mortensen, Skovgarrd & Lose, 2006).

Whilst there have been studies to correlate sleep disturbances with autism (Liu, Hubbard, Fabes & Adam, 2006) and prevalence rates for general parasomnias amongst autistics (Ming, Nachajon, Brimacombe & Walters, 2009), the subjects of these studies have been children, which has perhaps limited the assessment of the well-being of the participants, as the effects of disruption may be masked or more easily accommodated in a very young population, than a working age group of participants with other responsibilities, for example, a seven year old may be able to meddle through a day at primary school more easily than an adult parent with a job that involves operating machinery.   These autism specific studies about dreaming are relatively few in number and the effects of dreaming on the well-being of both adults and children with autism remains largely untested, although the studies that have been undertaken have suggested that there should be further investigation in the relationship between autism and dreaming.

2.9 A general overview of dreaming literature

Literature on dream research can be very broadly grouped into discussions around definitions of dreaming, models of dream production, dream function and dream affect, the following section will review the literature available in these areas.

2.9.1 Definitions of dreaming

Research has not yet developed a predominant definition of the dream state and the position of nightmares and bad dreams within this (Pagel, 1999). Even within clinical manuals such as DSM-5 (2013) or the American Academy of Sleep Medicine International Criteria of Sleep Disorders (1990) there is no categorization of dream states beyond that of a nightmare being a frightening dream (Pagel, Blagrove, Levin, States, Stickgold & White, 2001). Some studies have focussed solely on nightmares which might be characterized as disturbing experiences with at least a partial arousal (Schredl, 2013), or the perception of a threat within the dream state (Nielson, 2007). However, dreams can have troubling or distressing legacies in waking life because of their bizarreness rather than having a content of threat (Knudson, 2001). Some researchers have used instances of partial arousal from sleep as criteria which have been measured by polysomnographic indicators (Ming, Sun, Nachajon, Brimacombe & Walters, 2009), rather than the individual reporting or recognising an experience of waking. There is also an issue of categorising hypnagogic or hypnopompic hallucinations with some tensions as to whether these are included on the dreaming spectrum or other phenomena related to sleep paralysis (McCarty & Chesson, 2009).

Studies that have used broader definitions of dreaming have shown quite distinct differences in dream content between the autistic and non-autistic populations (Daoust et al., 2008; Craig and Baron-Cohen, 1998). From these studies there is evidence to suggest an atypicality about the dreaming experience of people with autism, however due to the widely varying range of definitions that feature in the literature overall, a more generalised picture of how dreaming affects the autistic population cannot be compiled from existing literature.

Whilst there are a number of broad categories of dreaming including lucid, vivid, nightmare and archetypal in practical terms concrete definitions are elusive (Blagrove Farmer & Williams, 2004).

There are many exponents of Lucid Dreaming who feel that it is a rewarding and even beneficial activity (Voss, Holzmann, Tuin & Hobson, 2009), and there have been academic studies into the different ways to access this state, either by consciously waking and returning to sleep or by a pharmacological intervention (LaBerge, LaMarca and Baird, 2018). Lucid Dreaming can be induced through Dream Induced Lucid Dreaming (DILD), Wake Induced Lucid Dreaming (WILD and Mnemonic Induction of Lucid Dream (MILD) and within these there is a plethora of techniques and sub categories such as dream incubation and looking for dream signs and reality checks. Through using techniques of Lucid Dreaming, such as not being able to switch off a light or read an analogue clock (Schredl & Noveski, 2018), the individual is able to determine that they are in a dream state and then influence the direction of the dream, even ‘choosing’ activities such as flying or out of body experiences (autoscopic and heautoscopic) (Cheyne & Girard, 2009).

There have been attempts to distinguish nightmares from bad dreams, using criteria such as whether the episode resulted in waking or if there was an element of fear or threat involved in the content of the imagery (Zadra & Doneri, 2000; Fireman, Levin & Pope, 2014), other studies often combine the two categories and decisions about distinction or combination tend to be related to the purpose of the study (Levin & Nielsen, 2009).

Progress towards a working, widely accepted definition of what is a dream has been made more complex by the range of epistemologies engaged in research in the area. The measurement of dreams, the analysis of dream content and the study of the model of dream production all have an impact upon any working definition that is used in the study, and because of the interrelationships between these fields it may be unrealistic to envisage a universal definition (Pagel et al., 2001).

One potential solution to the issue of a universally acceptable working definition might be that proposed by Windt in which the post-dreaming well-being is the critical area of judgement rather than the contemporaneous act of dreaming. This minimal definition of Immersive Spatiotemporal Hallucination states that dreaming is:

- an immersive spatiotemporal hallucination - an experience that has the sense of being located somewhere and at some point in time with some perception of imagery.
- something that occurs in sleep or during sleep-wake transitions
- has an assumption of reportability - this might not be in the sense of the dreamer being able to fully re-call the content but rather a non-amnesic episode of which the dreamer has some awareness of.

(Windt, 2010).

Such a minimal definition will enable the participants to relate their own construal of the dreaming experience and the impact that this is perceived to have on their well-being. Using a minimal definition is also firmly within the traditions of a phenomenological approach, 'obtaining descriptions of experiences through first-person accounts' and 'focussing on the wholeness of the experience' (Moustakas, 1994 p21).

Whilst there have been attempts to produce a taxonomy of different dream states, especially between the categories of nightmares and bad dreams, these are highly subjective experiences the content of which might not be fully recalled or re-told by the dreamer but which have negatively toned content which still has an impact of the wakeful state of the individual (Zadra & Donderi, 2000). The individual's experience of that episode and the influence that it has upon their well-being is not changed by the title. In the most unhelpful context, it may even be perceived to be trivialising that person's experiences by categorizing it as a 'lesser' bad dream because it did not meet the technical criteria for a nightmare which technically requires full or partial arousal (Schredl, 2013).

2.9.2 Models of dream production, dream function and dream effects

The continuity hypothesis of dreaming is an established and well researched theory which 'states that dreams reflect waking-life experiences' (Schredl & Hoffman, 2003, p299). Whilst life events and mood are reflected in the dreaming process, this might be in a way that is distorted, 'for example, the place where we find ourselves in a dream may be a peculiar conglomerate of several actual places; dream characters and objects may be encountered in contexts where they do not belong' (Revonsuo & Salmivalli, 1995, p16).

The dreaming experiences can be vital in allowing the sub conscious to assimilate and consolidate new knowledge, memories and to process information; they enable a processing function which allows the brain to re-cover day time learning experiences. These processing function are historic, dealing with information and memories that have already been acquired, but there is also a more predictive aspect to dreaming in the sense of rehearsal and of problem solving and, in this way, individuals may have dreams about the possibilities surrounding events in the future which may be one reason why dreams are often interpreted as being ‘prophetic’ (Wiseman, 2011).

This theory of dreaming activity as representative of the brain’s unconscious activity was developed into the activation-synthesis hypothesis by Hobson and McCarley (1977). The activation-synthesis model reduces dreaming to the transmission of random neural signals which the higher-level cognitive processes in the cerebral cortex try to integrate into some form of dream ‘plot’ (Hobson & Stickgold, 1995).

The other area of dream theory is based on Freudian principles, that there is an element of ‘fulfilment of repressed wishes’ or ‘ironic control’ often involving sex and violence. Freud suggested that the wishes were represented in dreams by symbols to make them less anxiety producing for the individual and that decoding the symbolism of the dream was paramount in ascertaining what the repressed desire or thought was (Freud, 1954).

Ironic Control theory or the dream rebound theory of supressed thought suggested that thoughts and emotions supressed during waking hours are more likely to feature in dreams when those monitoring and operating systems that supress the unwanted thoughts are largely deactivated during sleep (Bryant, Wyzenbeek & Weinstein, 2011), this can have unfortunate consequences for those recovering from addiction (Hajek & Belcher, 1991; Reid & Simeon, 2001) or from trauma, especially Post Traumatic Stress Disorder, as suppressing unwanted thoughts can lead to these becoming intrusive in dream states, so the individual relives that which they are trying to escape. Kroner-Borowik et al. (2013) demonstrated that those attempting to suppress thoughts were more likely to experience increased target-related dreams and Schredl suggests that there is a gender bias in ironic control theory as woman tend to experience more nightmares due to an evolutionary tendency to suppress negative thoughts rather than expressing them and in doing so processing them in some form (2008).

Dreaming has been proposed as a coping mechanism for dealing with stress, suggesting that these episodes have a beneficial function rather than being purely pathological. Picchioni et al. (2002) concluded that the increased frequency of dreams reported by anxious Type A individuals was as a response mechanism to cope with the stress rather than as a reaction to being in a stressed state. The process of dreaming allows a rehearsal of various options of activity in waking life to a stressful or harmful situation, which Revonsuo (2000) referred to as a Threat Simulation Theory. This is an evolutionary theory of dreaming through which early historical ancestors might rehearse and develop adaptations to life threatening situations and part of the rationale behind this theory is the percentage of dream content that involves life-threatening situations, chases and aggression (Malcolm-Smith & Solms, 2004). A study by Bjorvatn, Gronli and Pallesen. (2010) demonstrated that the chances of self-injury in sleep were 4.3% and 3.8% for injuring someone else, however the root cause of these injuries has not been explored, just attributed to parasomnias in general.

Although dreaming is mostly considered to have negative connotations there have been some studies proposing that dreams can have a range of positive effects if they are experienced in ways which are not disturbing to the dreamer upon waking (Schredl, Brenner & Faul, 2002). Within a creative population this process has been linked to contributions to artworks, solving work related problems, motivating the dreamer to attempt something new or giving some emotional insight into a situation (Schredl & Erlacher, 2007). There is some discussion that such a creative population may have a tendency to recall their dreams in rather more detail than other populations, and that the effect of these detailed descriptions may be to give the impression that the dreams are longer or have more impact than is actually the case (Schredl & Erlacher, 2007).

Schredl, Fricke-Oerkermann, Mitschke, Wiate and Lehmkuhl (2009) demonstrated that parents underestimate the frequency of nightmares experienced by their children by 50%. The participants in this study were drawn from a large cross section of the population with sample sizes of 4834 parents and 4531 children. Although population wide surveys suggest that around 5% of the population will be experiencing nightmares, this is widely felt to be underreported as 'the clinical impression is that most nightmare suffers do not seek medical help for the problems' and so they frequently go unrecorded (Schredl, 2013).

Schredl, investigating why more people do not seek professional support for their dreaming activities suggests that this might be because sufferers may have become habitualised into accepting their dreaming activities as normal or may not perceive this as an activity that may be influenced through counselling or a medical programme even though 'dreams incorporating negatively toned events of the previous day have a stronger effect on the mood of the next day' (2013, p263).

A further issue with studies on parasomnias is that is can be problematic to ascertain what the sleep problem may be as the categories used to describe different sleep disturbances may overlap or may not differentiate sufficiently, for example, night waking may be triggered by a dreaming experience, although the event is recorded as a night waking, and sleep onset difficulties and sleep anxiety may be attributable to a fear of nightmares but not recorded as such.

Difficulties with dreaming and nightmares has been demonstrated to be an indicator of future mental health issues in longitudinal studies:

> a recent study based on data collected by the Avon Longitudinal Study of Parents and Children (ALSPAC) has found that 'there is a significant association between the presence of nightmares at 12 and psychotic experiences at 18' concluding that 'the presence of nightmares might be an early risk indicator for psychosis
>
> (Thompson et al. (2015).

2.9.3 Dreaming frequency, recall and distress

A theme of investigation in research into the impact of dreaming explores the links between frequency, recall and distress and how they impact upon nightmare suffering with multiple investigations trying to ascertain whether it is how the dream is recalled, the frequency of dreaming episodes or the distressing impact of the dream that it the dominant factor influencing how the dream is perceived by the individual (Duval, McDuff & Zadra, 2013; Robert & Zadra, 2008; Blagrove, Farmer & Williams, 2004).

Bielecki (1992) concluded that the distress of the event was more related to the waking adjustment of participants; of their ability to satisfactorily process the legacy of the dream. This introduced the personality type of the participant as being an influencing factor which was confirmed in a further study by Blagrove and Akehurst (2000).

Measuring nightmare frequency cam be further complicated by the measures used, in that a study by Lancee, Spoormaker, Peterse and Van den Bout (2008) concluded that there was a significant disparity between the frequency recorded in dream logs as compared with the rates recalled in retrospective questionnaires which tend to underestimate the frequency.

Whilst this study acknowledges that there is debate about the links between distress, frequency and recall, as this is a phenomenological study, it will be left to the participant to determine which of these, if any, they perceive as being a dominant factor in their dreaming experience.

2.10 Literature on dreaming specifically related to the autistic population

Whilst the focus of this study is to investigate the experience of dreaming and its impact on waking well-being rather than to investigate the content of dreams. I have included the following synopsis and discussion of the article by Daoust et al (2008), to highlight that there is a case for viewing the autistic experience of dreaming through a different lens to that of other groups; that there are differences across a range of influencing factors that have been linked to a tendency to experience a greater frequency and recall of vivid or impactful dreaming experiences.

Consideration was given to how the following academic papers where to be evaluated to ensure that there was a consistent approach. The checklists from the Critical Appraisal Skills Programme (CASP) were initially considered as a framework. However, the articles following have been published in peer reviewed journals so an element of scrutiny or validation is implied and some of the information to be gathered through the CASP checklist would not be routinely available within the article, for example 'which bibliographic databases were used?' (2018, p2). The CASP checklists were not felt to be sufficiently relevant to the research covered by these articles and so a series of questions to be used was drawn up based on the following model by Hart (2014).

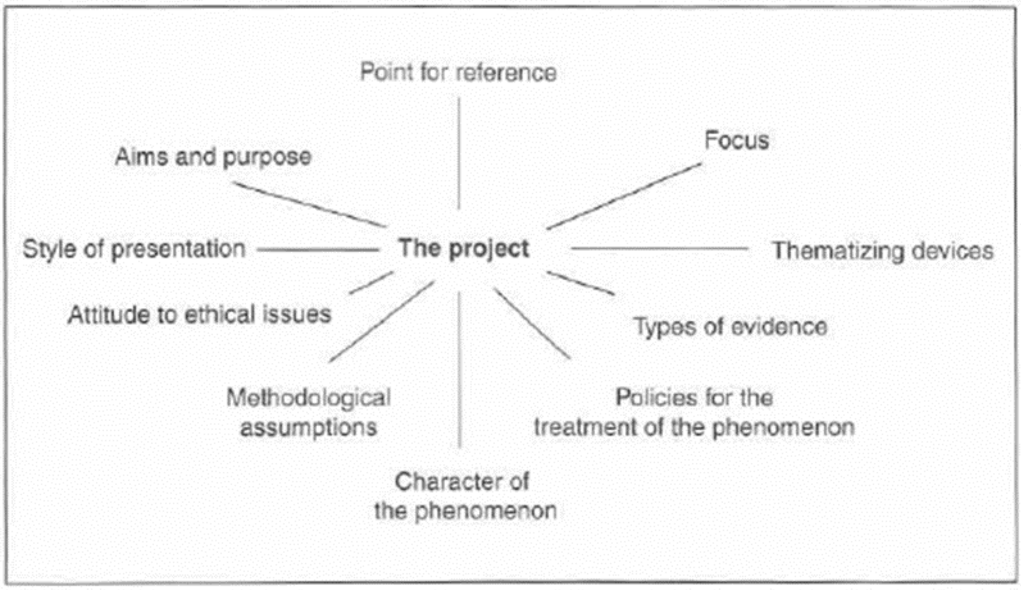


Figure 3.1 Elements for analysing the reason in research (p 56).

2.10.1 Daoust, A.-M., Lusignan, F.-A., Braun, C., Mottron, L., & Godbout, R. (2008). Dream Content Analysis in Persons with an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *38* (4).

2.10.1.1 Overview

This study analysed the dream content of young adults with autism and included a non autistic control group. Drawing on suggestions from earlier studies that dream recounts by children with autism tended to be more concrete and around actual life experiences than non-autistic controls (Craig & Baron-Cohen,1998; Godbout, Stip & Mottron,1998), the aim of the project was to use the Hall and Van de Castle coding system (1966) to analyse the content of the dreams in a laboratory setting. It was anticipated that there would be fewer social interactions and less emotional content reflected in the dreaming experiences of the autistic participants. In the introduction to the project the authors reported 'Although the literature on dreaming in ASD is scarce, qualitative and quantitative atypicalities in dream reporting are suspected' (p634).

The study recruited 28 autistic participants and a further 79 ‘typically developing’ members to the control group; smaller subsets were selected for the laboratory assessments.

Using the Hall and van de Castle’s system (1966), the dream questionnaires and reports from laboratory dream collection were analysed and the results showed that there were significant differences in the reported instances in the categories of positive emotions, settings, descriptive elements, social interactions, face elements and emotions in the data collected from the autistic and control groups. The study also showed that the autistic group reported more nightmares, recurrent dream elements and dream reality than the control group and showed a greater incidence of regularity of dream recall and of being able to recall the dream the next evening (p637).

Daoust et al. studied related conditions, specifically alexithymia and how this might influence the dream content and experience of people with autism who are understood to display more signs of alexithymia than typically developed individuals (Hill, Berthoz & Frith, 2004). Alexithymia is also thought to be a contributing factor to contentless (‘white’) dreaming reports from studies into dreaming experiences of asthmatics who are thought to have a high incidence of the presentation (Monday, Montplaisir & Malo,1987). (Although the link between asthmatics and alexithymia may be more related to the late reactions of alexithymics to asthmatic symptoms which results in more alexithymic asthmatics being detected as they experience more asthmatic crises than the non alexithymic asthmatics who detect early onset of their symptoms and take preventive action (Feldman, Lehrer & Hochron,2002).

It may be argued that, currently, there is not sufficient research into levels of alexithymia in the population as a whole to determine if certain groups categorized by neurodevelopmental or other diagnoses are more susceptible to the condition.

Daoust et al. also reported that the dream reports of people with schizophrenia featured less detail, objects and characters than the control group, but more animals than the autistic group (Chouinard et al., 2002).

The study suggested that the ways in which autistic people recounted their dreaming experiences were significantly different to controls, with the narratives being briefer and less descriptive.

2.10.1.2 Critique

The study began with the aim of investigating the frequency of ‘white dreams’, where there is no recalled content, and the emotional and socially related content of the experience of autistic participants and then appeared to broaden out with the inclusion of discussion about alexithymia, schizophrenia and asthma. It was not made apparent whether the members of the control group had been screened for alexithymia, schizophrenia or asthma.

Whilst the study was able to reach some conclusions about the dream content and make recommendations for further research, the narrative arc of the report was rather fragmented by the inclusion of issues and concerns which may have justified a study of their own. This may be a reflection of the research group undertaking the study in that the core researchers were collaborating on a series of projects with differing populations and aims. The diversion into different aspects of dream production and dream effects also reflects the potential within the overarching literature on dreaming to make connections and pursue concepts and ideas that are perhaps very different from the originally intended trajectory of a study.

2.10.1.3 Conclusion

This study, and the partner study into ‘EEG correlates of emotions of dream narratives…’ (Daoust, Lusignan, Braun, Mottron and Godbout, 2008b) is one of a number of reports relating to studies undertaken by a relatively large research team on the dreaming narratives of several non-atypical populations and suggests that there is a difference between the dream content of autistic and non-autistic groups. The study also found that there was a longer duration of recall of dreams within the autistic group and a greater tendency to experience nightmares, which confirms that there is a potential for the well-being of autistic individuals to be adversely affected by longer recall duration of an increased frequency of negative dream experiences.

In relation to this project this was a most influential paper, concluding that the dreaming content and the recall and duration of recall were substantively different for the autistic population, which supported the emerging research aim, to investigate the dreaming experiences for the autistic population and its impact upon well-being.

2.10.2 Miano, S., Bruni, O., Elia, M., Trovato, A., Smerieri, A., Verrillo, E., Roccella, M., Terzano, M., Ferri, R. (2007). Sleep in children with autistic spectrum disorder: A questionnaire and polysomnographic study. *Sleep Medicine*, *9* (1).

2.10.2.1 Overview

This study investigated the Cyclic Alternating Pattern (CAP) which is an element of sleep architecture that can influence the production of dreaming activity. The CAP is a long-term oscillation between two electroencephalogram levels of activity; phases A and B. Phase A is split into three sub phases A1, A2 and A3 and whilst A1 correlates with the beneficial effects of the CAP A2 and A3 are more related to sleep disruption and arousal. What this polysomnographic study found was that individuals with autism were more likely to have shorter phases of A1 and longer phases of A2 and A3. The study found differences in the CAP's structure between autistic and non-autistic groups.

Although there has been some research on dreaming in other stages of sleep (Oudiette et al., 2012; Cavellero, 2000), it has been identified from polysomnographic assessments that most dreaming episodes with an element of recollection are triggered during periods of rapid eye movement (Ogawa, Nittono & Hori., 2005).

The children in this study were all screened for snoring, obesity, epilepsy and all were drug-free for at least 2 weeks before the trial began. And the trial included parental questionnaires and polysomnographic assessments.

2.10.2.2 Critique

All of the children involved in this study were categorised as being ‘mentally retarded’, so the study may have concluded that children with ‘mental retardation’ have these slow wave sleep alterations in the CAP, rather than ascribing it to an autistic phenotype. However, as other studies have confirmed the slow wave sleep spindle differentness (Tessier, Lambert, Chevrierm Scherzer, Mottron & Godbout, 2013; Limoges et al., 2005; Gruber, Wise & Seibt,2016), it is probably reasonable to concur with the authors that the variances in the study were attributable to differences in autistic sleep architecture.

2.10.2.3 Conclusion

Assuming that the findings of the study are applicable to the autistic population rather than those with ‘moderate/severe mental retardation’, this is a significant study showing that the sleep architecture is demonstrably different in people with autism, providing a longer duration of phase A2 and A3 in which autistic people may experience sleep disruption and when dreaming activity occurs. This study is a further extension of research into the ways in which the mechanisms and architecture that create dream production are substantively different in people with autism. The findings of study by Miano et al., (ibid) validate the proposal for this research, in that, if the autistic population is likely to experience more dreams, then the potential for those dreams to have an impact of waking well-being will also be increased, and this requires further investigation as has been the case with other atypical populations or groups with specific conditions as discussed previously.

2.10.3 Ming, X., Sun, Y.-M., Nachajon, R., Brimacombe, M., & Walters, A. (2009). Prevalence of parasomnia in autistic children with sleep disorders. Clinical Medicine. Pediatrics, 3, 1–10.

2.10.3.1 Overview

This study investigated the historical backgrounds of children's parasomnias through parental questionnaires and narratives and then used polysomnograms to investigate patterns of REM and Non-REM sleep. This historical analysis of sleep patterns, whilst not prompting per se for experience of dreaming, did show that 21 out of 23 subjects had problems with sleep initiation and maintenance, 16/23 had parasomnias in general and that 10/18 experienced some form of partial arousal, The polysomnographic analysis revealed that the arousal levels in the autistic group were twice that of the control group and that there were significant differences in the percentage of REM sleep, periodic limb movement, REM latency and overall number of parasomnias between the groups: ‘the most important finding is that children with ASD had significantly more parasomnias than those children in non-autistic comparison group’ (ibid).

2.10.3.2 *Critique*

The children in the sample had a multiplicity of sleep associated issues including enuresis, bruxism, sleep apnea, tachycardia and periodic limb movement.

A further issue with the study were the margins of the criteria used to indicate the presence of a parasomnia: ‘it was difficult to further determine the behaviors as to which of the two subtypes of the Disorders of Partial Arousal was present, i.e. sleep terror or confusional arousals’. The difference between these two behaviours could be quite elusive and it would be interesting to replicate the study with a broader definition of dreaming such as that of Windt (2010).

The sleep laboratory part of the assessment may have affected the results as the cohorts had different ‘lights out’ and waking times. The later ‘lights out’ for the autistic group may have rather suited them if they had sleep latency issues and the actual reported duration of the latency might be under reported in the laboratory setting in comparison with how it might be at home with a more usual bedtime.

One of the limitations of the study, which is referenced by the researchers themselves, is that the participants were recruited as autistic people with sleep disorders, rather than this being as assessment of the general autistic population to see what the differences were. As this cohort already had acknowledged sleep issues the probability of finding REM disorder may have been higher in comparison to a cohort with no sleep issues.

2.10.3.3 Conclusion

The relevance of the study by Ming et al. (ibid) to this project is that it does establish a link between atypical REM cycles and autism, thus confirming the difference of the sleep mechanisms that influence dream production within the autistic population. Whilst it investigates the REM patterns of a group of autistic children, as neural plasticity remains stable in adulthood unless there is some incidence of degenerative condition (Power & Schlaggar, 2017), it may be concluded that the 'hard wiring' of the brain, in terms of sleep architecture, will not alter significantly with age and so the findings of this study may reasonably be applied to an adult group. The lack of studies into REM sleep disorder in adults is not a consequence of this study, but this lack of research into adult patterns is highlighted by it.

2.10.4 Thirumalai, S., Shubin, R., & Robinson, R. (2002). Rapid Eye Movement Sleep Behavior Disorder in Children with Autism. *Journal of Child Neurology*, *17*(3).

2.10.4.1 Overview

Thirumalai et al. used a polysomnographic study to identify sleep disorders in a group of 11 children with autism to investigate how sleep quantity and quality might be being degraded. The research found abnormal patterns of REM or REM Sleep Behaviour Disorder (REM SBD) in the cohort of children, whose parents 'complained that their child's sleep was disrupted with frequent awakenings, with 'bad days' often following poor sleep at night' (p173). The study showed that almost half of the participants had REM sleep behaviour disorder which frequently presents as night terrors with full or partial arousals from sleep and the way in which the individual awakes can be quite violent, often involving screaming and physical movement. For the sleeper these episodes are mostly amnesiac, although they can be distressing to witness. The findings where that just over 45% of the cohort (5 out of 11 children) met the study's criteria for REM SBD in contrast to general population prevalence rates of 19% for neurotypical individuals (Thomas, Bonanni & Onofri, 2007).

Lack of further and more extensive research into this disorder is particularly startling given Thirumalai's abstract comments 'Since REM sleep behaviour disorder typically affects elderly males with neurodegenerative disease, this phenomenon in autistic children could have profound implications for our understanding of the neurochemical and neurophysiologic bases of autism'.

This polysomnographic study also identified obstructive sleep apnea and higher than usual rates of periodic limb movement and bruxism amongst the study cohort.

2.10.4.2 Critique

The study itself appears to have the straightforward aim to undertake s polysomnographic study into the brain activity of sleeping autistic children and it did find that REM behaviour disorder was more prevalent in the cohort.

However, the description how the research was undertaken reveals some rather unsettling aspects, such as a preparedness to use sedatives on the participating children:

> Parents attended the studies to comfort their children and put them to sleep, allowing us to avoid the use of sedatives

of adults overriding the preferences of the children, albeit whilst they were asleep:

> We placed electrodes with collodion gel after sleep onset especially in those children who were hypersensitive to touch. Several children pulled out their leads which our technicians replaced, in some cases more than once

of children being too distressed to fall asleep:

> most of the recordings were terminated early when patients, during a possible physiologic awakening, were confused by the strange environment and unable to return to sleep

and of a significant number of aborted and withdrawn participants

> an additional three studies were aborted because of lack of patient cooperation, and the parents of four patients evaluated in clinic refused further work-up, including nocturnal polysomnography.

These issues suggest that the design of the project had failed to anticipate the sensory sensitivities of the participants and that there had been little contingency planning. Given the small number of children being observed, it might have been more fruitful if the polysomnographic assessments had been undertaken in the young person's home rather than in the clinic setting. The relatively large number of participants (around 22%) who had passed through the recruitment and then the evaluation phase and then withdrew, suggests that, either the recruitment information was not sufficiently detailed so that they understood what would happen during the assessment, or that there was some unexpected revelation during the evaluation which led them to withdraw from the study and *refuse* to continue.

2.10.4.3 Conclusion

This was another study which made recommendations for further research which do not seem to have been followed up:

> Rapid eye movement sleep behaviour disorder is accepted to be a premorbid marker for Lewy body disease [a sub type of dementia], and has been linked to degenerative conditions such as Alzheimer's dementia and Parkinson's disease.

The study was not just an investigation into sleep disruptors on autism, the further part of the study was to assess the use of clonazepam, a benzodiazepine type of drug, concluding that this 'treatment of REM sleep behaviour disorder resulted in sleep that was no longer disrupted, benefiting the child and, perhaps to an even greater extent, the family'.

The article's use of language and disposition to those participating is very indicative of the medical model of disability discussed in Chapter 1, which was perhaps more prevalent in 2002 when the article was published and is congruent with the aims of the funding partner of the research; 'We thank CAN (Cure Autism Now) for a grant providing partial financial support for this project'.

In terms of this project, the research by Thirumalai et al. (ibid) does confirm the difference in the sleep architecture in the autistic population, and that it is different in such a way as to generate more opportunities for the individual to experience dreaming,

2.10.5 Godbout, R., Bergeron, C., Stip, E., & Mottron, L. (1998). A Laboratory Study of Sleep and Dreaming in a Case of Asperger's Syndrome. *Dreaming*, *8* (2).

2.10.5.1 Overview

This study was the 'first laboratory investigation of sleep organization and dream recall in a patient with AS' (p76) and 8 neurotypical controls. The study recognised issues around low density of sleep spindles and shorter slow wave sleep. The patient (F.I) was a 25 year old man who had been diagnosed with Asperger's syndrome at age 25.

2.10.5.2 Critique

Given that the singular Aspergian subject 'was also diagnosed with hypoparathyroidism and Fahr's disease' (p82), it may be problematic to generalise a lack of dream recall ability in the Aspergian population from this study. The authors do spend some time in explaining their rationale for proposing that the hypoparathyroidism and Fahr's disease have not adversely affected the study, but given that there is only one autistic participant in the project, it is perhaps an unexpected complication that the individual has this co-existing combination of conditions.

This choice of this particular singular Aspergian participant is perhaps more complicated given that he was subject to a variety of assessments from age 9, including EEG recordings, psychometric testing (twice), a referral to a psychologist, chromosomal testing, and a psychiatric assessment at age 24 appears to have triggered the assessment for autism with the diagnosis of Asperger's being made at age 25. It may be concluded that the presentations of this young person were perhaps not clearly indicative of autism during the 16 years from the initial neurological evaluation to the diagnostic outcome; the

Fahr's disease was diagnosed following the autism diagnosis and so could not have been positioned as a differential diagnosis which may have explained why autism was not suggested sooner. It may be that the autism diagnostic pathway was not well-established or that parents did not wish to pursue an assessment, however the recruitment of this particular Aspergian participant does not appear rigorous given their assessment history and other medical conditions.

Interestingly, the control group criteria included individuals with the same handedness or hemispheric preference as the Aspergian subject, although there is no explanation for this criterion or if it was accidental or planned. Handedness links to the extreme right brain theory of autism (Baron-Cohen, 2002) and is associated with both a propensity to recall the dreaming experience with right- and mixed-handed individuals reporting more dreams than left-handed participants (Schredl, Beaton, Henley-Einion & Blagrove, 2014).

2.10.5.3 Conclusion

The significance of Godbout's findings to this study are that it concluded that there were differences in the sleep architecture of the Aspergian subject in comparison with the control group and these findings were confirmed in other studies including those cited previously. The study by Godbout et al. suggested that, whilst there were elevated periods of brain activity, that these did not reveal themselves in dream recall. Overall, the recruitment of and number of autistic participants in this study is such that it is not possible to generalise any of its findings, but it is a useful contribution to the discussion about autistic differences in sleep architecture.

2.10.6 Conclusions relating to the autism specific articles above

Interestingly, were the above studies required polysomnographic input, this was always undertaken in a laboratory. Young people who may not respond well to change in environment, routine and sensory familiarity were observed in settings that would have been very different to what they were used to at home. The artificial nature of the setting for the polysomnographic tests and their impact upon participants is not discussed in any of the reports. Perhaps for any young person the novelty of sleeping in a clinical setting with unfamiliar adults, even if the settings were sympathetically dressed and parents could be present, would be unsettling, but the further potential impact upon the autistic members of the group is not referenced in the discussion of findings and limitations of the studies.

An overarching issue with the studies is that they appear to try to be very prescriptive about definitions and criteria without perhaps considering the practical consequences of this precision; in the paper by Ming et al. (2009), Partial Arousal had 3 subtypes: sleep terror, confusional arousal and sleep walking, obviously sleep walking would merit a category on its own but there is a potential overlap between sleep terror and confusional arousal and from a practical perspective it may not serve any purpose to the experiment to maintain the two categories.

Overall in reviewing these articles there was some discomfort about the terminology, some of the methods used and the intentions or aims of the studies, especially in the case of the study by Thirumalai et al.

The studies all refer to either children of young adults and all recommend that there should be further research in the field; echoing the findings of Pellicano, Dinsmore and Charman (2014) that there should be more research into adult autism and more longitudinal studies.

The articles above all suggested that there were some ways in which dreaming or dream production were different in an autistic cohort to the predominant neurotype cohort. That is the relevance that they have in terms of this study in that they demonstrate a difference that requires further investigation.

2.12 Autistic participants in phenomenological studies and other areas of research

There are only a limited number of qualitative research studies, especially those involving phenomenological methodologies that involve the autistic population. This population has been traditionally researched qualitatively through seeking the views of parents and carers and practitioners rather than obtaining first person narratives. Newman, Cashin and Waters (2010) and Kirby et al. (2015) refer to the paucity of studies involving children with autism; 'First person perspectives of children are widely absent from empirical investigations of their experiences, especially when the child has a disability'. It may be as Kirby et al. comment that first-person perspectives 'may not be valued or taken seriously due to a lessened social stance related to being... people with disabilities' (2015, p317). Whilst there is a limited range of first person perspectives from adults on the spectrum (Miller et al., 2008; Hurlbutt & Chalmers, 2002), there is however a high incidence of autistic individuals reporting their life experiences and emotional responses in books (Grandin, 2008; Tammet, 2006) and blogs (for example Musings of and Aspie and Purple Ella) and there appear to be an interest in these perspectives, judging from the sales and viewing data.

Kirby et al. suggest that being associated with a disability in some way lessens the validity of the response or participation in the research; they also suggest that there are factors specifically associated with the autism diagnostic criteria which make engaging this population problematic, that 'in particular, deficits in social skills and communication as well as restricted and repetitive interests ... make daunting the prospect of interviewing this population' (2015, p317).

Research with autistic participants is moving from this ‘normalising’ process to one which is more fully participatory and inclusive (Klein, 2002).

Research that engages directly with the autistic population as opposed to parents and practitioners is not widespread, whilst there are some phenomenologically based studies that have autistic participants, for example, Beteta, 2009 (lived experiences of adolescent females with Asperger Syndrome); Stewart, 2010 (experiences of girls with Asperger’s syndrome and anxiety, and Western Herbal Medicine); Schwaerzler, 2012 (autism and the experience of closeness), these comprise only a small proportion of autism studies.

2.13 Issues with diagnosis and recruitment to autistic research projects

There has been a tradition within the community of ‘self-identifying with a label of’ (Linton, 2014) but in recent years this has been challenged by some people including many of those who associate with #actuallyautistic. #actuallyautistic was originally introduced to discourage neurotypical people from flooding the autism thread on social media with what were seen as unhelpful perspectives on what it is like to be autistic. The hashtag enables a group of like-minded individuals to locate each other on digital platforms

Whilst associating with a label of may be a comfortable process for adults who have capacity, it may be a more complex process for children and teenagers, and there could safeguarding issues if parents were presenting a child as being identified as autistic if there was no clinically recognised diagnosis in place, and there would be issues about the age at which it might be appropriate for an individual to self-identify with a label of.

Diagnostic service pathways have become more established and clearer overall in the last 20 years, at least in terms of children and young people’s services, but overall are still struggling to meet demands for assessments. Adult pathways are often less clear and there is also the issue of thresholds for referrals and intervention; there needs to be a concern or problematic behaviour for a case to escalate to a diagnostic process, so in instances where an individual may have a passive presentation or may be expert in masking in their public life then they may not meet the threshold to initiate a diagnostic assessment and, in an era of austerity and responsibilities to the public purse, being curious about where someone may or may not be on the spectrum is usually not sufficient to secure access to a diagnostic service (Crane et al., 2018). Private diagnoses vary in price from around £500 to £2000 and these amounts can be prohibitive for many individuals.

There are issues around who authors the diagnostic criteria and administers the assessments and concerns have been raised that the autistic community have not been allowed to participate in wider discussions around what it is to have autism and what criteria should be used to formulate who does or does not receive a diagnosis (Attwood, 1999). There are many people who can be a ‘near miss’ on the diagnostic threshold and then life circumstances change and the alteration in behaviours would meet criteria, for example a child in a small nurturing village primary moving to a very much larger secondary school with far greater expectations regarding independence and organizational skills.

At a Conference in Birmingham in 2016, Tony Attwood suggested to the audience that people who are diagnosed as children should be re-assessed as young adults to see if they would still meet the criteria and that a diagnosis should be withdrawn if they did not. However, there may be misunderstandings around perceived levels of ‘functioning’; a person’s learnt ability to perform in accordance with society’s expectations may appear to be ‘normal’ and this might not be indicative of an inner autistic state that is experiencing high levels of anxiety, or, as with the example of the primary aged child above, the person may be coping in a very supported situation which, if disrupted, may have an adverse effect upon their well-being and trigger other presentations.

One of the aims of research is that it should be replicable, that another researcher of group of researchers should be able to undertake the same study using the same methods and accessing a similar group or participants and produce results that are comparable to the original (Luca & Brent, 2013). In terms of gaining ethical approval for a project, this may mean that researchers are more inclined to use a clinical diagnosis as a criteria for participation so that the replicability of recruitment may be assured. In terms of this study, participants were sked to confirm that they had a diagnosis of autism.

2.14 Critical Autism Studies

> In the history of autism studies, expertise has been claimed by many differing academic schools of thought, practitioners, parents, quacks and so on. Yet, the one voice that has been traditionally silenced within the field is that of autistic people themselves
> (Milton, 2014).

The timeline of autism related milestones and themes of discourse discussed in the introductory chapter show how autism and autistic people are moving away from the disability model towards a more participatory and emancipatory social model.

Critical autism studies (CAS) is a relatively new field of scholarly activity which shares and reflects these developments within emerging networks of autism advocacy and self-advocacy (O’Dell et al, 2013). The ethos of groups such as PARC, Autistica, CRAE, ANI, and CAN are concepts arising from and shaping the dialogue around CAS,

A central the of CAS is the work of Ian Hacking a Canadian philosopher who developed the concept of looping ‘that the classifications and categories we use to define populations – in this case, autistic people – transform not only the categories but also the populations so defined’ (Davidson & Orsini, 2013, p4)

Tanya Breen summarises the 10 steps of Hacking looping process as follows:

- counting, when the focus is on identifying how many people fit into the category
- quantifying, which focuses on developing or changing diagnostic criteria
- norming, against which categorised people are measured
- correlating, when even unrelated factors are correlated with the category
- medicalising, when the labelled people are defined as ill or disordered
- biologising, the search for biological causes
- geneticising, the search for genetic explanations
- normalisation, implementing treatments and interventions designed to make the categories people as normal as possible
- bureaucratising, consisting of state implemented systematic strategies of diagnostic surveillance and intervention
- the final stage of resisting, when the people who are classified reclaim control back from the experts and institutions, and in doing so sometimes create new experts and institutions

(Breen, 2017)

The third critical autism studies conference was held in London in June 2017, with a theme of “Travelling Through Autistic Worlds in Policy, Practice and Identities”. Interestingly in the Book of Abstracts for this conference there are several presenters using the term (Autism Spectrum *Disorder* (Accessed via www2.le.ac.uk/departments/psychology/research/child-mental-health), and using this particularly clinical reference seems to be a contradiction to the overarching narrative of regarding the rejection of the medical model of autism in which the individual is disadvantaged and replacing it with the social model which seeks to overcome the social barriers that do not support equality or promote concept of ableness:

> the formation of a pathological identity is a recursive process, which involves a narrowing of the repertoire of available narratives and the dominance of problem-saturated meanings, which are typically associated with the medical discourse
>
> (Avdi, 2005 p495).

Critical autism studies supports the creation of debate and research that is exceptionally dynamic and reflectively produced. Participatory research is a major theme of CAS aimed at overcoming the 'lack of interactional expertise between researchers and autistic people and a breakdown in trust and communication' (Milton, 2012b) which has led to an increase in tension between stakeholder groups (Milton, 2011). The new emerging direction of development of theory and practice is orientated towards a legitimisation of the speech of 'autistic persons as active and demanding rather than passive and submissive' (Charmak, 2008).

In terms of the following methodology this shows that autism is not an entity, a thing in itself but that its ontological status is contested by stakeholders. The autistic voice itself is contextualised in the negotiated territory between individuals whose experiences of autism are influenced by so many variables, it manifests from individuals who are influenced by their comorbidities, how they are associated with a diagnostic label and their own experiences of living in the world (Davidson & Orsini, 2013).

> Accepting an autistic identity is crucial for mental wellbeing. I don't mean that once you accept the identity everything is immediately going to be perfect, but it does allow for improvement and self-confidence. It helps you understand who you are and how you experience the world. If you are constantly fighting against that aspect of your identity, it makes it very difficult to progress because you are essentially at war with yourself, rather than utilising your strengths and being kind to yourself with and accepting of your difficulties. Since discovering I was autistic, I have been much more gentle with myself when I struggle, reminding myself that it's OK if I don't feel able to cope with somewhere with multiple background noises, that it's OK to request that people are clear and direct rather than dropping hints (because I cannot pick up on hints, ever!), etc. But also, I have come to recognise my strengths and utilise those.
>
> Katherine Lawrence in the blog Autism and Identity 31.05.2018.

2.15 Conclusion

The literature review for this project has found research that shows that there are measurable and now well documented differences in the sleep architecture of people with autism, and that the differences in this architecture are in key areas that stimulate dreaming activity and recall, and yet only the Daoust et al. research has sought to study what this means in terms of the dreams produced by the atypical architecture. Daoust et al. showed significantly different dream content within the autistic group, not only in comparison to the neurotypical control group but also in terms of other non-neurotypical and non-autistic groups (schizophrenics and people with alexithymia).

Studies into dreaming have been undertaken with various other groups; in the case of research into dreaming and anorexia this has helped to produce and scaffold various therapeutic interventions, for other groups, reviewing dream patterns can be an indicator of symptom severity as in the case of post natal depression and multiple sclerosis.

One interesting, if somewhat complicating factor with regards to the Literature Review, is the pace at which autism related studies and articles are being published. The Literature Review for this thesis was one of the first activities started for the project and completing this chapter to reflect these new studies meant that it was the last to be completed.

The literature review has been more of a process of constructing a frame around a gap in current research than about developing an existing body of theory or extending a previous study. In looking at each of these areas:

- why quality sleep is universally important and how it can be impaired?
- what we understand about the sleep profile of autistic people?
- a general overview of dreaming research definitions, models of dream production, function and effect
- research undertaken around the dreaming processes of an autistic population

- why it is important to explore any challenges that a dreaming experience might pose to a population that may be compromised by societal norms and disadvantaged by responses to it ‘differentness’?
- how dreaming has been studied to promote understanding of other atypical or loosely affiliated groups.

and, in conjunction with the anecdotal evidence collected from online blogs and forums and discussion with families and people affected by dreaming, it has been possible to construct the frame for the research area; to investigate the dreaming experiences of people with autism and the effects it has upon waking wellbeing.

In order to gather these intensely personal accounts, the research design will involve speaking to autistic people and so, as the focus is to engage with the population as seamlessly as possible and to produce a piece of work with an inclusive ethos which removes barriers to participation together with a methodology that is sufficiently flexible and pragmatic to facilitate this.

Whilst there is a concept of the aims of the research and how it is envisaged the data will be collected to meet those aims, this will be reflected upon and can be amended during the course of the project with

> 1. Careful attention to how power relations shape the field of autism
>
> 2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture;
>
> and
>
> 3. Commitment to develop new analytical frameworks using inclusive and non-reductive methodological and theoretical approaches to study the nature and culture of autism. The interdisciplinary (particularly social sciences and humanities) research required demands sensitivity to the kaleidoscopic complexity of this highly individualised, relational (dis)order
>
> (Davidson & Orsini, 2013, p12).

The research design and methodology will be discussed in greater detail in the following chapter.

Chapter 3 Methodology

3.1 Introduction

This Chapter is divided into three sections:

Part I: The basics of methodology commencing with identifying an appropriate research design

Part 2 The philosophical underpinning of the study

Part 3 How the research design was implemented in practice.

3.2 Part 1 The basics of methodology commencing with identifying an appropriate research design

1. What is the social reality of the phenomena to be investigated? (i.e. the ontology)
2. What might represent knowledge or evidence of the social reality to be investigated? (i.e. the epistemology)
3. What broad area of research is the research concerned with?
4. What is the intellectual puzzle and the specific questions to be explored?
5. What, and for whom, is the purpose of the research?

Table 3.1: Mason’s five questions to generate an effective research design (adapted from Mason 2002, pp.13-18.

3.2.1 Methodological approach

Components of the methodological approach adopted within this study will be discussed in greater detail but can be generally conceptualised in the following diagrammatic representation adapted from Grix (2002):

(ontology)
Constructivist

(Epistemology)
Interpretivism

(Theoretical perspectives)
Phenomenology – Hermeneutics – Iterative

(Methodology)
Thematic Analysis

(method)
structured interviews, on line survey

(sources)
Survey data, interview transcripts

3.2.2 Ontological Perspective

Ontology is a study concerned with the nature of being; 'to what exists in the world, to the nature of reality' (Punch, 1998, p170) and is either objectivist and positivist or subjective and constructivist depending on the researcher’s Weltanshauung or worldview (Heidegger, 1927/1962).

This project is ontologically grounded in subjective constructivism which has developed from phenomenology. Constructivists understand that knowledge/reality is local and specific and that it can vary between groups of individuals (Guba & Lincoln, 1994). In this perspective, knowledge is constructed by humans through intentional interaction with the world, rather than existing in some form waiting to be happened upon or discovered (Burr, 2003). With constructivism, and in contrast to objectivist positivism, building knowledge structures is a social activity which is influenced by communication and culture (Berger & Luckmann, 1966). It is a paradigm in which 'social phenomena and their meaning are continually being accomplished by social actors' (Bryman, 2001, p18).

'This approach is not particularly theory-orientated; the focus is rather on the 'disclosure' of how social phenomena are socially constructed' (Alvesson & Skoldberg, 2000, p15). Within this school of thought, knowledge is understood to be socially constructed and transmitted not only between individuals and groups but also between generations as traditions (Gergen, 1995). Sense-making in constructivism involves the actor being influenced by the local knowledge/reality at the same time as their actions of local sense-making are influencing the local knowledge/reality, making it a hermeneutic process (Guba & Lincoln, 1994).

3.2.3 Epistemological perspective

Epistemology is philosophically linked to ontology and is concerned with how an individual knows what they know and what methods there are for gaining an understanding of knowledge. The interpretivist view of this process is that it is essentially a subjective one in which a general overview and determination by laws of science and nature are replaced by the influence of values and bias in actions (Myers, 2008). In order to understand the rationale of actions, interpretivist studies usually focus on meaning and may use multiple methods to produce empathetic and qualitative data through which to explain activity (Collins, 2010). Epistemologically, the interpretivist interest is not only in the experience but also in the context and the dynamic of how it evolves and is conveyed, and this links into the hermeneutic traditions of phenomenology where the central concept of 'dasein' (being in the world) is 'relatedness' (Heidegger,1927/1962).

Crotty, (1998) does not specify a particular epistemological area within the methodological continuum, but rather amalgamates this into the ontological perspective of the process and the Grix model shown earlier can be seen as representing a spectrum rather than discrete areas. Crotty's assumption that a particular ontological position will segue into a corresponding epistemological position is possible because it is a continuum and the assumption can be extrapolated across other areas as the processes inform and shape each other. For example, it would be unlikely that a positivist objectivist ontological position would produce a phenomenological theoretical perspective.

An interpretivist epistemology requires a flexible and personal research structure so that the interaction between the researcher and the participants can develop. A fixed research design would not be philosophically congruent with a view that the multiple, complex, hermeneutic construction of reality is taking place through an interpretative process (Hudson & Ozanne, 1988).

3.2.4 The broad area for study

Mason's (2002) third question requires that the broad area of inquiry should be an extension of the ontological and research position of the researcher, and this project builds upon and extends knowledge acquired by the researcher during previous academic studies.

3.2.5 The intellectual puzzle

The response to Mason's (ibid) fourth question is the formulation of the specific research questions for the project:

1 How do people with autism perceive their dreaming experience?

2 How do people with autism think that dreaming affects their well-being?

3 What adaptations have people with autism made to their dreaming

experiences?

3.2.6 What and for whom is the purpose of the study?

In response to the fifth question that Mason poses, the purpose of the study is to potentially highlight the knowledge and practice gap around autism and dreaming. It may be that the implications of the study, as opposed to the conclusions, can be further developed in future research projects to offer more defined ways forward than those conclusions and findings that may be derived from this relatively small sample project. The study aims to facilitate greater understanding of the issues around autism and dreaming and so to contribute to understanding causes and effects. It may be of interest to individuals and practitioners wishing to find out more about how to mitigate against any negative experiences arising from dreaming or for those with a more general interest in the subject.

3.3 Part 2 The philosophical underpinning of the study

This section will detail the philosophical underpinnings of the study and will review the selection of the chosen methodology and discussion of alternatives.

3.3.1 Definitions of phenomenology

The term phenomenology was first used by Lambert in 1764 to mean 'the theory of appearance fundamental to all empirical knowledge’ (Cairns, 1958, P231), and can have philosophical and non-philosophical associations. Phenomenology is the study of how people experience some phenomena and what sense or interpretation they make of their experiences. Broadly;

> that it is a theoretical point of view advocating the study of individuals' experiences because human behaviour is determined by the phenomena of experience rather than

> the objective, physically described reality that is external to the individual
>
> (Sloan & Bowe, 2014, p2).

'Phenomenology has been conceptualised as a philosophy, a research method and an overarching perspective from which all qualitative research is sourced' (Kafle, 2011, p182). Phenomenology seeks to understand how people construct meaning and is either descriptive or interpretative. Husserl’s phenomenology, which historically precedes that of Martin Heidegger, is a descriptive phenomenology and is also known as transcendental phenomenology or pure phenomenology. Heidegger's development of phenomenology was to extend the interpretivist element moving from a transcendental to an existentialist approach; it is also known as hermeneutic phenomenology (Langdridge, 2007).

3.3.2 Phenomenology (theoretical perspectives)

Crotty defines the theoretical perspective of the research as 'the philosophical stance informing the methodology' (1998, p3); it develops the positions outlined in the ontology and epistemology and uses them to inform how the research methodologies and methods will evolve (although Crotty himself conflated ontology and epistemology with the rationale that a particular view of one would imply a corresponding view in the other). Taking into account the constructivist ontological and interpretivist epistemological positions, the purpose of the research and the research questions, this study will adopt a phenomenological theoretical perspective to inform methodology and method choice.

Van Manen, suggests that a phenomenological approach is particularly useful when a phenomenon of interest has been inadequately defined or conceptualised or when the nature of the issue is suspected but not demonstrated by preceding research (1990). In such cases a phenomenological study will provide qualitative data which further studies may develop using appropriate methodologies. In relation to investigating how people with autism experience dreaming and the impact that this has upon their waking states, there are suggestions, arising from initial evidence gathering and from research such as that of Daoust, Lusignan, Braun, Mottron and Godbout (2008), that there may be some form of difference in how people with autism experience dreaming that might be clarified through a phenomenologically informed evaluation of the issues and their interrelationships.

In the phenomenological process, 'the external world is shown to be an artefact of consciousness; phenomena are shown to be willed into existence through intentional acts. Man is shown to live in a world created through consciousness' (Burrell & Morgan, 1979, p233). Whilst there are a number of schools of thought within the overarching canopy of phenomenology, the three main types are Realist, Transcendental and Existential Phenomenology; however, these are united by a shared preoccupation with method to elucidate the appearance of phenomena and how the phenomena are presented.

Phenomenology uses a particular set of methods and analysis which are essentially descriptive. There are different types of methods but these are not significantly diverse with the exception of the treatment of bracketing or epoche which is treated very differently between the Husserlian transcendental phenomenology and the existentialist traditions. Epoche assumes that it is possible to overcome or go beyond one’s own values and beliefs by bracketing these values and beliefs off into some corner of existence and putting them beyond the process of reading and interpreting the narratives. The Heideggerian school of thought is that this process is redundant from the start, that it cannot be achieved; how can we thoroughly understand and recognise the manifestations of our beliefs and values in our world? Heidegger did not simply dismiss the concept of bracketing but rather his response was to view the issue from the being-in-the-world perspective to recognise the part that beliefs and values play upon interpretation in an existentialist way.

3.3.3 The Historical context

The First World War was the culmination of a period of transformation in Europe which had seen the creation of the nation states of Germany and Italy, an increase in colonial influence and economic and industrial expansion. These political alterations impacted on cultural and philosophical values and as Eagleton comments on the end of World War One (1914 –1918):

> The social order of European capitalism had been shaken to its roots by the carnage of the war and its turbulent aftermath. The ideologies on which that order had customarily depended, the cultural values by which it ruled, were also in deep turmoil. Science seemed to have dwindled to a sterile positivism, a myopic obsession with the categorizing of facts; philosophy appeared torn between such positivism on the one hand, and an indefensible subjectivism on the other; forms of relativism and irrationalism were rampant, and art reflected this bewildering loss of bearings. In the context of this ideological crisis, the German philosopher, Edmund Husserl (1859 – 1938), sought to develop a new philosophical method which would lend absolute certainty to a disintegrating civilization
>
> (Eagleton, 1983, p54).

The history of the personalities and schisms between them within phenomenological movement has in some respects overshadowed the development of the philosophy and methodology. Although Merleau-Ponty (Phénoménologie de la perception, 1945) has attempted to in some way reconcile the views of Husserl and Heidegger, or at least to re-interpret Husserl's epoche to reveal it as being more in line with the existentialist tradition, for the first 50 years phenomenology was characterised by the Heidegger-Husserl rift and Martin Heidegger's notorious association with the Nazi party of Germany. In order to fully understand the typologies of phenomenology one needs to understand the historical context and interactions of its early proponents.

3.3.4 Husserl

Husserl (1859 - 1938) is suggested as being the 'father' of the philosophical movement known as phenomenology. Husserl studied mathematics and his interest in philosophy developed from a scholarly interest in mathematical philosophy which accelerated when he returned to Vienna and came under the influence of Franz Brentano, who developed the concept of psychognosy based on concepts of intentionality and classifying psychical phenomena (Morrison, 1970). He became an Associate Professor at the University in Gottingen where he lived and wrote several significant works in the period 1901 to 1913 assisted by Edith Stein. Around 1907 Husserl became greatly, if somewhat reluctantly, influential around the Gottingen or Munich Circle of phenomenology which included amongst others Roman Ingarden, Kurt Stavenhagen, and Edith Stein, although the Munich circle of phenomenologists eventually distanced themselves from Husserl's transcendental phenomenology.

In 1916, Husserl moved to the University at Freiburg and Martin Heidegger became his assistant. At first Heidegger was exceptionally influenced by Husserl but the relationship was to become hostile as their philosophical positions diverged and through Heidegger's flirtation with Nazism. In a Germany becoming increasing dominated by Hitler and the National Socialist Party, the Jewish Husserl was to become increasingly isolated before his death in 1938.

Husserl sought to use phenomenology to develop scientific enquiry, publishing his first work ‘Philosophie der Arithmetik’ in 1891 so beginning his prolific writing career, producing a vast catalogue of written work, research papers, lectures and articles before his death. In 1913, Husserl introduced the concept of Phenomenology in his book 'Ideas: A General Introduction to Pure Phenomenology' (Ideen zu einer reinen Phänomenologie und phänomenologischen Philosophie. Erstes Buch: Allgemeine Einführung in die reine Phänomenologie (Ideas). The Logical Investigations (Logische Untersuchungens), (2001) revealed the new method for studying consciousness the aim of which 'was to explore the intentional structures involved in our perception, thinking, judging, etc', (Zahavi, 2007, p667).

Husserl believed that his work was a lifelong experiment with phenomenological thinking and that the only thing that he was writing was an introduction to phenomenology, or investigations into preliminary problems with phenomenology rather than developing the philosophy of the entire subject. Husserl’s phenomenology is descriptive, it aims to discover the essence of the things by a process of epoche, of the bracketing aside of the beliefs and values of the researcher so that they do not contaminate the process. Husserl was motivated to find the relations between the consciousness and objects of knowledge - 'the things themselves' (zu den Sachen selbst) (Logical Investigations, 2001, p168). This cognitive relation of the way in which humans interpret and interact with their world was paramount for Husserl’s phenomenology.

3.3.5 Central themes and concepts in the Husserlian tradition of phenomenology.

3.3.5.1 *The Natural Attitude*

Essentially, the natural attitude is the way in which individuals perceive the world as being made up of objects, people and ideas that simply are and for the most part exist unquestioned in our lives. People look around and see the world without giving thought to all the elements that comprise it and this is what Husserl referred to as the natural attitude developed in 'Ideas Pertaining to a pure phenomenological philosophy: first book, general introduction to a pure phenomenology' (1982).

However, in this work Husserl goes on to write that objects have a being that is reliant upon the perception of an other;

> It is not merely an individual object as such, a ‘This here,’ an object never repeatable; as qualitied ‘*in itself*‘ thus and so, it has its o*wn specific character*, its stock of *essential* predicables which must belong to it…if other, secondary, relative determinations can belong to it.
>
> (Husserl, 1982, p7-8).

It is not phenomenologically possible to have a sense of the world without self-involvement; we interact with the world constantly and with almost unconscious reflection and internal dialogue about those interactions; the world is not separate from our being; we are always implicated in it and vice versa. For Husserl there is a difference between almost passively accepting through the natural attitude the world that which we encounter and intentionally phenomenologizing:

> Seeing the car passing by outside, thinking about who might be driving it, wishing we could have a car like it, later remembering the car going by, even wishing that a car would go by when it had not done so - these are all activities happening in the everyday, natural attitude. Once we stop to self consciously reflect on any of

> this seeing, thinking, remembering and wishing, we are being phenomenological
>
> (Smith, Flower & Larkin, 2009, p13).

3.3.5.2 Intentionality

Intentionality is the inverse of the natural attitude. Intentionality is related to a transitive verb, that is to say that someone would intend upon an object or to an intangible or abstract concept (Sokolowski, 2000). An empty intention would be when someone notices an absence of an expected thing rather than presence of something. Intentionality is a central theme in Husserl's works and is developed in Logical Investigations (1973) *Logische Untersuchungen. Erster Teil: Prolegomena zur reinen Logik* 1, (1900) and *Logische Untersuchungen. Zweiter Teil: Untersuchungen zur Phänomenologie und Theorie der Erkenntnis 2* (1901) and in 'Ideas pertaining to a pure phenomenology and to a phenomenological philosophy ' (1913).

Franz Brentano (1838 - 1917), Husserl's mentor, had previously developed his interpretation of intentionality within his work on the philosophy of psychology. Essentially Brentano saw intentionality as the act of presentation and the response that it elicited without the actual thing:

> Every mental phenomenon is characterized by what the Scholastics of the Middle Ages called the intentional (or mental) inexistence of an object, and what we might call, though not wholly unambiguously, reference to a content, direction toward an object (which is not to be understood here as meaning a thing), or immanent objectivity. Every mental phenomenon includes something as object within itself...
>
> (Brentano, 1995, p88).

For Husserl, intentionality is made up of three elements: the actual thing, the act of presentation and what is presented. For Husserl there is a difference between what appears and the appearance of what appears; the what appears is constant and immanent and the appearance of what appears can change between human beings and is transcendental. The appearance of what appears can be affected by the act of intention: 'Husserl's interest is in those mental states or experiences that do give us a sense of an object, and those mental phenomena are intentional; he calls them “acts” of consciousness' however there are unconscious values, motivators and beliefs which are now widely accepted as informing our intentionality (McIntyre & Woodruff Smith,1989, p2).

3.3.5.3 *Reduction and epoche or bracketing*

Reduction is the thematization of the relation between the issue and the experiences around it, it is the process through which the researcher detaches from the natural attitude and assumes intentionality. Husserl referred to phenomenological, philosophical, psychological, eidetic, transcendental, ethical, and intersubjective reductions in the sense that these are the attitudes through which the reduction can take place (Kockelmans, 1967).

Epoche or bracketing is the counterpart to reduction, as the researcher promotes the reduction, through epoche the researcher 'reduces' empirical reality:

> General thesis of belief in factual existence characteristic of the natural attitude is inhibited, suspended, bracketed…or turned off, and which uncovers in transcendental subjectivity the acts which constitute pure phenomena.
>
> (Spiegelberg, 1965, p724).

Epoche leads to a co-subjectivity (mitsubjectivitat) as it is impossible to have a sense of 'I-ness' without a sense of 'you-ness'. In Ideas (Vol 1, 1973), Husserl develops the theme of reduction as a way that the researcher can recognise their embeddedness in intersubjectivity; through a setting aside of questions about the real existence of objects or experience, the researcher can fully focus on the study of the first-person narrative of the experience:

> Performing the [psychological] reduction upon himself, the psychologist, in analysing his own conscious life, becomes aware of its relationship to and connectedness with, the conscious life of other persons…in his very experience of himself as human being are implied references to other

> human beings, to an open horizon of humanity…and co-subjectivity (*Mitsubjectivität*). Experience of oneself proves to be inseparable from that of others.
>
> (Gurwutsch, 1966, p443).

Husserl introduced the concepts of noesis and noema in Ideas and Logical Investigations and in doing so gave another description of the way of seeing the objects and the intentional act that sees the objects as meant. The noema is that which is experienced and the noesis is the way that it is experienced. The noema and noesis could be described as being what is left of the subject and object after the methodological process of the reduction. The noesis is part of every intentional act and gives sense to the immanent object through noeses such as believing, considering and remembering. Noema is that which the noesis acts upon, for example in the act of believing (noesis) there is the believing as believed (noema). Husserl gives the example of the apple tree in the garden in 'Ideas' in which there are 3 things, the act of perception, the perception itself and the tree. The actual tree will be very different to the reported sense of the tree (noesis) and the state of perceiving the tree (noema). The noema is both a part of and a product of the noesis (McIntyre & Woodruff Smith, 1989).

Lifeworld (Lebenswelt) is a central concept in all forms of phenomenology, it has been described as ‘that province of reality which the wide awake and normal adult simply takes for granted in the attitude of common sense’ (Schutz & Luckmann, 1973, p3) and being in lifeworld 'involves our immediate, pre-reflective consciousness of life: a reflexive or self-given awareness which is, as awareness, unaware of itself’ (van Manen, 1997, p35); as such lifeworld is the basis for all epistemological studies. Husserl introduced the concept of lifeworld in the unfinished 'The Crisis of European Sciences and Transcendental Phenomenology' (*Krisis der europäischen Wissenschaften und die transzendentale Phänomenologie: Eine Einleitung in die phänomenologische Philosophie)* in 1936 and marks a departure for Husserl as it recognises that consciousness can only operate in a context of meanings, values and pre-judgements, it cannot be pure or transcendental. Lifeworld is both personal and intersubjective and its incorporation into Husserl's development of phenomenology is a revision to a more Hiedeggerian perspective:

> In whatever way we may be conscious of the world as universal horizon, as coherent universe of existing objects, we, each "I-the-man" and all of us together, belong to the world as living with one another in the world; and the world is our world, valid for our consciousness as existing precisely through this 'living together.' We, as living in wakeful world-consciousness, are constantly active on the basis of our passive having of the world...
>
> (Husserl 1936, p108-109).

3.3.6 Existentialist (hermeneutic) phenomenology

Existentialism has a precedent in the writings of Kierkegaard and Nietzsche, but it was Martin Heidegger's Being and Time (1927/1962) that incorporated existential themes into the phenomenological tradition, although its author strenuously denied any attempts to brand him as an existentialist. Hermeneutic phenomenology is a branch of phenomenology that extends understanding of human experience through a reflective position on the experience of the researcher interpreting the experience of others (Spielberg & Schumann, 1982).

3.3.7 Heidegger

Martin Heidegger (1889 - 1976) had been influenced by Husserl's early writings. In 1916 Heidegger became a junior colleague of Husserl at the University of Freiburg and became his assistant in 1919. Whilst Heidegger continued to value Husserl's earlier work 'Logical Investigations', he did not ontologically agree with the transcendental position that Husserl had moved to and began a radical re-interpretation of Husserl's phenomenology to develop the existentialist and hermeneutic tradition.

Heidegger's major unfinished work is Being and Time (Sein und Zeit) (published in the original German in 1927 and translated in 1962). Under pressure to publish, this lengthy work was unfinished in 1927 but was still reviewed as being like an 'electric shock' or 'lightning strike' amongst philosophical writings (Schmidt (foreword), 2010).

Heidegger set out his ontological aims to understand

Das Suchen – seeking

Das Gefragtes – that which is asked about

Das Befragtes – that which is interrogated

Das Erfragte – that which is to be found out by asking

3.3.7.1 Heidegger's development of existentialist phenomenology

Heidegger characterised the state of human existence as Being in the World (in der Welt):

> What is meant by "Being-in"? Our proximal reaction is to round out this expression to "Being-in" 'in the world'", and we are inclined to understand this Being-in as 'Being in something' ….as the water is 'in' the glass, or the garment is 'in' the cupboard. By this 'in' we mean the relationship of Being which two entities extended 'in' space have to each other with regard to their location in that space…… Being-present-at-hand-along-with in the sense of a definite location-relationship with something else which has the same kind of Being, are ontological characteristics which we call 'categorial
>
> (Being and Time, 1927/1962, p340).

Heidegger suggested a notion of the worldhood (die Weltheit) and that this might be accessed or understood through everyday things starting with tools (das Zeug). The world is present, not in the sense of being at hand (Dar Vorhandsesien) but in the sense of interrelatedness of tools and actions and involvements. Heidegger conceptualises Dasein's relation to things as 'being-in' and its relation to others as 'being-with'. This being-with is again in the sense of interrelatedness with Das Man (the They).

Originally Da Sein, Dasein is a concept which permeates the entirety of Heidegger's work. Heidegger, through his investigations into the nature of Being in 'Being and Time' introduced the concept of Dasein which he defined as:

> entangled-desclosed, thrown-projecting, being-in-the-world which is concerned with its ownmost potentiality in its being-together with the 'world' and in being-with the others
>
> Being and Time (1927/1962, p175)

or perhaps more simply expressed as:

> Dasein is essentially being-with... Even Dasein's being alone is being with the world. The other can be missing only in and for a being with. Being alone is a deficient mode of being with; its very possibility is the proof of this
>
> (Being and Time, 1927/1962, p156-157).

In the same way that Heidegger positions being alone as 'a deficient mode', he also argued that nothing influences the existence of being, in a way similar to the way in which death shapes life. In 'The way back into the ground of metaphysics', Heidegger further examines interrelatedness, exploring being through contrast with nothing with the suggestion that it is redundant to attempt to explore being through beings (1949).

The concepts of being-in and being-with, of being in a constant state of interrelatedness are central to the construction of Dasein. Immediately this ontological perspective is at variance with Husserl’s view that the being can be reduced by the process of epoche and Heidegger’s development of these ideas are a significant revision of and departure from Husserl’s original writings. With Heidegger's Dasein came a remarkable challenge to the Cartesian dualism on which Western European philosophy had been largely anchored; the ideal of separation of body and soul (Sikerry, 2006). von Eckartsbury and Valle (1981) in 'Heideggerian Thinking and the Eastern Mind' compares what became known as hermeneutical phenomenology with eastern philosophical traditions in which the highest form of consciousness are those states in which individuals gain freedom of enlightenment by becoming unattached from things or concerns.

In Being and Time, Heidegger distinguishes between ontological inquires that are philosophically linked to being and those that impact upon or are relevant to being but not about being per se. These ontic processes are positioned as being with and Heidegger suggested that the distinction between and ontological and an ontical approach was; 'Ontological inquiry is indeed more primordial, as over against the ontical inquiry of the positive sciences' (Being and Time 1927/1962 p2):

> Dasein is an entity which does not just occur among other entities. Rather it is ontically distinguished by the fact that, in its very Being, that Being is an issue for it…. Understanding of Being is itself a defining characteristic of Dasein’s Being. Dasein is ontically distinctive in that it is ontological
>
> (Being and Time, 1927/1962, p12).

and:

> Dasein’s facticity is such that its Being-in-the-World has always dispersed itself or even split itself up into definite ways of Being-in. The multiplicity of these is indicated by the following examples: having to do with something, producing something, giving something up and letting it go, undertaking, accomplishing, evincing, interrogating, considering, discussing, determining…. All these ways of Being-in have concern as their kind of Being
>
> (Being and Time, 1927/1962, p56-7).

Temporality (Temporalitat) and Spatiality (Raumlichkeit) are key concepts to understanding the existentialist analytic of Dasein. Heidegger saw the human condition as being one that is in the present but always projecting into the future. In anticipating the future, we interpret and project our previous experiences and history so that the anticipation reproduces the past, or 'having-been-ness (Gewensenheit) so that 'Temporality temporalizes as a future which makes present in the process of having been' (Being and Time 1927/1962, p334). This contextualises Dasein in the past-present-future (Ekstae) temporality and because human existence is situated in a particular time it must also be present in a particular social space (Wollan, 2003):

> The handiness which belongs to each region beforehand has as the being of what is at hand the character of

> inconspicuous familiarity in a more primordial sense. The familiarity itself becomes visible in a conspicuous manner only when what is at hand is discovered circumspectly in the deficient mode of taking care of things. [. . .] Space, which is discovered in circumspect being-in-the-world as the spatiality of a totality of useful things, belongs to beings themselves as their place
>
> (Being and Time 1927/1962, p104).

Gaal and Szabo links consideration of Heidegger's concepts of ready to hand and present at hand to having a temporal horizon and also a sense of knowing of things in their meaningful emplacement; in Dasein 'The dynamic continuity resulting from this kind of dwelling is responsible for the subject’s sense of place, which, then, does not only reflect a geographical constraint, but also a temporal one' (2013, p2).

The being is not something that stands beyond or outside of us but rather informs the way that we understand and construct ourselves. Dasein's existence is not a presence of a thing, present to hand, but a possibility of one. Heidegger uses the terms authentic and inauthentic to describe these distinctions in Being and Time, not in a comparative manner but rather in the sense that authentic equates to the existentialist Dasein and inauthentic refers to the categorical meaning. For Heidegger achieving authenticity is the vision that can save mankind from a culturally controlled and directed life:

> This process can be reversed only if we explicitly bring ourselves back from our lostness in the 'they'. But this bringing-back must have that kind of being by the neglect of which we have lost ourselves in inauthenticity
>
> (Being and Time, 1927/1962, p312-313).

These concepts of authentic and inauthentic are further developed in the writings of Jean-Paul Sartre, notably in Being and Nothingness (L'Etre et Le Neant, 1958).

Heidegger's phenomenological approach basically refuted Husserl’s fundamental proposition that it was possible to transcend values and beliefs and locate an essential 'thing' through the processes of epoche and bracketing:

> Whenever something is interpreted as something, the interpretation will be founded essentially upon fore-having, fore-sight and fore-conception. An interpretation is never a presuppositionless apprehending of something presented to us
>
> (Being and Time, 1927/1962, p150).

3.3.7.2 The methodological development of hermeneutical phenomenology post Heidegger.

Following Heidegger, the discussions and developments in phenomenology have been existentialist and hermeneutic rather than transcendental. The phenomenology of Husserl, Heidegger and Merleau-Ponty (1962) was written at a philosophical and theoretical level not as a methodological application. Although their works identified key areas of the process and made some procedural indications more distinctive research methodologies have only been emerging since the mid to late 1980's.

A range of methods has evolved since that time not least because there is no single way to undertake phenomenological research since 'the specific method used depends ... on the purposes of the researcher, his or her specific skills ... and the nature of the research question and data collected' (Hein & Austin 2001, p.2).

During this period there emerged two prominent schools of thought informing and developing phenomenological methodologies and the two approaches are summarised below:

van Manen **Utrecht School** **Hermeneutic Phenomenology**	**Giorgi:** **Duquesne School** **Empirical Phenomenological Psychology**
Influenced by “human science pedagogy” and the Dutch movement of phenomenological pedagogy	Used the insights from phenomenological philosophy to develop a human science approach to psychology

Important concepts include description, reduction, essences and intentionality Aim is to produce insights into human experience Focus is on the phenomenon (i.e. studying in subjects the object of their experience) Outcome is a piece of writing which explicates the meaning of human phenomena and understanding the lived structures of meaning May use "self" as a starting point; relies on others and other sources (i.e. fiction and non-fiction, observations, etc) of data Uses imaginative variation to help illuminate themes during data analysis Uses less prescriptive methods of doing research Is not inductively empirically derived Uses a literary and poetic approach Has a strong moral dimension	Important concepts include description, reduction, essences and intentionality Aim is to produce accurate descriptions of aspects of human experience Focus is on the phenomenon (i.e. studying in subjects the object of their experience) Outcome is a general structural statement which reflects the essential structures of the experience being investigated May use "self" as a starting point; but relies mainly on others for data Uses imaginative variation to help illuminate themes during data analysis (i.e. "meaning transformations") Follows a fairly strict method of data collection and data analysis Is an empirical analytic science Uses a psychological approach Does not necessarily have a moral dimension

Ehrich,1999.

3.3.8 The methodological design

In this section there will be an overview of the methodological considerations of the project and how these were developed in response to changes in the data collection to a multi method approach.

it is possible to alter an ontological and epistemological position, but it is perhaps an unlikely shift (Jessop, 2005). Given that there are practicalities that will influence the selection of methods and sources which will be linked to the nature of the subject under enquiry, the more likely area to be reviewed would be the methodology, and it may be that there are changes in this area of approach whose requirement becomes apparent once the data capture becomes a live process.

Given that I have a constructivist ontological perspective, an interpretivist epistemological perspective and have decided that phenomenology provides a theoretical perspective or best fit lens to view this study through, the natural progression, moving through Grix's model (2002), would be to employ a methodology based on a phenomenological approach, such as those described above. Whilst phenomenology is a theoretical perspective on which a number of methods have been based, there have been some developments of the original process, notably increasing the number of 'steps' in the process to view the data through additional lens (Colaizzi, 1973; Edward & Welch, 2011), and the hermeneutic 'refractive' approach which introduces a series of filters to the analysis (Abawi, 2012).

The methodologies associated with a phenomenological approach are discussed below and then there follows a discussion of how a multi method approach was formulated to view the data collected through two lenses.

3.3.8.1 Note on the use of terminology

Given the constructivist perspective of the study is unlikely that themes would be ‘discovered’; knowledge does not pre-exist rather it is the construction of an interactive process. In the same way it would be equally at variance with the view of the researcher to say that these themes ‘emerge’, and yet, ‘emergent themes’ is a prevalent description used by many leading developers of phenomenological writing – there are 17 pages referenced under ‘emergent themes’ in the index of the seminal 2009 publication by Smith. Flowers and Larkin and more recent studies continue the tradition of using this phrase (Mole, Kent & Hickson, 2019; Davys, Mitchell & Haigh, 2016; Miller, Chan & Farmer, 2018).

In Thematic Analysis the final step in Braun and Clarke's 2006 process model states 'the researcher is positioned as active int eh research process: themes do not just emerge' (p37), and a search of recent TA studies suggests that there remains little if any use of the phrase 'emergent themes', something that has been carefully reflected in the analysis for this project (Castro & Andrews, 2018; Ferrar, Schaltegger, Zakrajsek & Strohacker, 2018; Breeder & Samplaski, 2018).

Braun and Clarke re-iterated their epistemological position in 2019:

> For us, qualitative research is about meaning and meaning-making, and viewing these as always context-bound, positioned and situated, and qualitative data analysis is about telling 'stories', about interpreting, and creating, not discovering and finding the 'truth' that is wither 'out there' and finable from, or buried deep within, the data. For us, the final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative. We emphasise that themes do not passively emerge from data to capture this process'
>
> (Braun & Clarke, p591).

It may be that these concerns around how congruent an phenomenological epistemological position is with the phrase 'emerging themes' may be resolved by the adoption of a modified terminology, Nowell, Norris, White and Moules (2017) refer to 'emerging impressions' and this may be in the longer term a more helpful phrase for researchers to use in terms of data analysis, as the implication that an impression is formulating within the researcher is more congruent with a constructivist view that 'truth' resides somewhere waiting to be fund.

3.3.8.2 Grounded Theory

Grounded theory is a methodology that develops a theory from data. Although it is an iterative process, 'the goal of grounded theory is to develop an explanatory theory of basic social processes, studied in the environments in which they take place' (Starks & Trinidad, 2007, p1373). The process of conducting a grounded theory study is similar to that of a phenomenological process, in that there are stages of data collection and analysis, looking for themes and categories, however it differs significantly from a phenomenological study in that grounded theory includes conceptualisation, the production of an explanatory concept. Glaser, considered to be one of the originators of grounded theory has in more recent years explored how the process can be moved onto the conceptualising stage rather than becoming 'stuck' in data emphasizing that 'Grounded Theory is the study of a concept! It is not a descriptive study of a descriptive problem' (2012, p5). As this is an assessment of the dreaming experience of people with autism, it is not possible to determine if there will be a production of an explanatory concept or concepts as a conclusion; if this conceptualisation is a requirement for a project to be a robust grounded theory project, then the use of this method as being suitable for this project was questionable.

3.3.8.3 Interpretative Phenomenological Analysis (IPA)

IPA has been developed by John Smith to understand lived experiences and how people make sense of these. It is phenomenological in that it intends to explore the perception of the event rather than producing an object view of the event itself. IPA draws upon the hermeneutical or existential phenomenological traditions developed by Heidegger:

> This means that the IPA study is a dynamic process with the active role of the researcher who influences the extent to which they get access to the participant's experience and how, through interpretative activity, they make sense of the subject's personal world
>
> (Pietkiewicz & Smith, 2014, p8).

A two-stage process or double hermeneutic is involved in that the researcher's own conceptions are instrumental in accessing and making sense of the experience of the other as they make sense of the phenomena (Smith & Osborn, 2008). 'The aim of IPA is to understand and make sense of another person's sense-making activities, with regard to a given phenomenon, in a given context' (Palmer, Larkin, De Visser & Fadden, 2010, p99).

IPA studies, like other phenomenologically based studies, traditionally have smaller sample sizes than other qualitative projects, largely due to a practical constraint on the amount of work that is required to produce a thorough analysis of the cases involved and so it is not unusual for IPA based research studies to have single figure numbers of cases (Smith & Osborn, 2008). IPA has an idiopathic element and it may be that data saturation occurs before all the data collected is analysed. Data saturation is a problematic concept within IPA as the analysis might continue ad infinitum (Smith et al., 2009) although this would not be practical from a research perspective; Brocki and Wearden conclude that 'perhaps it is when the researcher feels that their analysis has achieved these goals whilst telling a suitability persuasive story that the analysis may be considered sufficiently complete' (2006, p95).

An issue with this idiopathic element might be with the security of generalising from small samples. Smith et al., considers that the method does not avoid generalisations but that it suggests a different way of developing them 'more cautiously' having first located 'them in the particular' (2010, p29). This would develop Van Manen's process by which a potential issue might be explored and conceptualised in greater detail before being cautiously developed or interpreted using alternative methodologies and methods.

A further limitation in working with this method is the ability of the participants to relate their experiences fully to the researcher to enable understanding to take place and, in this double hermeneutic process, upon the researcher's ability to reflect upon the process (Brocki & Wearden, 2006).

IPA involves research with groups or populations which are usually either homogeneous or those that have a common property throughout, so that divergences and convergences can be examined, 'the aim of the study is to say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims' (Smith & Osborn, 2008, p55).

IPA is an experiential qualitative approach often used in phenomenologically based studies in psychology, health and social sciences. It employs a hermeneutic model of phenomenology based on Heidegger's writings, and structures the research and analysis into a series of steps that can be modified to suit the emerging research.

In the UK, there has been a cluster of activities around the development of interpretative phenomenological analysis as a methodology. Its application has been extended to explore different processes of data collection, for example on-line communities (Chappell, Eatough, Davies & Griffiths, 2006) and also to work with focus groups (Palmer et al., 2010), allowing for greater sharing or co-construction of the data with the participants.

3.3.8.4 Thematic Analysis

Essentially, thematic analysis is a method rather than a methodology and is the process of identifying themes or patterns within qualitative data (Maguire & Delanhunt, 2017). The term was first used to describe the process in 1975 (Merton) and whilst it has been claimed as a phenomenological methodology by some (e.g. Guest, MacQueen & Namey, 2012, Joffe 2011) others have positioned the approach as an analytical method (Braun & Clarke, 2006). Braun and Clarke suggest that thematic analysis can be learnt without theoretical knowledge which means that it can be a relatively easy concept for new researchers to grasp (2013), however this relative independence in terms of theoretical underpinnings may be a reason why the method is considered to be not as sophisticated as IPA for example (Braun & Clarke 2014). There have been different ways proposed to undertake thematic analysis (e.g. Sandelowski & Barroso, 2007; Javadi & Zarea, 2016), in this project the intention is to follow the 6 step process outlined by Braun and Clarke (2006):

Step 1: Become familiar with the data
Step 2: Generate initial codes
Step 3: Search for themes
Step 4: Review themes
Step 5: Define themes
Step 6: Write-up

The coding process may be inductive, in which every piece of data is coded on a line by line basis, or theoretical, in that the codes relate or are relevant to the research questions asked (Maguire & Delahunt, 2017). The process of coding Step 2 may be an evolving one in which initial codes are suggested in Step 1 of the above model and these are then modified, expanded and new codes created.

In the context of this project, the familiarisation process and initial code generation will be accomplished through working with hardcopies and transcripts, some further analysis may be completed using NVivo, a qualitative data analytic software (Bazeley & Jackson, 2013).

Codes are then linked together to form themes (Step 3) and are reviewed in step 4 for prevailing relevancy and to check that these are themes rather than sub themes. In Step 5, to ‘identify the ‘essence’ of what each theme is about’ (Braun & Clarke, 2006, p92) and how the themes relate to each other and the project’s aims, Finally, step 6 concludes the process, writing up the report, to bring together the analysis and narrative for the data and to contextualise the data within existing literature.

Braun and Clark identify a 15-point check list to overcome the issues that they identify as failure to analyse the data, using the data collection questions as themes and an ‘unconvincing’ analysis where the themes do not work or are not relevant.

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for ‘accuracy’.
Coding	2.	Each data item has been given equal attention in the coding process.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.

	4.	All relevant extracts for all each theme have been collated.
	5.	Themes have been checked against each other and back to the original data set.
	6.	Themes are internally coherent, consistent, and distinctive.
Analysis	7.	Data have been analysed rather than just paraphrased or described.
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12.	The assumptions about Thematic Analysis are clearly explicated.
	13.	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15.	The researcher is positioned as *active* in the research process; themes do not just ‘emerge’.

(Braun & Clark, 2006, p37).

Nowell, Norris and White, (2017) make the recommendation that 'researchers include markers such as the reasons for theoretical, methodological, and analytical choices throughout the entire study, so that others can understand how and why decisions were made' ; as part of the validation of the data analysis and findings of the project an independent coding of an element of the data will be undertaken and this process will be discussed further in Chapter 4 Data Analysis.

3.3.9 How the methodology design was implemented in practice.

The original design concept for the project was to undertake a series of SSIQ and conduct a, Interpretative Phenomenological Analysis. However, this was discounted when the decision was taken to move to an on line survey rather than host a small number of SSIQs. The number of responses that were generated through the on line questionnaire was far in excess of the numbers considered to be optimal for an IPA methodology:

> As a rough guide, we would suggest that between three and six participants can be a reasonable sample size for a student project using IPA. Indeed, many studies by experiences IPA researchers now have numbers in this range. This should provide sufficient cases for the development of meaningful point of similarity and difference between participants but not so many that one is in danger of being overwhelmed by the amount of data generated. In effect, it is more problematic to try to meet IPA's commitments with a sample which is 'too large', than with one that is 'too small'.

(Smith et al., 2009, p51)

and

> 'As first suggested by Reid et al. (2005) less is more in IPA: fewer participants examined at a greater depth is always preferable to a broader, shallow and simply descriptive analysis of many individuals, as commonly seen in thematic analysis, grounded theory or poor IPA. Smith et al. (2009) highlight the fact that sample size is contextual and must be considered on a study-by-study basis. However, as a rough guide they suggest between three and six participants' the BPS journal

Smith also suggests that not only is there the danger of being ‘overwhelmed’ by a large data collection but also that the quality of the analysis would be compromised: ‘It is only possible to do the detailed, nuanced analysis associated with IPA on a small sample size’ (Smith, 2004, p42). Smith goes on to suggest that reducing the number of participants or having just the one participant may be how IPA develops in the future, how ‘ the very detail of the individual also brings us closer to significant aspects of a shared humanity, and the particular case can therefore be escribed as containing an ‘essence’’. (Smith, 2004).

When the decision was taken to move to the online survey as the responses started to accrue to around 100, it became apparent that to persist with an IPA methodology would be to risk the quality and overall success of the project and at that point the decision was taken to use phenomenological Thematic Analysis.

TA differs from IPA and grounded theory in that it is not attached to any existing theoretical framework; it can be an essential method reporting meanings and experiences or it can be a constructionist method exploring how these meanings are produced: ‘thematic analysis can be a method that works both to reflect reality and to unpick or unravel the surface of ‘reality’’(Braun & Clarke, 2006, p81).

The major advantage of thematic analysis is its flexibility. IPA is a complete process, a theoretically informed framework for how to do research (Smith, Flowers & Larkin, 2009), whereas thematic analysis can be used across the ontological and epistemological spectrum. Some researchers have explored the possibility of delaying a research method selection until after the data generation/collection and pilot study or pre analysis (Mason, 2002), which would be feasible in the cases of Thematic Analysis, Grounded Theory and IPA which have similarities in their initial processes.

In the context of this research project, where so little is known about how people with autism experience dreaming and their perceptions of how it affects their well-being it was helpful to have a range of methods to draw upon which were congruent with my ontological and epistemological positions and the subject or the research. The choice of method was determined once the data collection was underway and following the alteration in the data collection to make it more accessible to participants. The changes that that produced in terms of the number of participants and the way in which they were delivering their information (i.e. through the on line survey as opposed to semi structured interviews), resulted in a revision in the intention to use IPA and the decision to use thematic analysis was made as this was a more appropriate method for this increased sample size generated by the online survey.

However, as the project developed there emerged the possibility to enrich the findings of the study by developing a multi methods approach using the descriptive lens of TA with all the findings and the idiopathic IPA lens to the original face to face questionnaires.

3.3.10 The development of the multi method approach

Multi method research is a further development of mixed methods research which typically involves the collection and analysis of qualitative and quantitative data within the same study:

> There has been a developing practice of using a plurality of methodologies to explore a research area often this is on the form of ‘mixing disciplines by engaging in epistemological pluralism, or approaching a research problem through more than one way of conceptualising it.
>
> Nightingale (2016).

Mixed methods research allows ‘researchers to explore diverse perspectives and uncover relationships that exist between the intricate layers of our multifaceted research questions’ (Shorten & Smith, 2017). Phenomenology has been combined with different quantitative methods to investigate a range of issues (Ambrose, Goodchild and O’Flaherty, 2017; Ziaka & Boukas, 2014). Mayoh and Onwuegbuzie suggest that there could be a number of motivations for undertaking a Mixed Methods Phenomenological Research (MMPR) ‘including experiential theory generation and testing, orientation toward phenomenological phenomena, exploration of unanticipated findings, improving utility and generalizability and cross-validation or triangulation' (2015, p103).

Multi method approaches are becoming more widespread and are increasingly defined as a combination of methodological approaches from either qualitative or quantitative traditions.

'Multimethod research designs may be the outcome of prescriptive planning (i.e. enacted) or an unfolding, evolutionary, pragmatic research process (i.e. emergent)' (Busetto, Luijkx, Calciolari, Gonzalez-ortiz, and Vrijhoef, 2017). In the case of this project it was in response to the changes that took place in the data collection method. The methodological implications of this will be discussed below and other considerations of these changes will be discussed in the following chapter on data collection.

There has been a specific academic precedent set for the pairing of TA and IPA in a multi methods approach. Spiers and Riley (2019) undertook research aimed an uncovering the barriers to help seeking for poor mental health in a group of 47 General Practitioners (GPs). In this study the transcripts of the 47 responses were analysed using TA, from these eventually 10 were selected for the IPA analysis, with Spiers taking the lead on both analyses. Although this might constitute a challenge in approaching the second IPA analysis with fresh eyes, the process of re-reading the transcripts with an IPA approach in mind 'transforms' the data, as Sandelowski (2011) suggests:

> What is commonly referred to as the "same" data is different, at the very least, because they are now viewed within the context of a different project. The "same" data are therefore not re-analysed; rather data are transformed to fit the purposes of the projects in which they are put to use.

The IPA and TA analyses are distinct processes although

> The TA alerts the researcher to a broad group of stressful issue within practice culture, whilst the deeper IPA lens allows the researcher to engage more critically with the existentialist aspects of participants'' experiences by focussing the lens beyond an explicit interpretation and so offers more detail
>
> (Spiers and Riley p283, 2019).

The use of both phenomenological methods has the potential for a multi-layered understanding of experiences that autistic people have of dreaming and the impact it has upon their well-being and who this developed practically will be described in the following chapter – The Data Collection.

Chapter 4 - Data Analysis

4.1 Introduction

This chapter will detail the methods of Thematic Analysis and Interpretative Phenomenological Analysis utilised to analyse the data and will extend the methodology described in the previous chapter.

4.2 Preparing the data for analysis

4.2.1 The three initial semi structured interviews.

The transcriptions were prepared by the researcher by typing the audio recordings into a Word document which was then transferred into the Nvivo software. The audio transcripts were recorded verbatim, although the researcher did not record gesture or tone of voice and 'filler' sounds like 'ermm' and 'uh huh' were also taken out at this stage. The original interview question was included in the transcribed version in order to give greater context, but was shown in italics to be clearly identified as originating with the researcher. Once the data had been transferred in full any identifying markers such as names of friends of relatives were anonymised. Although the data was to be analysed using NVivo software the transcriptions were formatted using numbered lines to make future navigation of the text easier. Transcribing the data in this way provided the researcher with the opportunity to become immersed in the experiences of the participants.

(see Appendix 12 for an example of transcription).

4.2.2 The on line questionnaire

The online questionnaire was closed on 30th April 2019; at this point there were 91 completed questionnaires and a number of partially populated ones from which some data might be retrieved. Reports from the on-line platform were saved in a Word format to assist with manipulating the text, these included by question and by survey reports so that convenient vertical and horizontal referencing could take place efficiently. The online questionnaire data was extracted from the SmartSurvey Platform in an anonymised form and transferred in Word format to NVivo.

4.3. The Thematic Analysis

In this section the analysis of the data using Thematic Analysis and its organisation into Thematic Networks will be discussed.

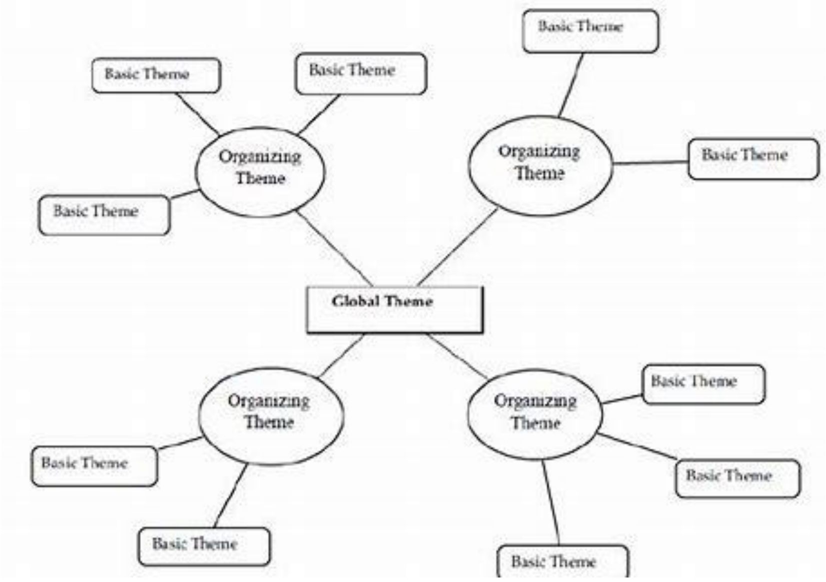
4.3.1 Thematic Networks

Braun and Clark’s (2006), 15 step over view of the complete process of a thematic analysis was used in conjunction with Attride-Stirling’s (2001) development of Thematic Networks to show the vertical and horizontal development of the coding structure for the project.

The process of coding the materials was grouped into 3 levels of process; building from units of meaning (basic or component themes), to grouping these together into clusters of significance (organising themes) and then summarizing these clusters of meaning in global themes (the term superordinate themes will be used interchangeably for global themes in the following chapters):

> They are macro these that summarize and make sense of clusters of lower-order themes abstracted from and supported by the data. Thus, Global Themes tell us what the texts as a whole are about within the context of a given analysis. They are both a summary of the main themes and a revealing interpretation of the texts
>
> Attride Stirling (2001, p389).

The interrelationship and hierarchy of these themes can be seen in the diagram below:



Structure of Thematic Networks

Attride-Stirling (2001, p388).

4.3.2 Coding of content at manifest or semantic level

The coding was open rather than a priori which is congruent with the epistemological perspective of the project. Through familiarisation with the narrative through the processes of interviewing, transcribing and reading, an initial group of codes had been produced which had become apparent as they featured repeatedly through the three initial interviews. The initial coding took place over several days, and due to the open coding process, there was some variance in terminology for example text might be coded to ‘anger’ one day or ‘rage’ in another instance. These variances were not material as the codes were review and grouped into codes of similar meaning.

This initial coding was linked to the three initial interviews and was not completed until the data from the online questionnaires was imported into the NVivo project. At this point the initial coding network expanded greatly as there were descriptors of units of meaning related to a range of very specific issues from all the usable questionnaires.

The initial coding exercise used the terms and adjectives that participants had used in the responses and this immediately generated a plethora of codes in number and range and a list of these are in the Appendices (Appendix 13). These codes were refined through an Excel spreadsheet. Using this format enabled the researcher to view all the codes in one location and to colour-code and manipulate them into more coherent groupings (Appendix 14). After the initial reading and coding had taken place, the descriptors were rationalised, for example codes such as ‘exhausted’, ‘tired’, ‘shaking’, ‘sweating’, may be grouped under the heading of ‘physical response’. As the codes became more stable, each was given a description of its attributes which was helpful in ensuring that coding was accurate. This reflection and refinement of codes into these clusters allowed the development of initial themes at a more latent level of understanding to emerge.

The data from the online questionnaire and the initial interviews was not merged although the same coding structure was applied to both sets of data. The codes were developed during the analysis of the initial interviews which were completed before the online questionnaire closed. The initial reading of the on line questionnaire responses provided some additions to the list, and this was perhaps to be expected given that the questionnaire had largely followed the structure of the SSIQ that had been produced and developed during the initial interview phase of the project.

Where codes or themes are referred to in the following chapters these will be capitalized to prevent the descriptor becoming embedded in the surrounding text.

4.3.3 Code Verification

Following the establishment of a coding structure that could be applied to the text, a colleague who had used thematic analysis for their Educational Psychology Doctorate was asked to read through the list of codes and their descriptors and sections of text from the questionnaires and interviews to check for omissions and duplications and then to link section of text to the codes. This text had already been coded by the researcher but the Educational Psychologist was not given these results to ensure that the verification process was rigorous.

In terms of linking text to codes our results were congruent following discussion around the intention of one manifest code. The process of code verification took place as soon as the code list became stable so that if there had been any significant disparity between to Educational Psychologist's analysis and the researcher's this could be explored without the need to revise significant quantities of coding.

4.3.4 Coding using NVivo Software

NVivo is a form of Computer-Assisted Qualitative Data Analysis Software (CAQDAS) and is offered to research students through Sheffield Hallam University on a no fee basis. Other forms of CAQDAS were considered including the use of Excel, but these were discounted on either basis of cost or ease of creating a project.

Prior to going live with the analysis for the project, I was able to familiarise myself with the software using a variety of online tutorials and the NVivo website guidance. As this is a widely used software tool for research the supporting online guidance answered any question or provided solutions to resolve any issues with the data handling.

Some of the features such as the text search and the word trees were useful; for other parts of the data analysis such as mind mapping and grouping codes, I found it more useful to draw these or to use an excel spreadsheet and I did not utilise aspects of the programme relating to project management. Using NVivo with other programmes, techniques and devices optimised the data analysis.

A review of the use of NVivo in the project will be undertaken in the concluding chapter of the thesis.

4.3.5 From text to interpretation, the creation of thematic networks

The analysis was undertaken on a vertical as well as horizontal basis; in that individual questionnaires were reviewed for patterns of response and developing themes within the vertical structure of the narrative and also that the analysis looked at themes horizontally through the clusters of units of meaning around given topics or questions. This allowed the researcher to interrogate the data from a variety of perspectives and to look for any emergent themes around causality.

The codes were grouped and linked to show relationships and connections to the organising themes. Once the organising themes began to emerge it became apparent that it was possible to frame these around the 3 research questions, not in the sense of answering the research questions directly but rather in looking at the processes that enable each one to be answered.

- How do people with autism perceive their dreaming experience? is essentially about how people understand, in what ways do they consider and how do they value the activity of dreaming; these are sense making activities and this led to the conceptualisation of the superordinate theme of SENSEMAKING ACTIVITY OF THE DREAMING EXERPIENCE (SMADE).

- How do people with autism think that dreaming affects their well-being? Is a question about how dreaming effects them, their identity? It involves how participants construct and express these influences, how they will be influenced going forward and how they process the activity to make it manageable. It is about the IDENTITY ACTIVITY OF THE DREAMING EXPERINCE (IADE)

- What adaptations have people with autism made to their dreaming? Is a question about changes or adaptations made either in practical terms such as avoiding certain triggers or more theoretical terms such as re-framing the experience that have been made to improve the impact of the dreaming experience, it involves concepts around ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE (AADE).

The codes and the thematic networks will be discussed in more detail in the following chapter.

4.4 The Interpretative Phenomenological Analysis

The titles for the following sections have been taken from ‘A practical guide to using Interpretative Phenomenological Analysis’ by Pietkiewicz and Smith (2014). From a pragmatic perspective this analysis was undertaken after the TA so that the focus of the analysis would be directed solely towards an IPA process. The analysis took place over several months, not only as a result of the part-time status of the researcher but also to allow that immersion into the rich texts that is required to produce a quality IPA by allowing the hermeneutic circle to be constantly cyclical.

Six responses to the online questionnaire were chosen for the detail each contained about the dreaming experience. Of these two were considered to be more positively toned and four had a more negative view of dreaming and the impact it had upon waking well-being. The selection was made from the online questionnaire responses alone as this meant that the structure of the questions and responses would be more consistent than a combination of the face to face interviews and on line ones.

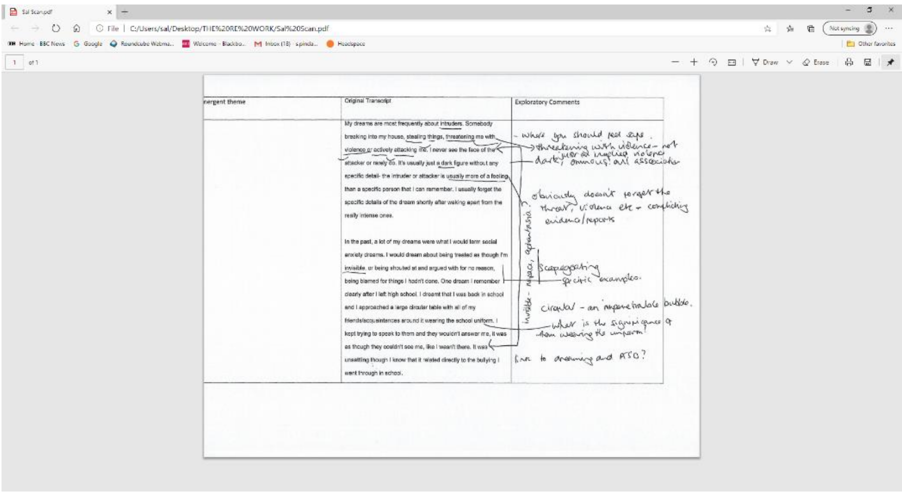
4.4.1 ‘Multiple reading and making notes’

The transcripts were printed out with the text centred in a landscape orientation to allow wide margins on either side for note taking and comments. The transcripts were read a number of times over several days to allow immersion in these experiences. One transcript was read and notes made and then the process repeated until the researcher felt that sufficient understanding had been developed of the text and that this was comprehensively reflected in the notes made, then re researcher would progress to the next transcript and repeat the process of emersion and note taking.

Reading the transcriptions this way enabled the identification of ‘objects of concern’ or what mattered to the participants and the meaning that these objects held for participants - their ‘experiential claims’. This produced an etic viewpoint, that is the understanding of the experience from the researcher’s perspective, the hermeneutic phase, the development of the emic perspective occurs in the next stage of analysis.

Note taking is a subjective exercise and in the screen shot example below are examples of the highlighting or commenting on anything that the researcher considered to be unusual or indicative in the use of language, interaction and emotion.

The screenshot below is an example of this initial note taking and the frame used is based on the one used in Smith, Flowers and Larkin (2009).



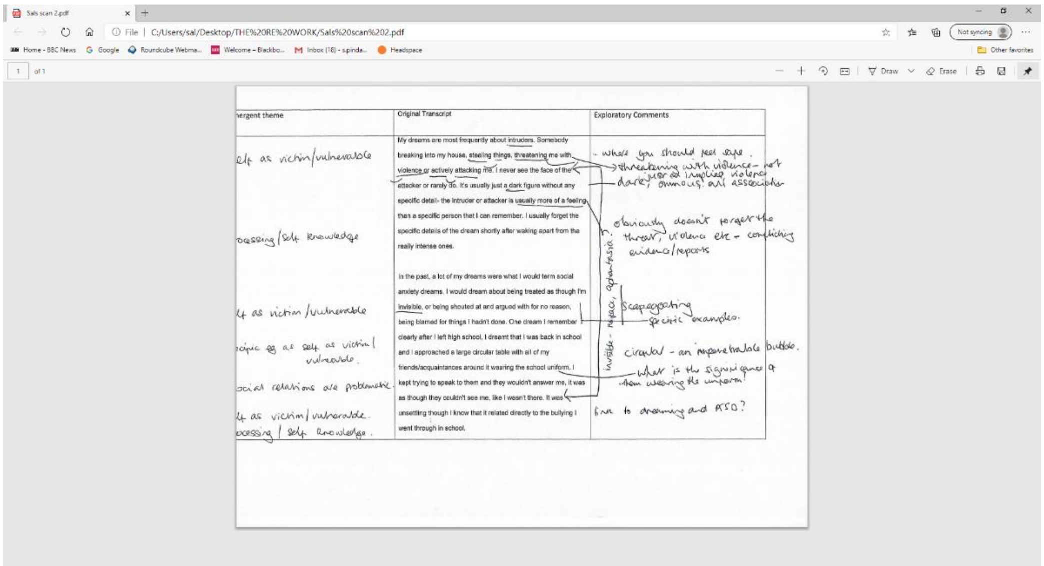
nergent theme	Original Transcript	Exploratory Comments
	My dreams are most frequently about intruders. Somebody breaking into my house, stealing things, threatening me with violence or actively attacking me. I never see the face of the attacker or rarely do. It's usually just a dark figure without any specific detail- the intruder or attacker is usually more of a feeling than a specific person that I can remember. I usually forget the specific details of the dream shortly after waking apart from the really intense ones. In the past, a lot of my dreams were what I would term social anxiety dreams. I would dream about being treated as though I'm invisible, or being shouted at and argued with for no reason, being blamed for things I hadn't done. One dream I remember clearly after I left high school. I dreamt that I was back in school and I approached a large circular table with all of my friends/acquaintances around it wearing the school uniform. I kept trying to speak to them and they wouldn't answer me, it was as though they couldn't see me, like I wasn't there. It was unsettling though I know that it related directly to the bullying I went through in school.	– where you should feel safe. threatening with violence – not just or implied violence dark, ominous, evil associations obviously doesn't forget the threat, violence etc + conflicting evidence/reports invisible – repeat, aphantasia? Scapegoating specific examples. circular – an impenetrable bubble. what is the significance of them wearing the uniform? link to dreaming and PTSD?

4.4.2 ‘Transforming notes into Emergent Themes’

‘This involves an analytical shift to working primarily with the initial notes rather than the transcript itself’ (Smith, Flowers and Larkin, 2008, p91), however the original transcript remains centrally placed in both the process and the template so that the researcher has a greater data set to draw upon in both the narrative and the initial notes. This produces an emic view of dreaming based on experiential perception of the challenges it poses to the nature of the phenomena and the impact on existence.

The notes and comments that had been made about the text were then reviewed. ‘The aim is to transform notes into emerging themes. The researcher aims to formulate a concise phrase at a slightly higher level of abstraction which may refer to a more psychological conceptualization’ (Pietkiewicz &Smith, 2014, p12).

The screenshot below shows the ‘emergent themes’ that made an impression upon the researcher in the two paragraph example, and in this way they reflect the participant’s original narratives and the interpretation that the researcher has placed upon them, showing an integration of the two views to augment an understanding of the original recount.



ergent theme	Original Transcript	Exploratory Comments
elf as victim/vulnerable ocessing/Self knowledge	My dreams are most frequently about intruders. Somebody breaking into my house, stealing things, threatening me with violence or actively attacking me. I never see the face of the attacker or rarely do. It's usually just a dark figure without any specific detail- the intruder or attacker is usually more of a feeling than a specific person that I can remember. I usually forget the specific details of the dream shortly after waking apart from the really intense ones.	- where you should feel safe. threatening with violence - not just an implied violence dark, ominous. all associations obviously doesn't forget the threat, violence etc - conflicting evidence/reports invisible - menace, aphantasia?
lf as victim /vulnerable ecific eg as self as victim/ vulnerable. ocial relations are problematic. lf as victim/ vulnerable. ocessing / self knowledge.	In the past, a lot of my dreams were what I would term social anxiety dreams. I would dream about being treated as though I'm invisible, or being shouted at and argued with for no reason, being blamed for things I hadn't done. One dream I remember clearly after I left high school, I dreamt that I was back in school and I approached a large circular table with all of my friends/acquaintances around it wearing the school uniform. I kept trying to speak to them and they wouldn't answer me, it was as though they couldn't see me, like I wasn't there. It was unsettling though I know that it related directly to the bullying I went through in school.	Scapegoating specific examples. circular - an impenetrable bubble. what is the significance of them wearing the uniform? link to dreaming and ASD?

4.4.3 ‘Seeking relationships and clustering themes’

Smith, Flowers and Larkin (2009) suggest the following basic ways to explore the relationships between themes; one a concrete representation involving spreading out pieces of paper each with a theme on and the physically moving these labels around into groups or typing a list and moving around into clusters on a screen. For this process the researcher used Excel from the Microsoft Office suite, which offered the opportunity to colour code the themes and then cluster them accordingly. Using this basic tool also meant that once clustered, themes could be re-colour-coded into further sub themes or codes amalgamated with another, so rationalizing without the removal of nuanced differences.

The first step in the process was to list the themes in cells in the order that they appeared in the transcripts, this was the process chosen as it was easy to audit. This resulted in a table of themes (snapshot of part of this below).

hoping for something better	fearing the worst	making links to others
use of STEM related language	lack of hope in the future	making links?
catastrophizing	feeling worthless	normalising
vulnerability	feeling hopeful	realms
cognitive dissonance	making links to relationships	wishing
resisting change	other worldly	attribute awarding
seeking predictability	seeking concreteness	spiralling metaphors

From this list of themes clusters could be generated. Some researchers prefer a method suggested by Smith, Flowers and Larkin (2009) of using post it notes or small labels that can be physically grouped and moved; the end result is arguably the same and having alternative options ensures that the researcher can use a process which suits their visual or kinetic preferences. In a similar way the phrasing of the themes will vary from researcher to researcher and will reflect the development almost of a ‘shorthand’ that has personal resonance but which at this stage may mean little to anyone reading through the notes or themes. The discussion and explanation of these themes will develop this ‘shorthand’ into more conveyable concepts.

4.4.4 The superordinate themes

Following the hermeneutic processes of reading and interpreting and then looking at the clusters of themes, three superordinate themes were developed from the data as being a new rich field of investigation; themes which had been highlighted in the initial TA but which under the co-construction of the IPA between the researcher and the participants' data took on a richer and more dynamic development. These themes are:

1. The creation of a mystical identity
2. Dreams as a means of finding order and control
3. The experience of dreaming as a creation of a connected self.

These themes will be further explored in Chapter 6 - Findings and discussion of findings from the IPA.

4.4.5 The structure of the findings and discussion chapters in the report

Whilst IPA studies frequently have separate sections on finding and discussion of findings, Smith et al. comment:

> it is possible, once you are more experienced, to choose not to have a clear demarcation between these two sections and rather to relate themes to the extant literature as you are going along. In this case results and discussions are merged into one section
>
> (p113, 2009).

Although the researcher would not necessarily consider themselves to be 'more experienced' the decision has been taken to follow guidance from the Internal and External Examiners in this matter namely:

> We would strongly recommend that the findings and discussion are not separated into separate chapters as with an IPA it would be much easier to provide examples of the data and a discussion and analysis of the data together.
>
> (Ingram & Cameron, 2019).

The finding and discussion chapters for the TA will be structured in the same way to ensure methodological and phenomenological consistency in the report.

Chapter 5 - Findings and Discussion of findings from the Thematic Analysis

5.1 Introduction

This chapter considers the 'answers' to the research question.

1 How do people with autism perceive their dreaming experience?

2 How do people with autism think that dreaming affects their well-being?

3 What adaptations have people with autism made as a result of their dreaming experiences?

The chapter will begin with an overview of the results collated at the end of the Data Analysis chapter and will continue to analyse the super-ordinate themes with examples from the initial interviews (II) and online questionnaire (OLQ) In order to manage the discussion of the extensive results in this chapter, they have been grouped into the areas listed below. This is not to say that the super-ordinate themes are exclusively spilt into three areas, they are very much interlinked, the device is intended to support the accessibility of the research findings and to show how the data collected responded to the three research questions.

The chapter will be structured as follows with each section demonstrating and discussing findings and concluding comments regarding the findings:

Part I: Results overview

Part 2: The super-ordinate theme: SENSE MAKING ACTIVITY OF THE DREAMING EXPERIENCE (SMADE).

Part 3: The super-ordinate theme: IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE (IADE).

Part 4: The superordinate theme: ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE (AADE).

Part 5: Summary of results.

5.2.1 Part 1 Results overview

Super ordinate theme	SENSEMAKING ACTIVITY OF THE DREAMING EXPERIENCE (SMADE)			IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE (IADE)			ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE (AADE)		
Organising theme level	UNDERSTANDING DREAMING	CONSIDERING DREAMING	VALUING DREAMING	CONSTRUCTING THE NARRATIVE	RECONCILING HEROES AND VILLANS	CONTINUING	PRE DREAMING ACTIVITY	IN DREAMING ACTIVITY	POST DREAMING ACTIVTY
Component (or basic) theme level	EXTERNAL FACTORS	REAL OR IMAGINARY	ENJOYMENT	SEDIMENTATION	GLAMOUR	HISTORY & FUTURE VIEW	ROUTINES	NAMED LUCID TECHNIQUES	SEEKING HELP
	PHYSICAL FACTORS	RE-TELLING	CREATIVITY	DEVELOPMENT	HORROR	NORMALISING	AVOIDANCE	PROTO LUCID TECHNIQUES	ALTERING PLANS
	MENTAL & EMOTIONAL FACTORS	FORMULATING	WELL BEING		ACCEPTANCE		RESIGNATION		DISCUSSSING/ REFORMULATING
		NOSTALGIA	NIGHTMARE			VIEW OF CHANGE			
			PROPHECY						

Figure 5.1 A summary of the categorisation of the themes and their relationship to each other, both vertically and horizontally.

Within the basic theme levels in the above table the themes should be interpreted as having equal weightings; they have not been arranged into a conscious hierarchy.

During the initial readings of the narratives, units of meaning were given descriptors. As the researcher became far more familiar with the texts, patterns and similarities started to emerge, this enabled merging and grouping of similar themes, for example references to ‘fever’, ‘melatonin’, ‘exercise’ and ‘food’, were grouped with several other descriptors in the component theme PHYSICAL FACTORS. A brief outline of how the researcher uses the descriptor will be included in the analysis.

There was an initial question in the survey which was ‘do you recall your dreaming experiences?’. Where participants responded that they did not, the skip logic of the questionnaire moved them directly to the exit page. The discussion of results following pertains totally to those participants who responded positively to the initial question.

In order to fully represent the information given by participants, there has been no attempt made to alter grammar, punctuation or spelling; passages within quotation marks have been transcribed to this report verbatim. This is intended to preserve the authenticity of the narrative.   Likewise, the use of [sic] to acknowledge any eras in grammar or spelling has been omitted from the report to provide uninterrupted reading of the extracts.

5.3 Outline of the themes

5.3.1 The super-ordinate themes

In the above table (Figure 5.1) the three superordinate themes are shown as:

- SENSEMAKING ACTIVITY OF THE DREAMING EXERPIENCE (SMADE)

- IDENTITY ACTIVITY OF THE DREAMING EXPERINCE (IADE)
- ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE (AADE).

5.3.2 Organising and component themes

These will be discussed in detail in Parts 2 to 4 so that their relational positions and links to other themes can be more easily followed.

5.4 Part 2: The super-ordinate theme: SENSEMAKING ACTIVITY OF THE DREAMING EXPERIENCE (SMADE).

This superordinate theme has been developed to answer the research question ‘how do people with autism perceive their dreaming experience?’ It has elements of understanding the contributing factors in their widest sense, with how individuals consider or think about their dreaming experience and the value either positive or negative that they ascribe to this.

Figure 5.2 following, shows the relationships of the organising and basic themes supporting the super-ordinate theme of sense making activity of the dreaming experience or how autistic people construct and convey the essence of their dreaming experience. Further thematic system diagrams will retain this shape association.

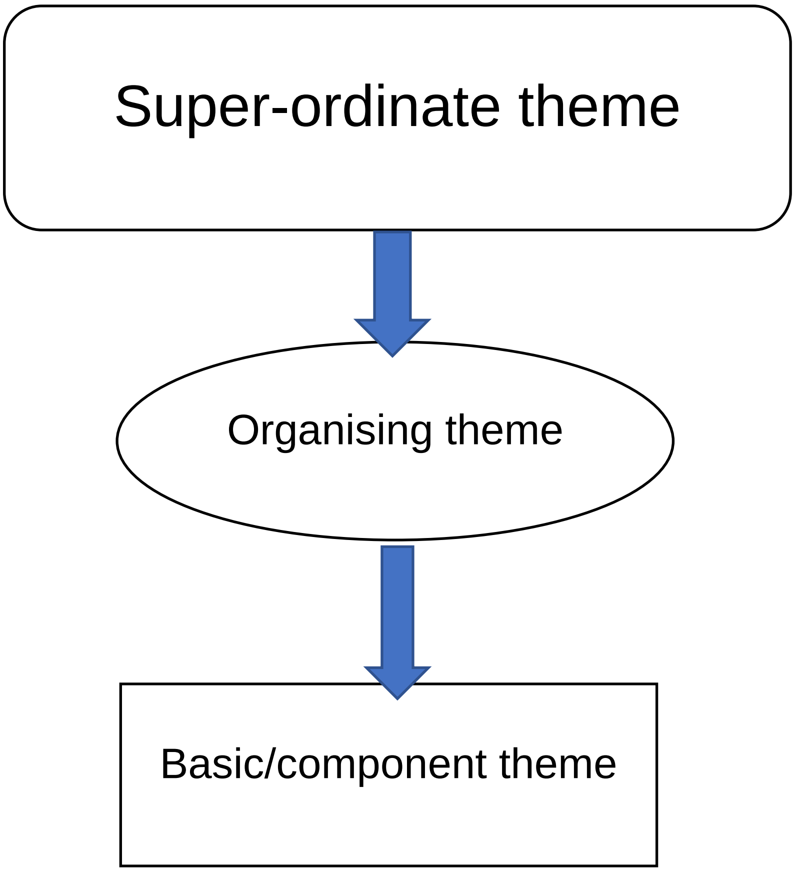


Figure 5.2 The thematic classifications and hierarchical levels.

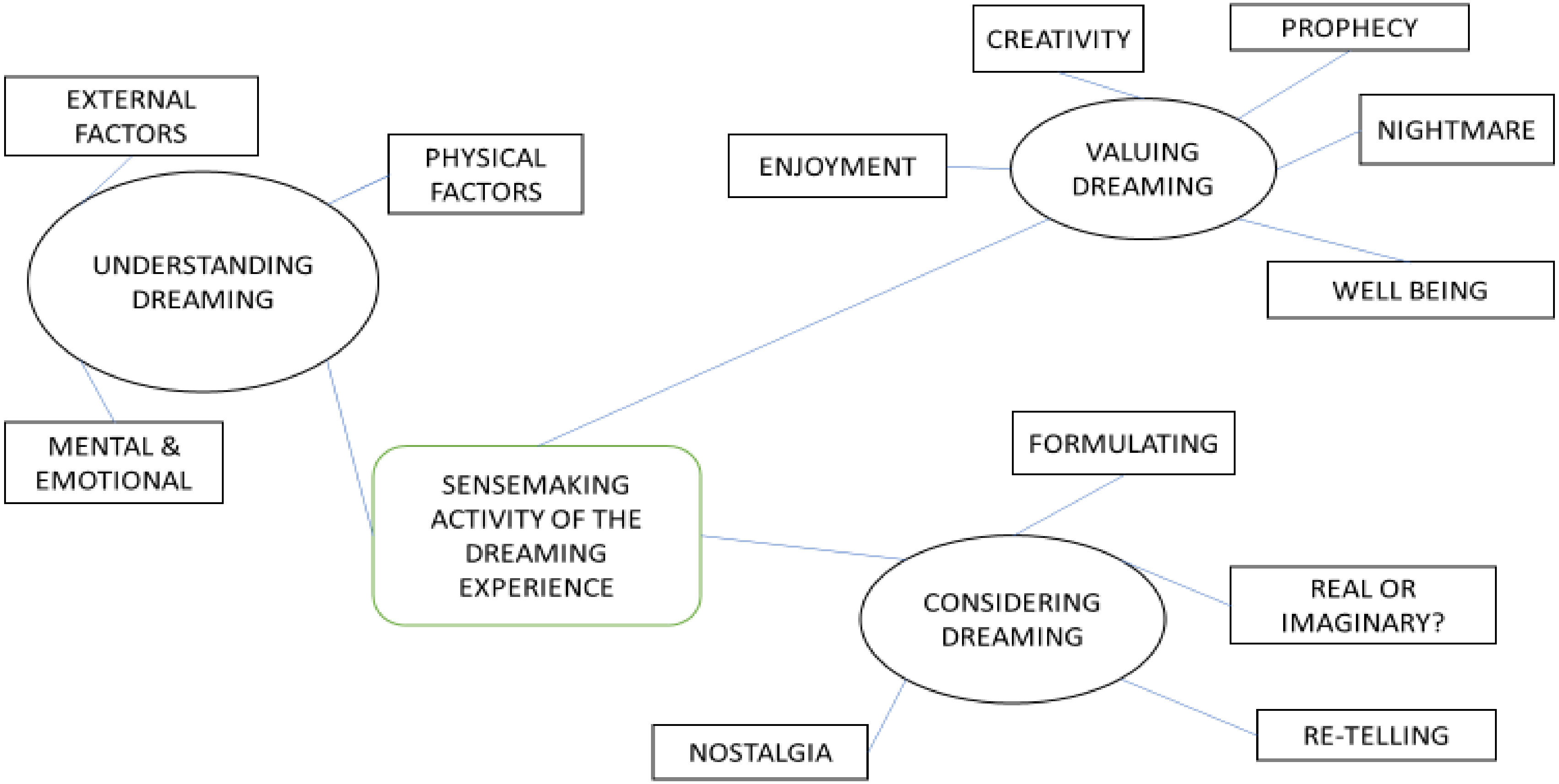


Fig 5.3 Themes contributing to the super-ordinate theme of SMADE

5.4.1 Introduction

SENSEMAKING OF THE DREAMING EXPERINCE (SMADE) is a concept that relates to the development of a worldview around the dreaming experience. 'Sensemaking is about the interplay of action and interpretation rather than the influence of evaluation on choice' (Weick, Sutcliffe & Obstfeld, 2005, p409) and the following identifies some of the properties of sensemaking.

Sensemaking Flux
Sensemaking Starts with Noticing and Bracketing
Sensemaking Is About Labelling
Sensemaking Is Retrospective
Sensemaking Is About Presumption
Sensemaking Is Social and Systemic
Sensemaking Is About Action
Sensemaking Is About Organizing Through Communication

Adapted from Weick, Sutcliffe & Obstfeld (2005)

Sensemaking is the 'process through which people work to understand issues or events that are novel, ambiguous, confusing, or in some other way violate expectations' (Maitlis & Christianson, 2014).

Using the concept of 'sensemaking' enables the analysis to move beyond the concept of dreaming activity per se and rather to look at all the activities that influence and feed into it as perceived by the participants. Just as the activity of 'running' has precursors and legacy, such as increased cardio function, improved fitness, increase of risk of injury, intention, physical ability and so on, so the activity of dreaming embodies a range of causal and contributing activities. The concept of Dasein incorporates this connectedness of continuum, of being-in-the-world and the organising themes of SMADE, how the participants value, understand and consider the dreaming experiences, are intended to reflect how participants compose their sensemaking activities

.

‘Sensemaking involves the ongoing retrospective development of plausible images that rationalize what people are doing’ (Weick, Sutcliffe & Obstfeld, 2005, p409).

5.4.2 The organising sub themes of SMADE

The component themes which describe the literal dimension of SMADE are grouped around three organising themes of UNDERSTANDING DREAMING, VALUING DREAMING and CONSIDERING DREAMING.

5.4.3 UNDERSTANDING DREAMING

UNDERSTANDING DREAMING is the organising theme reflecting how participants sensemake around the dreaming process in terms of the origins of dreaming and what factors may influence the frequency, intensity or content of the activity. This aspect of dreaming activity will provide an indication of the extent to which participants have recognised any correlates that might influence their dreaming experience which is a precursor to formulating if there is anything that they might do to affect that process.

The component codes linked to UNDERSTANDING DREAMING are:

EXTERNAL FACTORS

PHYSICAL FACTORS

MENTAL & EMOTIONAL FACTORS

There is some potential for overlap between the three component themes, for example, with regard to the response:

> ‘Poor sleep hygiene leading to light or restless sleep - too much coffee, too much screen time, not enough meditation’ OLQ

the increased screen time might be an attempt to manage levels of anxiety and the ‘not enough meditation’ could be because the participant feels too agitated or has too little time to meditate. In coding for these themes, the prima facie interpretation has been used.

5.4.3.1 EXTERNAL FACTORS

EXTERNAL FACTORS are those largely beyond the influence of the participant, relating to a physical state or habit, or information which the participants received but may not may have an element of unpredictability, for example a film or television programme’s content or story line for which the individual may be unaware of the conclusion:

> ‘Things that I watch on tv’ OLQ
>
> ‘also tv and reading material’ OLQ
>
> ‘Others can follow themes of books I’m reading or events from the day before’ OLQ
>
> ‘Things that have happened during the day become part of my dreams’ OLQ
>
> ‘things that happened during the day often feature in my dreams, sometimes, something will happened and I will think ‘how is this going to play out in my dream tonight?’’ II

There were references to temperature:

> ‘Another way that I can induce dreaming is to get physically cold so that my skin is really cold to the touch and then wrap myself back up in the quilt and get warm really quickly. I fall off to sleep quickly and then dream’ II.
>
> ‘I often leave a window open a tiny bit so that my room doesn't get too warm’ OLQ.

There were also some less expected responses:

> ‘New moon I always dream very vividly’ OLQ
>
> ‘Staying away blue light’ OLQ

Some respondents indicated that they were already using this understanding of the EXTERNAL FACTORS influencing their dreaming activity to manage this activity:

> ‘white noise when falling asleep’ OLQ.

In terms of EXTERNAL FACTORS, many participants had been able to trace back to some quite subtle dreaming triggers such as the phases of the moon and the blue light. Causal links between the events of the day and dreaming were apparent but the quality or directness of these links varied with the attention that the participants gave to them; the level of rumination around the event is more of an indication on the impact on dreaming rather than the seriousness of the event:

> ‘I think I came to the conclusion that most things can impact or trigger dreaming it really depends on the amount of thought that I give to whatever, so there can be some terrible news on 24 hours a day about something awful and that won’t have any impact. But the fact that someone has used my mug or missed out some punctuation in signs across the office – the ones on the doors that say ‘please can we keep the doors closed to maintain the temperature in the office’, and doesn’t have a question mark, those will be the sort of things that will feature in my dreams but in some grotesque form’ II.

5.4.3.2 *PHYSICAL FACTORS*

PHYSICAL FACTORS were themes that act in some way upon the body of the participant, intrinsically or externally to produce a recognised alteration.

Medication was identified as being a considerable contributor to PHYSICAL FACTORS. Studies into the use of melatonin and dreaming have shown a direct link (Thompson & Pierce, 1999) and this was something that several participants had identified and influencing sleep disturbances through dreaming:

> ‘Sometimes I don't take melatonin when I'm anxious because I don't want my anxiety dreams to be especially vivid’ OLQ

> ‘If I take melatonin to help me sleep, my dreams are more vivid’ OLQ
>
> ‘Some antibiotics have caused me to have extremely vivid and disturbing nightmares’ OLQ
>
> ‘I know certain medications can bring on more vivid dreams’ OLQ
>
> ‘Antidepressants give me extremely vivid, disturbing dreams every night. I experience such dramatic side effects that I can't take them any longer, and the nightmares were only a small part of that, but they're still responsible for some of the worst nightmares of my life’ OLQ.

Hormonal changes are perceived as influencing dreaming activity:

> ‘PMS is a major one for me. Also being too hot and getting dehydrated at night. I am sensitive to heat. I think PMS causes the body temperature to rise slightly so I think that is why I dream so much when I have PMS’ OLQ.
>
> ‘hormones (pregnancy has seen lots of vivid reoccurring’ OLQ dreams)
>
> ‘hormones like when pregnant’ OLQ.

Sleeping per se is associated with influencing dreaming activity:

> ‘A longer period of rest’ OLQ
>
> ‘a busy day, being extremely tired’ OLQ
>
> ‘I do not shift very well from on phase (deep to REM) to another’ OLQ.

With the duration of sleep being referenced:

> ‘So I might be optimistic about setting my alarm and bouncing out of bed to start the day all fresh and sparkly and then when the alarm goes off and I’ll think that 6.30 is too early and reset the alarm for 15 minutes later, so by the time that I actually do get out of bed at 7.30 I’ve fallen back to sleep four or five times and had that many dreams,

> which I usually remember really well and which are really vivid’ II.

And the position of the sleeper

> ‘Sleeping on my back. I am naturally a "front sleeper" and I have much worse dreams when I sleep on my back and I have no idea why, it's possible that I feel less safe falling asleep with my front (and my face) fully exposed. Lots of my bad dreams stem from feelings of being unsafe, exposed, or from social anxiety’ OLQ.
>
> ‘If the bed is the wrong way round then I know that it will disturb my sleep. I like my bed to be placed running roughly north-south, if it’s got an east west orientation then I don’t sleep so soundly and my dreams are more unsettling’ II.

Whilst some of these PHYSICAL FACTORS can be controlled or largely influenced by individuals, taking medications such as anti-depressants or antibiotics may be a medical requirement and it might not be in the individual’s best interests to cease taking these.

5.4.3.3 MENTAL & EMOTIONAL FACTORS

Anxiety and stress featured very prominently in this section. Several participants associated heightened levels of stress and anxiety with masking. Hull et al. (2017), propose that masking is the use of strategies which ‘mimic other socially successful individuals to give the impression that they too are socially successful’ (p2520) the ‘may include hiding behaviours associated with their ASC, using explicit techniques to appear socially competent, and finding ways to prevent others from seeing their social difficulties’ (ibid). It is also less frequently known as camouflaging and may hinder diagnosis especially in females (Kreiser and White, 2014; Holliday Willey, 2015).

Masking was an aspect of life which participants suggested was something that they might not choose to do without perceived pressure to conform to societal norms and something that they understood to be a cause of intense or frequent dreaming episodes. Masking and the stress and anxiety related to it was cited by many as a contributing factor to adverse dreaming experiences.

> ‘Possibly the unconscious acting out the frustration I feel at spending waking time in an unnatural state, i.e. I mimic and mask my natural self to fit in and be able to work etc’ OLQ
>
> ‘Stress, masking my natural self to manage every day life’. OLQ
>
> ‘Stress and overstimulation during the day leads to more intense and sometimes disturbing dreams’ OLQ
>
> ‘because so much of my real life, requires me to mask my real self in order to fit into society’ OLQ
>
> ‘If I am very tired or stressed, which I am often, mainly from masking almost constantly’ OLQ
>
> ‘nightmares tend to be more frequent when I'm going through a period of stress or emotional difficulty’ OLQ.

The words ‘stress’, ‘anxiety’, ‘anxious’, ‘worry’, ‘worrying’ and ‘worried’ occurred more than three times as those of ‘happy’, ‘creative’, ‘creativity’, ‘enjoy’, ‘enjoyment’, ‘enjoying’ and ‘enjoyable’. Stress and anxiety were terms used on their own rather than in relation to something in the sense of ‘my stress levels’, ‘maybe stress’, ’when I’m stressed’ and ‘often feel stressed’; any specific causes of stress were rarely detailed, although one participant did refer to ‘A heightened level of detail or sensory related stress’ (all quotes taken from OLQ). The term ‘stress’ appears to have become dissociated from its origins and no longer has a relational value but rather has become an entity in itself. This state of stress also appears to be located within the individual rather than as an external force working upon them, and the single word response of ‘stress’ occurred frequently in narratives.

Some participants had explored ways of managing MENTAL & EMOTIONAL FACTORS with varying degrees of success:

> ‘Yes, I can think about a topic whilst falling asleep and sometimes dream about it’ OLQ

> ‘I’ve tried Headspace before and that does work a bit if I remember to do it more or less every day’ II.
>
> ‘I also try to make sure that I manage my anxiety/stress levels more. I make sure that I take regular breaks to go for walks or to do some yoga or reading and I quite like colouring’ II.

Whilst many participants had a firm view of the EXTERNAL FACTORS, PHYSICAL FACTORS and MENTAL & EMOTIONAL FACTORS which were influencing their dreaming experiences in some way, a small number of others remained susceptible to dreaming but without any formulation as to what might be influencing the process:

> ‘Wish I knew. There does not seem to be commonality or theme between the separate patterns. There are three that I can think of, and I don't think the theme of a particular pattern is triggered by anything in particular, that I've noticed anyway, but I have a hard time with associations between separate events, so I could be missing them’ OLQ.

5.4.4 CONSIDERING DREAMING

Within the organising theme of CONSIDERING DREAMING are the component themes of:

REAL OR IMAGINARY

RE-TELLING

FORMULATING

NOSTALGIA

These are the ‘how’ of SMADE, the processes that form part of the thinking about or the CONSIDERING DREAMING. They refer to the activities and lenses used when participants think about the process of dreaming and how they express this conceptualisation.

5.4.4.1 REAL OR IMAGINARY?

In the early recruitment phase of the project, a work colleague had become aware of the project and had spoken to her autistic adult sister about dreaming. The sister had told her that dreaming had caused some discord in her relationships as in her dreams she would have conversations or arguments with people and then perpetuate these in waking life. A ‘blurry’ distinction between reality and a dreamed event was something that was reported or alluded to by several participants, however in the context of the colleague’s sister, there was a further revelation that her dream content involved bizarre imagery including walking and talking dolphins and unicorns and despite the inclusion of these fantasy animals she believed the arguments which took place in their presence were real:

> ‘Just occasionally dreams can resemble reality so closely that I’m not sure whether I’ve done something or something has happened. Not often, but sometimes’ OLQ
>
> ‘Sometimes I have to remind myself it was a dream and not reality (especially if my husband was rude to me in my dream - I've argued with him about what dream-him said before)’ OLQ
>
> ‘I have also had periods of time were I have muddled up events I have dreamt and reality’ OLQ
>
> ‘I can have very vivid dreams to the extent I’m not entirely sure if something happened in reality’ OLQ
>
> ‘During the dreams I can often wake myself by shouting. But I seem to go through several “layers” of sleep, and it’s difficult to tell when I’m really awake’ OLQ
>
> ‘Sometimes I wake up and especially if I wake up mid dream, I just don’t know if the dream was real or not, it just takes me a little while to get my bearings and process what has happened. This is fine if a can just sort myself out at my own pace, but if I get interrupted or I need to do something else quickly then I don’t get that processing time and that is really unhelpful. Doesn’t get the day off to a great start’ II.

Concerns expressed within REAL OR IMAGINARY showed lingering self- doubt persisting into waking life:

> ‘Sometimes I have to phone the person I dreamed about, to check it wasn’t real’ OLQ
>
> ‘Sometimes it’s hard for me to differentiate between reality and what was a dream. It feels real, like a memory of an actual event’ OLQ
>
> ‘Sometimes I can’t look at or talk to a person if they’ve behaved badly in a dream’ OLQ.

Making sense of what is real or imaginary also highlighted strongly felt concepts of déjà vu from participants

> ‘I sense deja vu at the periphery some days. And sometimes fall into an extreme sense of deja vu that has not been diagnosed as anything else, and has happened for 10 years. Much like a temporal seizure is described -- visceral and physical response to rushing into a dream state’ OLQ
>
> ‘I've had a vivid dream about a work colleague I find it hard to interact with them because I get flashbacks of the dream’ OLQ.

REAL OR IMAGINARY is a pervasive theme involving self-doubt and questioning, this was a large area of activity in CONSIDERING DREAMING and a source of anxiety for participants.

5.4.4.2 RE-TELLING

The theme of RE-TELLING involves preparing and sharing a dreaming experience with someone.

> ‘Most of the time it is about my work related dreams with my work colleagues, who find it amusing I dream about work so much’ OLQ

> i feel excited to recall them and tell others about them OLQ

> ‘I wonder why most people can't remember their dreams and why aren't they as vivid as mine when they do’ OLQ

> ‘I’m cagey about how much I reveal as I like to keep most to myself’ OLQ

> ‘I don't generally discuss embarassing dreams. Just the weird or cool ones’ OLQ.

> ‘I mostly only discuss really bizarre/random dreams that I think will make people laugh’ OLQ.

The reaction of the other person in this process can be critical to the outcome:

> ‘Depending on the reaction of the person I have told, it can make me happy or depressed. If I think it was an amazing dream but the listener is dismissive then I can get depressed about that’ OLQ .

The success of the process of RE-TELLING can involve a level of social reading by the participant, that they do not reveal any information that might cause embarrassment or

> ‘I don't generally discuss embarassing dreams. Just the weird or cool ones’ OLQ.

> ‘I am careful not to discuss anything that might be too personal or potentially embarassing’. OLQ

> ‘I used to discuss my dreams all the time and then I realised that someone was using the dreams in an unkind way to ridicule me to other people so now I tend not to tell other people unless I have really thought about all the possible pitfalls of telling someone’ II.

5.4.4.3 FORMULATING

FORMULATING comprises of activities that suggest purposeful actions in understanding the dreaming experience, these may include some discussion or analysis:

> ‘I have many dream dictionaries and books on symbolism and relate to this knowledge very well. i.e. if I dream of someone with a conch shell, an ancient form of communication, I know it means they want to contact me or someone. I have taken part in shamanic dream journeying which was very profound, moving and truly awe inspiring. It proved to me that some dreams are much more than just a brain mechanism, they take us beyond this reality, although I already knew this as a child, from my father’ OLQ
>
> ‘It can help me analyse why other people behave as they do and rehearse my response’ OLQ
>
> ‘I also believe that they help me to process and make sense of the world’ OLQ
>
> ‘I tend to discuss my dreams with my friend who helps me process the dreams, almost like I need to be reassured it was a dream and not real’ OLQ
>
> ‘If I have a sad family dream it can linger for a day. Writing it down can help process it’ OLQ
>
> ‘I did keep a dream journal for a while, but when my dreams stopped for a while I got out of the habit. I don’t think that it helped that much’ II.

5.4.4.4 NOSTALGIA

Although dreams with elements of NOSTALGIA were not widespread in the online questionnaire narratives, there were references to early life experiences, some of which participants appeared to recall fondly and seemed to want to protect or perpetuate:

> ‘Pleasant nostalgia feeling - like remembering a happy memory’ OLQ
>
> Same locations and 'cast' that grows each time to take in more daily life. Dreams about relationships that are not active in real life but continue vividly in dreams. Dreams in which I remember an old community/place/people that I have left but that have amalgamated the reality and the unspoken reality into a new dream landscape (ie people say and act what they hid) OLQ
>
> ‘A lot tend to be in my childhood home’ OLQ

> ‘I often feel strongly tied to the emotions of the dreams, nostalgic, sad, hurt etc.’ OLQ.

Other aspects of retrospective dreams were not recalled in the same fond manner:

> ‘I remember dreams that I had at the age of 7. I suppose they must have been very unsettling at the time for me to remember them so many years later’ OLQ.

5.4.5 VALUING DREAMING

VALUING DREAMING is the sensemaking activity around the legacy of the dreaming experience; the value that the participants perceive that the process contributes to their lives either positively or negatively. This organising theme draws upon the basic themes of:

ENJOYMENT

CREATIVITY

ESSENTIAL FOR WELL BEING

AS NIGHTMARE

PROPHECY

5.4.5.1 ENJOYMENT

Dreams were valued for their ability to provoke ENJOYMENT in participants. The details and beauty of the dreamscapes was a very positive factor.

> ‘I like that most of my dreams are incredibly vivid and detailed, I enjoy the complete escapism of a good dream’ OLQ
>
> ‘My lucid dreams when I'm not stressed are the most fascinating experiences. I've learnt to fly and to alter

> gravity. And see some amazingly beautiful dreamscapes' OLQ
>
> 'I have awesome weird dreams that are fun and impossible to actually happen and j like it. It's like escapism' OLQ.
>
> 'If I'm relaxed and have the time to get into a positive state of mind about it then lucid dreaming can be a really great experience, it just takes such a lot of effort to get into that state' II.

Participants also suggested that the enjoyment was not just about escaping into something positive but that it was about escaping from something more negatively toned:

> 'I enjoy dreaming it's an escape from reality'. OLQ
>
> 'I feel happy being elsewhere in my mind rather than the real world especially wheb I am stressed' OLQ.

Where participants reported a high level of enjoyment in the dreaming activity this produced further enjoyment in waking life; a participant who described their dreams as 'vivid' and 'exciting' went onto describe how they felt about dreaming:

> 'i enjoy my dreams and i feel happy thinking about them during the days following' OLQ

and how this enjoyment was increased by further consideration and processing of the dream:

> 'it makes me feel happy during the day when i think about my dreams and i will often daydream about how the dream might have continued. i also have a desire to talk about my dreams to other people' OLQ.

5.4.5.2 CREATIVITY

CREATIVITY was a theme that participants referred to as being a perceived benefit from the dreaming process. CREATIVITY had elements that were inspirational and stimulating:

> ‘I generally enjoy it and find it enriches my creativity in my waking life’ OLQ
>
> ‘I sometimes get really good ideas from dreams, or solutions to problems’ OLQ
>
> ‘just to revel in the fact that I have a good imagination :)’ OLQ
>
> ‘I find them interesting and helps my imagination’ OLQ
>
> ‘Improves creativity. I am more inspired to draw and write and make music. Improves my performance at work (science teacher) as I can better use analogies, write revision songs and make more creative lessons’ OLQ.
>
> ‘I think that it can help with problem solving, sometimes I wake up with a really clear view of what I should do about something, like an action plan’ II.

Whilst others reference writing and storytelling directly which links in with some of the articles considered in the literature review. (Schredl & Erlacher, 2007):

> ‘Promotes my creativity and story telling’ OLQ
>
> ‘I write so sometimes they are useful inspiration’ OLQ
>
> ‘sometimes it inspires my writing’ OLQ
>
> ‘I enjoy tapping into the otherworldy experience and writing about it’ OLQ
>
> ‘I sometimes use my dreams for writing fiction’ OLQ.

Although not referenced in the responses to this questionnaire there have been connections with other aspects of problem solving and creativity in dreaming such as musical creativity (Konig, Fischer, Friedmann, Pfeiffer, Goritz & Schredl, 2018).

5.4.5.3 *WELL BEING*

WELL BEING in this context is taken as being any influence that the participant reports or suggests as being a positive outcome for them.

One area of WELL BEING was in the sense of processing thoughts and memories:

> ‘Sleep well my health and mental health better’. OLQ
>
> ‘I think my dreams are helping me process grief and trauma’ OLQ.

Other participants reported that dreaming provided an indication of mental health and well-being:

> ‘Dreaming is an amazing thing and can be beneficial to me by giving me insight into my internal struggles and promotes creativity and is also entertaining despite the nightmares’ OLQ
>
> ‘I think that dreaming sometimes releases psychological pressure that is building up. It also sometimes alerts me to people and situations that could be harmful’ OLQ
>
> ‘It’s strange to say but this is probably the first time I have spoken to any one about this dream in any great detail – I told work that I had a migraine when I rang in sick – but I think that it was a huge event in terms of my mental well being and signalling that I was in a very difficult place. After months of living with the stress and trying to jog along like everything was alright, I knew that it just wasn’t and that I needed to take action to prevent myself becoming quite ill’ II.

5.4.5.4 *NIGHTMARE*

Perhaps not surprisingly, there were very many references to dreams as nightmares, these are events that are negative in their unfolding and their legacy and have overtly antipathetic connotations for the participants. It would have been unhelpful to represent them in any other way other than NIGHTMARE:

> ‘I life in fear of sleeping which leads to sleep-deprivation which leaves me a zombie half the time. Comorbidly it

> increases my pain levels because I don't get restful sleep' OLQ

> 'My dreams are very rarely positive or enjoyable. I am most often being pursued by (unknown) animals / humans - mostly fearing for my life. Occasionally I am caught and wake up fighting for my life. Dreams that I have regarding one of my old jobs involve not having carried out certain important tasks expected of me. Another common theme is that my dreams are completely nonsensical and sometimes can be quite amusing to recall after waking (even though my initial feeling after waking is of having had a disturbing dream)'. OLQ

> 'Running away from horrible people, usually people who are trying to hurt or kill me. Arguing with people, but usually in the dreams I can't say much to the people. They shout at me and I try to say a few things but mostly my voice comes out muffled, as if I'm speaking underwater' OLQ

> 'I often dream I am running up staircases which turn into really fast escalators as I am running up them, so I never get to the top' OLQ.

> 'It's just a total nightmare at times and that's the only way to describe it – a nightmare' II.

NIGHTMARE can resonate beyond the dream and can adversely affect the ability of the participant to regain further sleep, so exacerbating the impact of sleep deprivation:

> 'I often wake at 4 or 5am and deliberately don't go back to sleep for fear of the disturbing dream continuing (which it has done in the past)' OLQ.

NIGHTMARE can be linked to elements of REAL OR IMAGINARY?:

> 'Because my dreams are often so vivid and it's sometimes hard to separate the memories of the dream from reality' OLQ.

Leaving the dreamer with further emotion work to do to decipher the dream and distinguish it from reality, which may mean for some, checking in with, calling people to confirm that they are safe, so further processing is required to attempt to neutralise the dream:

> ‘They can be a huge distraction and i disassociate thinking about them, or it makes not waking life seem less like my reality and it causes me distress to think too much. I also have unprecedented flashbacks to dreams ive had in my past almost daily. These flashbacks are surreal aand vivid and cause me to feel what i felt in the dream.’ OLQ.

5.4.5.5 PROPHECY

Participants gave the impression that they valued dreaming for its PHROPECY potential. Plans had been altered in some cases quite radically to enable participants to avoid situations or people:

> ‘Sometime something I have dreamt about come true and this will confuse me. there is strong feeling that comes with it’ OLQ
>
> ‘if i thought something dangerous would happen based on a dream I had, I would cancel or reschedule an appointment or trip or not go to a certain place’ OLQ
>
> ‘I once had a premonition in a dream. Exactly predicted something which happened at work the next day’ OLQ
>
> ‘I have thought that my dreams are prophetic, and avoided people and events I have dreamt about negatively’. OLQ
>
> ‘if I felt I was going to be in danger in my dream from something I was going to do in the future, I might modify that plan. That's if I understood the dream. When I was 15 I had a dream that I now realise was showing me an underlying medical condition in a symbolic way. Had I known then what it meant it could have changed many paths and created a better life’. OLQ
>
> ‘I might avoid a place or time. As a teenager I dreamt I was raped in a certain place walking home from college so I always walked the other way if I was on my own. It was a very vivid and distressing dream. I can still see it now’. OLQ
>
> Or fate:

> ‘If something bad happened I see it as a sign/fate so avoid it’ OLQ.

5.4.6 Conclusions to VALUING DREAMING

Very few participants had a neutral attitude towards VALUING DREAMING, most held strong beliefs that dreaming has a positive value, at least in the sense of allowing cognitive processing activities to take place that was in some way compensatory for all the distress that negative dreaming experiences brought. Others felt that it was worthwhile accepting the disturbing dreams and their consequences for an occasional enjoyable dream. In the questionnaires with positively toned responses throughout the perceived value of dreaming was reflected in the effusive language used to describe them: ‘amazingly beautiful’, ‘fascinating’, ‘entertaining’, ‘I love dreaming’. There was also a suggestion that the experience could be improved:

> ‘Keep good dreams remove bad ones’ OLQ
>
> ‘would choose to carry on dreaming if I could have at least 75% positive dreams’ OLQ.

5.4.7 Concluding discussions on SMADE

For the purposes of this project, a minimal definition of dreaming has been used so that the participants were not led by any predetermined concept of dreaming and were able to apply their own definitions. None of the participants attempted to define a dreaming episode with any of the criteria explained in the literature review (Pagel et al., 2001: Neilson, 2007). There was a commonality of understanding about a concept of dreaming, or a way of thinking about dreaming throughout the responses, even in those cases in which participants had commented on having alexithymia or aphantasia, which had the potential to produce an altered state of dreaming.

5.4.7.1 Providing personal insight

Dreaming and the analysis of the experience provided the participants with a means for developing a sense of self in its widest context. Through participation on this project people had to opportunity to explore the production of dreams, what dreaming meant to them, what issues it raised and its impact upon other members of the family amongst a myriad of other possibilities. Reponses suggested that people were also looking through different lenses at the issue, of how childhood relations or bullying impacted upon the process, the role of PTSD and other conditions:

> ‘It makes me realize how abstract dreams are. It also helps me process the information I have viewed in my dreams, potentially discovering the root thoughts and impressions that caused them. I find it quite fascinating as it gives me a view into my own subconscious’ OLQ.

5.4.7.2 REAL OR IMAGINARY?

Discussion of this component theme has been included as this was a key area for many respondents and one that required further processing in waking life to make the dream events in some way manageable:

> These are dreams that I was convinced really happened and I only know they didn’t now because they’re impossible. For example – I remember my older siblings and I flying kites up in the air, except that instead of just the kite going in the sky: we went on the sky with the kites.
>
> I remember years later that my mum or dad said we’d buy a kite and I was convinced that we’d be flying in the sky with the kite but this wasn’t the case. We just let the kite fly into the air. I remember asking about the kind of kites that you could fly in the air with. I was told that those type didn’t exist. But I didn’t buy it. I distinctly remember flying in the sky with a kite. I remember thinking, “I know we flew with one and I one day I will find this type of kite we can fly with!” Eventually I did come to a realisation that the type of kite I was looking for didn’t exist and I realised it must have been a dream. It’s the only explanation.
>
> **Have you ever believed a dream was real?**
>
> Written on 23rd Aug 2018 by Alex Lowery from the blog Alex Lowery speaks about autism..

Interestingly, when permission was sought to quote from Alex’s blog, Sylvia Lowery, Alex’s mum, replied that it had taken Alex ‘years to distinguish between reality and dreams’.

From related works in the literature review (Levin & Young, 2002; Graveline & Wamsley, 2015), and further, albeit brief, research around how people with autism interpret fantasy and their conceptualisation of where the fantasy is located, that is to say, understanding fantasy as something other to reality (Higham, Piracha, & Crocombe, 2016; Morsanyi & Handley, 2012), REAL OR IMAGINARY? may be a further area of difference in the dreaming experience of the autistic population. A propensity towards literal interpretation (Hobson, 2012; Mitchell, Saltmarsh & Russell, 1997) may be making the dreaming experience more complex for autistics.

One of the requirements of the questionnaire design was that it should appear a manageable task for a potential participant and so the questions were selectively chosen to support the aims of the research rather than to delve into details about dream content; to ascertain how dreaming affects autistic people as opposed to how they dream. From the responses, it could be inferred that the clearly fantastical elements such as flying, could be logically processed with relative ease, however this was more difficult when the vivid dreams featured real people and context:

> ‘My dreams generally centre around me doing things or experiencing things that might go wrong or be frustrating/unusual/bizarre in some way. Might be scary (end in me being stabbed or something similar) or sexual (sex or sexual advances from some person in my life, not necessarily someone I'm interested in or attracted to). Sometimes my dream is a repeat of something I did that day but the event takes a bizzare turn (for example the teacup melts when i want to fill it, doors wont open, people don't understand what I am trying to say, etc.). Occasionally I have lucid dreams that are like something out of a fantasy book. No idea where my brain gets the ideas but it comes up with entirely new universes’. OLQ.

Participants referred to the time and effort that they spent in processing the activities:

> ‘Just that when I'm having bad dreams a lot I tend to sleep badly, lack of sleep worsens my anxiety and drains my energy’ OLQ.

> ‘Takes a long time to come out of the unsettledness and be fully aware od what is happening upon waking. Confused and uneasy in the morning’ OLQ.

And the disruption that it can cause to people’s plans, even those that derive some enjoyment from dreaming:

> ‘it may take me longer to get going in the morning which has made me late for work’ OLQ
>
> ‘Yes, if it's particularly bothersome it'll stunt my day, i'll sleep longer if the dream was interesting to me which disrupts plans also it can cause depressive episodes if the dream was disturbing or confusing to me’ OLQ.

These results were not reflective of any of the dreaming legacy attributes in studies reviewed in the literature review, the recall periods and the distress, or excitement at the recall far more pervasive from the reports of the autists. (Blagrove & Akehurst. 2000; Bentes et al., 2011; Bonanni et al., 2012).

The results of the study suggest that there is a greater propensity towards dreaming, and that there is a trend of longer duration of dream recall and effect than in the general and other atypical populations previously studied.

5.4.7.3 Rumination

The responses did indicate that the participants spent a lot of time trying to analyse and understand their dreams, for some this will have been a pleasant experience whilst for others it will have entailed going over the cause of distress over and over again:

> ‘It is often upsetting, to the point of bringing me to tears. It sometimes makes relationships with others difficult if I feel like they “wronged” me in a dream. Sometimes if something scares me in a dream it’s hard to come down from fight or flight or a state of anxiety for several hours’ OLQ.

These re-enactments of the dream can be seen to be as detrimental as the original experience.

Alternatively, it may be that the autistic participants need to go through this process to build up from small details to the bigger picture of the dream, rather than immediately sensing the overall view and then drilling down to details, this process is reversed and so an extended period of consideration is required to attain a wider view.

> When you see an object, it seems that you see it as an entire thing first, and only afterwards do its details follow on. But for people with autism, the details jump straight out at us first of all, and then only gradually, detail by detail, does the whole image float up into focus.
>
> (Higashida, 2014).

5.5 Part 3: The super-ordinate theme: IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE (IADE)

5.5.1 Introduction

The super-ordinate theme of IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE (IADE) is designed to explore the answer to the second research question: how do people with autism think that dreaming affects their well-being?

The organising themes of IADE are CONSTRUCTING THE NARRATIVE, RECONCILING HEROES AND VILLANS and CONTINUING

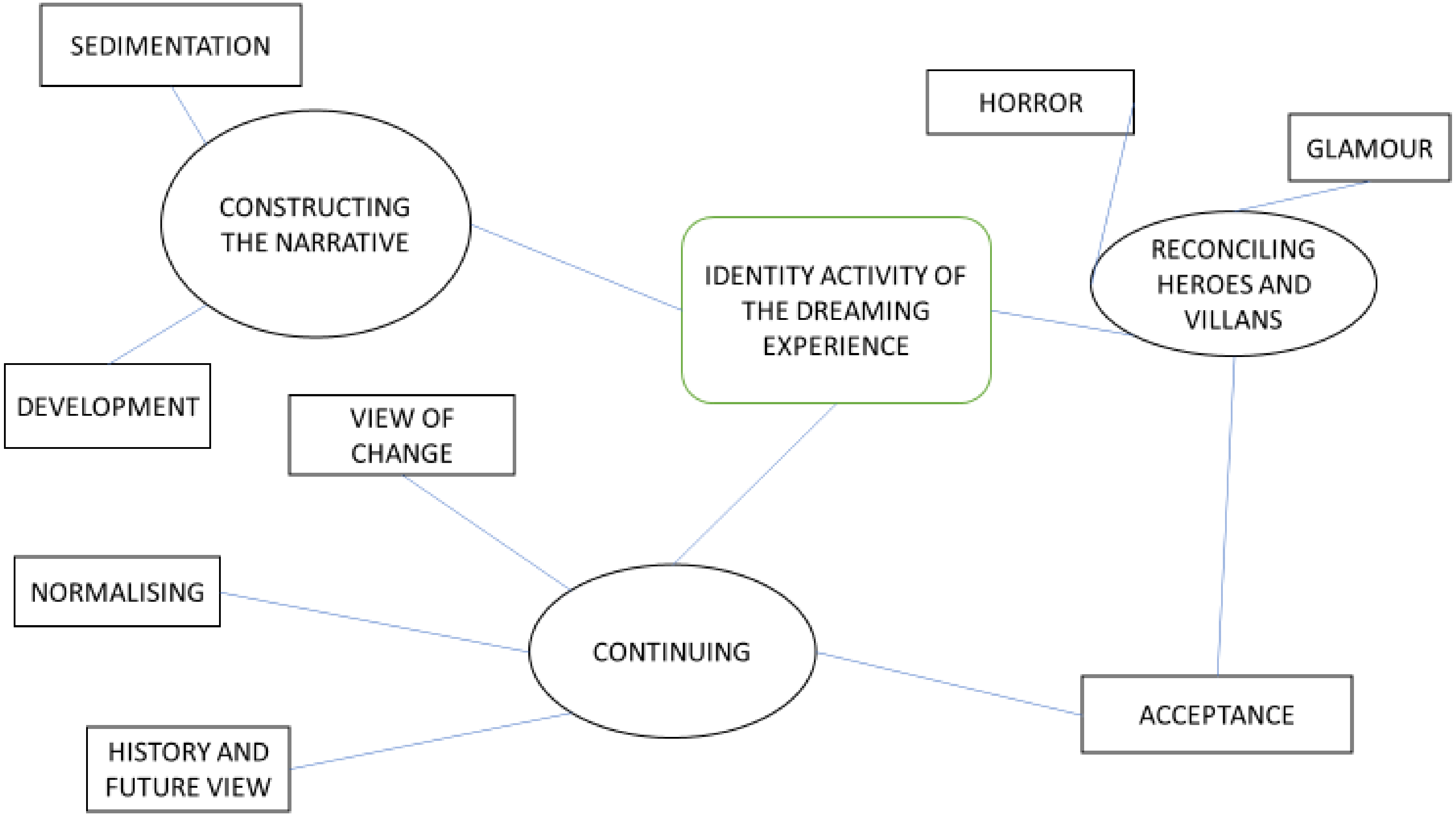


Figure 5.4 Themes contributing to the super-ordinate theme of IADE

5.5.3 CONSTRUCTING THE NARRATIVE

This is comprised of the three stages of narrative development:

SEDIMENTATION

DEVELOPMENT

These themes represent the progressive stages of the formation of the narrative and the definition of the what the experiences means to the participants.

5.5.3.1 SEDIMENTAION

Essentially this is the origin of the interest in the subject or the origins of the engagement with the narrative in the immediate aftermath of dreaming. These origins tend to be in the form of distress or curiosity largely determined by the tone of the dreaming experience:

> ‘Not great! I usually manage to stop thinking about them after about one hour of waking up’ OLQ
>
> ‘i think about all dreams during the day’ OLQ
>
> ‘Usually I like to analyse them, see where they came from’ OLQ
>
> ‘If it was a bad dream then I am very tired the next day and can be anxious. If it was good i am distracted all day because I’m trying to work out the meaning’ OLQ
>
> ‘Questioning why did I dream that last night. what does it mean’ OLQ
>
> ‘Usually, I try to analyse it, and try to relate it to something that may have happened’ OLQ.

SEDIMENTATION is the gradual building of the narrative; it is the ways in which the narratives around dreaming become an ongoing part of the lives of the participants. and how participants privately process this over time:

> ‘For the first few hours after waking I have what feels like flashbacks of the dream where I replay it over in my mind and with that is the associated feelings the dream brought about’. OLQ
>
> ‘Occasionally I have a really vivid dream which I'll think about for 3 days or so. Theae usually have a big emotional impact’. OLQ
>
> ‘I recall a dream almost every morning. It is very rare I don’t’. OLQ
>
> ‘I've then gone onto spend time looking at lucid dreaming and other issues on line, so it just sucks up time that I could be doing other more helpful things’ OLQ
>
> ‘One of my problems is that I have a ridiculous memory – photographic and aural and borderline hyperthymic so I can replay the dream, not quite with the same intensity but still in a very vivid form and even now I can see the settings in which the dream took place’ II.

5.5.3.2 DEVELOPMENT

The theme of DEVELOPMENT is an extension of the process of SEDIMENTATION and has elements of discussion with others or comparison and a formulation or conceptualisation about the dreaming experience and relationships affecting it:

> ‘when one has a sad dream, one might be sad upon waking. When one has a confusing dream, one might be confused upon waking. This is a causal relationship that I think can be safely assumed’ OLQ
>
> ‘In the past, a lot of my dreams were what I would term social anxiety dreams. I would dream about being treated as though I'm invisible, or being shouted at and argued with for no reason, being blamed for things I hadn't done.

> One dream I remember clearly after I left high school, I dreamt that I was back in school and I approached a large circular table with all of my friends/acquaintances around it wearing the school uniform. I kept trying to speak to them and they wouldn't answer me, it was as though they couldn't see me, like I wasn't there. It was unsettling though I know that it related directly to the bullying I went through in school' OLQ
>
> 'Usually if it's interesting enough to discuss with someone else I feel fascinated by all the layers of meaning in dreams after talking about it' OLQ
>
> 'It's become like a daily habit, I wake up, think about my dreams, what they mean and what I need to do about them to sort it all out and move on' II.

In some responses, it appeared that the initial act of SEDIMENTATION had not been successful, in this illustration an attempt to write about the dreaming experiences has taken place and been discontinued but considering this action remains part of the process of the DEVELOPMENT of the narrative:

> 'I think about then a lot. I can't write them down because there is just too much of them they are too big and full of stuff and it would take me weeks to write everything down and then I would be really bothered in case I had missed anything out and I would have to read it all through again and add more bits and then I would probably have had another 5 or 6 dreams to write about . I did try it but I couldn't keep up with it as I'm a bit of a slow writer' II.

5.5.4 RECONCILING HEROES AND VILLANS

The organising theme RECONCILING HEROES AND VILLANS explores narratives around the apparently polar opposites of dreaming as a positive or negative experience and how participants reconciled the two views. It is a curiosity around the idea that, in spite of some dreaming experiences being overwhelmingly negative in content and legacy which has led individuals to fear the act of dreaming, the vast majority of participants expressed the preference of wanting to continue to dream.

Within this organising theme are the component themes of GLAMOUR and HORROR.

The component theme of ACCEPTANCE is linked to the organising theme of RECONCILING HEROES AND VILLIANS and to the further organising theme of CONTINUING, as ACCEPTANCE is essential for the processes encapsulated in both organizing themes.

5.5.4.1 GLAMOUR

Much of the theme of GLAMOUR is tied into similes of television, books and films; the concept draws upon the ‘otherworldliness’ or fantasy of the dreaming experience:

> ‘because my dreams make me feel satisfied at points and its like an escape world at times, its like following a book or films’ OLQ.

Specific references to fantasy worlds on television or film:

> ‘I generally enjoy dreaming vividly. It's like having a bizarre private television station in your head that you can only sometimes change the channel on’ OLQ.
>
> ‘If it was a cool dream then I reflect on it kind of like when you've seen a good movie’ OLQ
>
> ‘My dreams also unfold like stories, an interactive film’ OLQ
>
> ‘I am often only an observer in my dreams and don’t take part in the ‘action’ (as if I was watching TV)’ OLQ
>
> ‘The earliest dream was from circa 1986-7 and inspired by Dr Who (the happiness patrol series). Many dreams feature tv or books that I have had a strong emotional response to’ OLQ
>
> ‘they often have landscapes, particularly sky views that are unusual, black disconnected circles like rainbows, or more than one moon like in the Star Wars films’ II

Where the cinematic references were made to more negatively toned dreaming, the ‘horror films’ were still imbued with some form of Hollywood treatment:

> ‘Sometimes they play out like horror films (I never watch horrors)’ OLQ
>
> ‘my dreams can be quite disturbing and would do any B horror creator proud’ OLQ
>
> ‘Even my anxious ones can be like movies’ OLQ.

In some instances, there is a clear aspirational quality to the dream:

> ‘I dream about being a famous rock star because my main interest is Queen and Freddie Mercury’ OLQ
>
> ‘Flying like superman. Escaping from the bad person like I’m Harry Potter but it’s a maze type place I am in (like the staircase scene at the end of labyrinth)’ OLQ
>
> ‘Superhero type physical abilities - leaping across tall buildings, high speed movement, physical camouflage - but not necessarily a superhero plot to the dream’ OLQ.

5.5.4.2 HORROR

As with the theme of NIGHTMARE, there was such a strong suggestion from participants about the imagery, emotion and response to the negative dreaming experiences that the term HORROR seemed to encapsulate all of these elements.

> ‘I often dream about dead bodies’ OLQ
>
> ‘I often think about relatives dying after the dreams’ OLQ
>
> ‘I usually dream that I have woken up in my own bed, and a relative is sitting beside me, but they are dead. It can be different people, but usually my mum or grandad’ OLQ.
>
> ‘Often violence in the extreme. Feeling of being smothered, and needing to get away from it, waking myself up and finding myself near a window, to get to the light (weirdly rarely do I try to get to the light switch)Feeling unable to move, or walk properly, stuck in one spot and unable to get

> away from something (not sure what that something is)' OLQ

Within this sense of horror was a sense of anxiety about the origins of the dream theme; almost of a sub conscious mind possessing some form of malevolent autonomy:

> 'Often within this concept of horror is puzzlement, embarssment or even guilt that they are the source of origin for such dreams' OLQ
>
> 'I'm 51 and used to them, but I often wonder at how my mind can create such vivid, intense and as I say violent dreams' OLQ.
>
> 'it bothers me that my mind creates these horror shows' II

The basic theme of HORROR, can be seen to cause the participant distress in the sense of the content of the dream but also in terms of questioning where the origins of the dream are; why would someone create these extreme dreaming episodes some of which included dead family members?

5.5.4.3 ACCEPTANCE

As discussed above. ACCEPTANCE is a component theme which is a requirement for the organising theme of CONTINUING, which will be discussed in the next section as well as for the current organising theme of RECONCILING HEROS AND VILLANS. Without ACCEPTANCE there could be no process of continuation or reconciliation:

> 'dreaming is like watching a film your subconscious makes to entertain your brain while your body rests. even when the dreams are disturbing or confusing, it's better than kissing the void' OLQ
>
> 'Because although the dreams are mostly negative, the experience itself is so vivid and intense, i would feel empty without it. Like something missing' OLQ
>
> 'it's weird, but despite the fact that the dreams are often dangerous and unpleasant, they often feel more real to me than my real life' OLQ.

5.5.5 CONTINUING

The organising theme of CONTINUING involves views of how participants see the dreaming process integrating into future life. It is comprised of the basic themes of:

HISTORY & FUTURE VIEW

VIEW OF CHANGE

NORMALISING

5.5.5.1 HISTORY & FUTURE VIEW

The component theme of HISTORY & FUTURE VIEW involves how participants experienced dreaming in the past and how they see this continuing into the future with some reporting the historical repetition of specifically themed dreams:

> ‘As a child I had a set of 4 different recurring nightmares which I had on a nightly basis, every night from age 4 or 5 until I was around 11. I occasionally still get dreams related to those nightmares when I've been reminded of them’ OLQ

> ‘I've gotten used to going through phases were I just have a lot of bad dreams and have done ever since I was a child’ OLQ

> ‘Of I think of specific things before I sleep I can create the same dreams over and over again’ OLQ

> ‘My dreams as I recall, are almost 100% negative since a child (I am now 44)’ OLQ

> ‘Lack of restful (or long enough) sleeping affects my cognition, reflexes, and pain. Overall, it's physically killing me’ OLQ

> ‘I don't see the value in continuing that experience unless there is some underlying benefit that we haven't yet understood’ OLQ

> ‘I look forward to the future because I know I will be a rock star’ OLQ

> ‘While I don't usually gain any benefit from dreaming I do wonder if I would feel like I read missing out on something if I knew I could never dream again’ OLQ

> ‘it I can become preoccupied with the dream which is historic and this can lower my future mood’ OLQ

> ‘thinking about it, it does seem to take up rather more energy and time than it should, if I had that time I could train for a marathon or learn a language or something’ II.

5.5.5.2 VIEW OF CHANGE

VIEW OF CHANGE in the organising theme of CONTINUING is about predisposition to the concept of change, where change was specifically referenced it was with a negative perspective:

> ‘I also don't like change’ OLQ

> ‘It would be a big change with unforseen consequences and i don’t like change or not being able to predict it’s effects or imagine sutch effects over a long period of time’ OLQ .

Within the theme of VIEW OF CHANGE is an element about the potential of the dreaming experience.

> ‘Because I aphantasia and this is about the last thing left in having any form of fantasy.. it could trigger it as well so I need to dream’ OLQ

> ‘If I could find a trigger for the happier, more exciting dreams, I'd use that knowledge to increase them. I'm also interested in the concept of lucid dreaming’ OLQ.

5.5.5.3 NORMALISING

There was a suggestion from some participants that they felt that dreaming was a normal activity within the general population and so there was a NORMALISING aspect to it:

> ‘It’s a normal thing to do’ OLQ
>
> ‘While I don't usually gain any benefit from dreaming I do wonder if I would feel like I read missing out on something if I knew I could never dream again’ OLQ.

Or *not* NORMALISING of rather contributing to situations in which the participants have a sense of differentness from others:

> ‘after discussing my dreams with others it seems i dream a lot more than the average person and i have more sexual dreams than the average person’ OLQ
>
> ‘I wonder why most people can't remember their dreams and why aren't they as vivid as mine when they do’ OLQ
>
> ‘People are always surprised how stressful my dreams are and they feel sorry for me. It makes me feel like there's something wrong with me - another way I don't fit in’ OLQ
>
> ‘normally situations where I have been very emotionally hurt and / or misunderstood. Times where I have been told I acted wrongly / strangely but I can't see anything wrong with what I did or said. Times when I feel that I was very badly treated. Arguments that I can't understand. Relationships that I believed were close friendships where it came to light that the other person thought we were just acquaintances or work mates. Memories from childhood and school that I don't really understand’ OLQ
>
> ‘Sometimes I feel that I dream in an unusually vivid way based on how he reacts’ OLQ.
>
> ‘Not normal’ OLQ
>
> ‘Sometimes it reinforces how ‘different’ I feel from others’ OLQ
>
> ‘Like I’m a freak’ OLQ
>
> ‘It makes me feel like there's something wrong with me - another way I don't fit in’ II.

5.5.6 Concluding comments on IADE

Identity activity is an appreciation of an individual's perceptions about connection with their environment and others in it, it is a location of self in a wider context.

> In my dreams now, I often tell people that I'm autistic or consciously think of myself of as autistic. That's completely new. Twice, when it seemed like someone was going to attack me, setting off a typical nightmare scenario in which I had to physically defend myself, the police showed up and took the threatening person away! That's never happened before. Another time, I was lost and couldn't find my new (in the dream) apartment. I told some people who worked in the building that I was autistic and couldn't remember where I lived and they all offered to help me. That never happens in my dreams either.
>
> Cynthia Kim (Musings of an Aspie, 2013).

Some of the participants did report that their dreams allowed an element of rehearsal which is congruent with findings from the literature review (Revonsuo & Salmivalli, 1995), and that there was also a sense that other agencies were supporting this internal working out with references to the subconscious, but overall participants did recognised that dreaming was enabling some form of sensemaking and processing:

> 'my subconscious trying to work out situations that have happened and trying to create to scenarios to help me understand situations' OLQ
>
> 'normally situations where I have been very emotionally hurt and / or misunderstood. Times where I have been told I acted wrongly / strangely but I can't see anything wrong with what I did or said. Times when I feel that I was very badly treated. Arguments that I can't understand. Relationships that I believed were close friendships where it came to light that the other person thought we were just acquaintances or work mates. Memories from childhood and school that I don't really understand' OLQ.

The main area of the IDENTITY ACTIVITY was to confirm the identitiy of the dreamer as someone who suffered from their dreaming experiences or benefitted from them. This may have been a product of the specific circumstances of the questionnaire, but participants created roles around their responses to their dreaming experiences.

5.5.6.1 Meta distress or sublime pleasure?

Participants overall either found dreaming a burden or a rewarding activity; there were few who were neutral about either the process or its legacy. Within the participant group there were a significant number of people who were very positive about their dreaming experiences, which was unusual as this is not representative of more general populations who do not report such high rates of positive experiences (Schredl, 2017).

Participants were not only positively or negatively impressed by the process, they also seemed to derive satisfaction or dissatisfaction from their response to dreaming in waking hours; for some ‘it feels like a gift most of the time’ OLQ, whilst others expressed frustration and bewilderment about their reactions:

> ‘It’s just the time and effort that it takes for me to try and sort out what the dream might have been about and then, that doesn’t make the memory of it go away and I’ve spent ages thinking about what it might be not necessarily what it actually is so it just doesn’t help’ II.

> ‘so it just sucks up time that I could be doing other more helpful things’ OLQ.

It was interesting to note that no one reported that they had a mixture of positive and negative dreaming experiences, overall, they were categorically one or the other. There was a small number of participants who went on to answer the question ‘If you could choose to not dream again would you make that decision?’, suggesting that they had occasionally positive dreams which were so influential and pleasing that they would not wish to relinquish their usual, more negatively toned experiences:

> ‘I'm not sure - it's weird, but despite the fact that the dreams are often dangerous and unpleasant, they often feel more real to me than my real life’ OLQ

> ‘Some dreams are positive and it would be a shame to miss out on these’ OLQ.

The proportion of people with an intensely positive view of dreaming and its legacy was significant and quite at variance to the findings of the literature review which showed only small percentages in general populations experiencing positive dreaming. (Weinstein, Campbell & Vansteenkiste, 2017).

5.6 Part 4: The superordinate theme: ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE

5.6.1 Introduction

Discussion of the themes comprising ADAPTATION ACTIVITY OF THE DREAMING EXPERIENCE (AADE) is intended to answer the third research question; what adaptations have people with autism made as a result of their dreaming experiences?

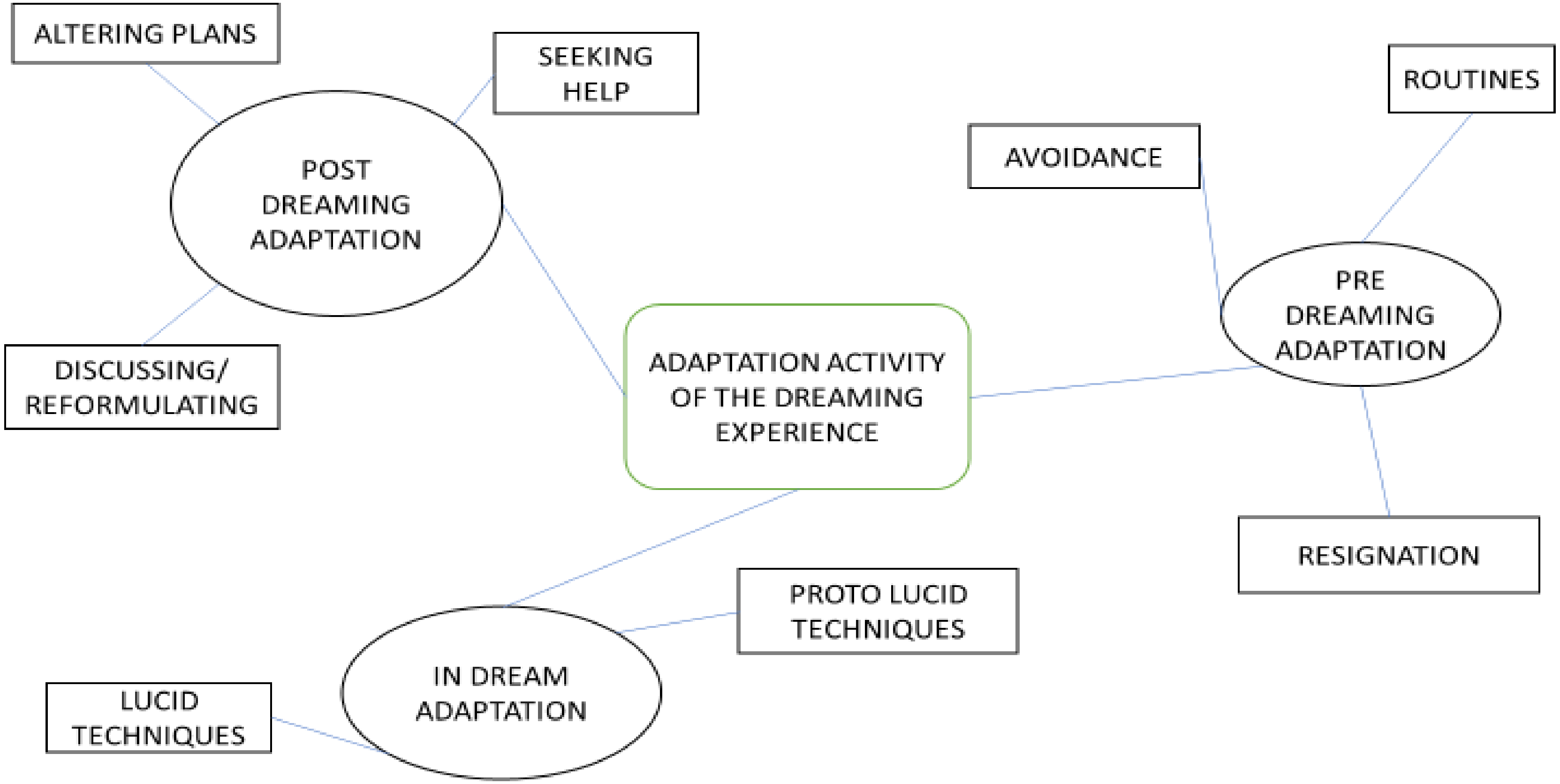


Figure 5.5 Themes contributing to the super-ordinate theme of IADE

AADE is comprised of the organizing themes of:

PRE-DREAMING ADAPTATION

IN DREAM ADAPTATION

POST DREAM ADAPTATION

5.6.3 PRE-DREAMING ADAPTATION

PRE-DREAMING ADAPTATION encompasses the basic themes of AVOIDANCE, RESIGNATION and ROUTINES.

It explores any adaptation that the participants have attempted to introduce to affect their dreaming experience before entering the dream state.

5.6.3.1 ROUTINES

ROUTINES are the habitual changes that participants have made in their activities to mitigate against the effects of dreaming:

> ‘I already do use this knowledge to avoid dreaming as much as I can. e.g. I sleep with a very thin duvet all year round and I often leave a window open a tiny bit so that my room doesn't get too warm.. make myself as comfortable as possible before going to sleep by opening a window, drinking some water’ OLQ

> ‘I I try to manage difficult situations in healthier ways than rumination. also try to reduce stress and other negative feelings through self care’ OLQ

> ‘I try to keep a regular sleep pattern. This avoids getting over-tired, so I’m less likely to have the dreams. But actually my main motivation for doing this is not to avoid the dreams, but just to be less tired and have better daytime functioning’ OLQ

> ‘I do a lot of the obvious sleep hygiene stuff already, so like no coffee after tea and I am careful about what I watch on tv. Even if I’ve been out, I try to have half an hour getting calm and not particularly doing anything that I have to think too much about before I go to bed’ II.

These ROUTINES were cross referenced with the SMADE organising theme of UNDERSTANDING DREAMING and in most cases positive or considered responses to UNDERSTANDING DREAMING were a precursor for attempted improvement through ROUTINES.

5.6.3.2 AVOIDANCE

AVOIDANCE has been included as a component theme as this was something that resonated through the online questionnaire and initial interviews:

> ‘if I seem to be in a period where I'm having lots of bad dreams (sometimes about my dad) then I can get really scared of going to sleep and I don't want to fall asleep and try and stay awake’ OLQ
>
> ‘Sometimes I don't take melatonin when I'm anxious because I don't want my anxiety dreams to be especially vivid’ OLQ
>
> ‘I would be afraid to go to sleep as the repeating dreams were nightmares’ OLQ
>
> ‘I only avoid nightmares as I have a certain feeling before I fall asleep and I keep myself awake until it passes’ OLQ
>
> ‘Sometimes if it’s been a bad day, I just know that I am going to have a really bad dream and that makes me really nervous. I try not to go to sleep so I’ll have a lot of coffee or something really sugary and then keep the lights on or try and read or watch a film or all of it, but I usually can’t help myself and a drop off and then the nightmares start’ II.

In practical terms it is not possible to avoid sleep totally; the world record of 11 days and 25 minutes set in 1964 by Randy Gardner (without pharmacological stimulants) is unlikely to be challenged as there is so much evidence that extreme sleep deprivation is dangerous that the Guinness Book of Records will not condone a further attempt. There is an inevitability about falling asleep and to try and avoid or delay that process might put the individual at risk from altered perspectives regarding risk (Womack, Hook, Reyna & Ramos, 2013). The origins of sleep avoidance and loss are important as well as these might be pharmacologically derived (Rusnac, Sptzenstetter and Tassi, 2018) and so sourcing substances to support the avoidance of sleep may be another form of risk taking, or may be pursued through excessive mental stimulation (Eickoff et al, 2015). Although the timing of exercise can disrupt sleep to an extent, physical activity is not thought to be a significant factor in sleep avoidance (Alley, Mazzochi, Morris, Smith & Collier, 2014). Sleep avoidance can have a damaging impact upon cognitive function (Spencer, 2013) as well as impairing a range of physical functions as discussed in the Literature Review (Chapter 2). One participant referred to the difficulties in avoiding sleep:

> ‘it can make me not want to sleep which messes up my sleeping pattern and makes me more tired, which then makes everything else harder to cope with, increases sensory difficulties, etc’ OLQ.

5.6.3.3 RESIGNATION

RESIGNATION is a passive version of ACCEPTANCE, whereas in ACCEPTANCE there was a suggestion of some consideration of alternatives and then ways forward that synthesised these, in RESIGNATION there was more of a sense of dreaming as an inevitable act that individuals just had to live with:

> ‘If I drink alcohol I know I will dream so I am prepared to deal with it’ OLQ
>
> ‘It just happens’ OLQ
>
> ‘You dream for a reason’ OLQ
>
> ‘Not sure what else I can do’ OLQ.
>
> ‘Dreams are part of the human experience. They’re just a part of life’ OLQ
>
> ‘I gave up trying, there’s nothing to do about them’ II.

5.6.4 IN DREAM ADAPTATION

IN DREAM ADAPTATION are those adaptations which individuals make, either consciously or unconsciously, in the dream state, they are grouped into NAMED LUCID TECHNIQUES and PROTO LUCID TENCHNIQUES.

5.6.4.1 NAMED LUCID TECHNIQUES

Lucid Dreaming is a process by which individuals practice certain techniques to affect the direction or outcome of the dream. There are proponents of Lucid Dreaming who consider it to be transformative (LaBerge, 2004). The category NAMED LUCID TECHNIQUES refers to narrative in which participants refer specifically to this as a formal approach aimed at improving the dreaming experience by being able to exert some influence over it:

> ‘Much as I tried the lucid dreaming approach, nothing seems to work to structure my dreams in the way I would like’ OLQ

> ‘I'm also interested in the concept of lucid dreaming’. Response OLQ

> ‘I've practiced lucid dreaming exercises, but I've not bothered in a while since lucid dreaming allowed me certain abilities in all my dreams, lucid or not’ OLQ

> ‘Lucid dream often when I'm not stressed’ OLQ

> ‘I have lucid dreams that are like something out of a fantasy book. No idea where my brain gets the ideas but it comes up with entirely new universes’ OLQ.

This technique can be difficult to understand and implement:

> ‘Much as I tried the lucid dreaming approach, nothing seems to work to structure my dreams in the way I would like’ OLQ.

However, in those instances when the techniques of Lucid Dreaming can be applied successfully, participants were enthusiastic about the outcomes:

> ‘Lucid dreaming for sure! It’s completely transformed my dreaming life, I started looking online to see if anyone else was having problems like mine and I found that people were and the there was this lucid dreaming thing. I don’t use lots of it like the finger pulling and the tapping but the reality checks have just been so helpful. I just try to look at a clock face, so either the watch on my wrist or a larger clock on a wall or somewhere. And that tells me immediately if I am in a dream. Once I know that I’m dreaming then I’m not as frightened about things happening in the dream because it’s not real. And I think that because I’m not frightened in the dream any more that the dreams have become happier or more positive, so I’m not as anxious when I’m awake or asleep because of dreams. If someone had told me to look for a clock when I was dreaming when I was younger, I think I could have had much less anxiety about the whole thing’ II

> ‘Now that I’ve got into the lucid thing its really great, although I do sometimes worry about how restful the sleep is and if it helpful to have my brain so engaged and active in sleep, but then I think that it would just be having awful nightmares if I didn’t so maybe it doesn’t really matter. But I like lucid dreaming, I’ve now worked out how to fly and how to make huge jumps up and down cliffs and buildings

> and mountains, so I can go anywhere I want in my dreams'
> II.

5.6.4.2 PROTO LUCID TECHNIQUES

The theme PROTO LUCID TECHNIQUES refers to narratives in which participants suggest that they can control or influence the dreaming experience without adopting or referring to any specific techniques that might be associated with Lucid Dreaming or the actual term Lucid Dreaming:

> 'I can often change the direction of a dream to something much more appealing to me' OLQ

> 'sometimes whilst i am dreaming i can control my dreams to change them or if i am not enjoying my dream then i can make myself wake up stopping the dream altogether' OLQ

> 'I think sometimes I can actually influence what happens as I'm dreaming actually, almost like I'm living in the dream. It's usually quite enjoyable, if odd. Unless an apocalypse is happening in the dream as has happened a few times recently. I blame brexit (seriously!)'. OLQ

> 'now I know that I can influence the direction and outcome of the dream they are not so frightening and my anxiety levels overall have radically decreased' OLQ

> 'While I'm dreaming if i realise I'm dreaming then i can usually direct the dreams trajectory or make myself wake up if its scary'. OLQ

> 'as a child I would have the same nightmares until I "solved" the nightmare. For example, getting trapped in a house, the dream repeated exactly for years until I escaped the house. Then I never had it again'. OLQ

> 'I can go to bed the next night and deliberately think about the previous dream and go back to it. Sometimes, I wake up then go back to sleep and continue the same dream' OLQ.

The PROTO LUCID TECHNIQUES are rather different from LUCID TECHNIQUES, AVOIDANCE, ROUTINES and RESGNATION, in the sense that these had not been considered conscious responses or strategies that had been researched or given thought to but were rather more organic solutions which had emerged at some point during a dreaming experience.

5.6.5 POST DREAMING ADAPTATION

POST DREAMING adaptations fell broadly into three component themes, SEEKING HELP, ALTERING PLANS and DISCUSSING/REFORMULATING. Some responses were quite reactionary whilst others were indicative of more developed strategies that had evolved over time.

5.6.5.1 SEEKING HELP

The questions around SEEKING HELP referred to formal, perhaps more clinical, models of support rather than informally discussing dreaming, and in the responses to the question no one reported that they considered talking to friends or family to be SEEKING HELP.

None of the participants reported that they had sought help but had been unsuccessful in being referred onto a service, either because there was no appropriate service or because the referring professional did not know where to refer to, so in this sense the small number of positive responses around SEEKING HELP did not reflect participants looking for support and finding that there was none available, but rather that they did not seek support for dreaming as the primary cause of concern. Of the small percentage of the participants who had attempted to seek help for the effects of dreaming, one of this group was already accessing therapy so had the opportunity to explore this phenomenon as part of that process rather than seeking a sperate referral particularly for a therapeutic intervention. Overall the results of SEEKING HELP were not positive:

> ‘Worse than a failure. Dreams got even more violent after attempting therapy to deal with them’ OLQ
>
> ‘I am currently in therapy. I haven’t made any progress yet but am hopeful about the future’ OLQ

> 'didn't fix the problem that was causing them, anxiety, which I now believe was due to being undiagnosed asd at the time' OLQ
>
> 'I had some counselling a couple of years ago and the counsellor was trained in EMDR therapy, so when I told her about a particular dream we did some of that and it worked. But then I stopped having the counselling and some rather different dreams started to appear and so it was back to square one' II.

These less than positive outcomes may be because the help and support was not sufficiently focussed on dreaming or because the issues around dreaming were being addressed in the context of an overarching problem.

The responses to this question reflects the findings of Schredl's article 'Seeking help for nightmares' (2013) which suggested that generally people were unsure of what support might be available and where to apply for that, and that there was often a sense that disturbing dreams were 'normal' because they had persisted for many years.

5.6.5.2 ALTERING PLANS

Reponses to the questions about ALTERING PLANS fell largely into the categories of pro or reactively changing schedules. Themes of ALTERING PLANS included proactively changing plans because of some element of prophecy on the dream

> 'If something bad happened I see it as a sign/fate so avoid it' OLQ
>
> 'I have canceled plans if the dream is particularly upsetting (someone I know dying)'. OLQ .

Alternative themes were more reactionary:

> 'I have had one or two massive dreaming experiences that have left me so mentally exhausted that I have been late into work' OLQ.

Some responses indicated that there was a planned, rehearsed strategy in place to deal with reactions to dreaming episodes:

> ‘postpone an hour or two’ OLQ
>
> ‘Work from home if I need to’ OLQ.

And some suggested that the participant would conceal the reason for the alteration and give an alternative explanation:

> ‘Texting people saying that I am poorly’ OLQ
>
> ‘I don’t think that I would ever actually tell people that I had had a nightmare. I think that if I’ve felt so off or upset by the whole dream think I would say that I had had a migraine and would be in later. I don’t usually need a full day off just a couple of hours but I think if I rang in and said I had had a bad dream that there would be some sort of issue, lots of raised eyebrows to say the least’ II.

5.6.5.3 DISCUSSSING/REFORMULATING

This post dreaming adaptation was perhaps the least reported of the three basic components of POST DREAMING ADAPTATION, with only one participant from the initial interviews describing this as a usual way of dealing with post dreaming:

> ‘if I have a really bad dream, I try and discuss it with my partner, we usually have breakfast and walk the dogs together so more often than not there is a chance to talk about it. I tell them what happened in as much detail as possible although if anything horrible happened to them in the dream I probably would tell them. And we would usually try to interpret the dream, or at least see if we could link it in to anything that had been going on recently. And I think that really helps me to have this chance to know that I can talk about it and get it out of the way. Talking about the dreams like this has helped me to see the patterns in them and has made them less scary, more neutral when I

> think about them when I’m awake, although they are still scary when I’m having one’ II.

The responses in terms of adaptation tended to have more passively orientated language for those with negative experiences and more active for those who enjoyed dreaming. There was a suggestion of the immovability of adverse dreaming, that it was in some way unalterable; the most prolific responses to the question ‘is there anything that you can do to later your dreaming experience either in the dream state of before falling asleep? were ‘no’, ‘don’t know’ and ‘not that I’m aware of’. These responses may just be resignation following years of suffering with dreaming, or they may be indicative of the possibilities to influence and improve the experience. The more positive responses were long and more detailed overall:

> ‘I’m usually aware while I’m dreaming. Sometimes I can make choices and change things’ OLQ
>
> ‘in the dream sometimes - I can refuse to accept an outcome or go back and replay a scene’ OLQ
>
> ‘I sometimes do 'to sleep' type meditation and/or white noise when falling asleep. Again for good sleep hygiene’. OLQ.

5.6.6 Concluding comments on AADE

Throughout the individual questionnaires were illustrations of debilitating experiences Looking at the responses vertically (by participant) suggested that scripts where more positive where individuals had been able to confidently discuss dream content with a respectful other or where some form of lucid intent, either consciously or unconsciously developed was established. Those questionnaires which showed that participants had a clear view of the triggers of their dreams and had developed strategies to manage these were more positively toned.

One participant had identified their dreams as ‘vivid’, ‘unsettling’ and ‘bizarre’ with reoccurring themes of

> ‘People I care about being attacked/hurt. Bizarre events (instead of 'school photo day' it was 'school beheading day'

> & everyone was lining up like it was perfectly normal having your head chopped off & a new one put on...)’ OLQ.

However, the participant had been able to identify strategies to mitigate against their more severe impacts such as ‘think of positive, happy memories’ and discussing dreaming: ‘I feel happier & more relaxed having spoken about them’.

Reponses in which participants were unsure about the origins of dreaming activity usually followed a more negative pattern:

> ‘I have tried to figure this out in order to break the cycle - with no success. I can only assume it is linked to my general overall mood but it may be that the recurring disturbing dreams are in fact causing my overall mood to worsen’ OLQ.
>
> ‘In the moments after waking, the disturbing dreams can have a big impact. My mood will be dark and I feel almost annoyed at having had such a dream. I am obviously less well rested and can wake up feeling more tired than when I first went to sleep. After prolonged multiple dreams in one night I can feel exhausted on waking. It also affects my relationship as I am not very good company soon after waking. However, I generally forget all about them within 15 minutes or so unless they were particularly disturbing. So I guess the main impact is that I may spend a couple of hours on my iPad from about 5am rather than going back to sleep’ OLQ.

It is perhaps to be expected that responses would follow a theme, that they would not alter part way through, but there was a link between being able to identify triggers effectively and the tone of the questionnaires, even in those instances in which triggers had been identified but compensatory strategies had not been found the participants appeared to be empowered just from the knowledge that they understood the origins of the dream, that there was some rationale for why these unpleasant experiences were happening:

> ‘I think that melatonin triggers my dreaming as I never dreamt before I took it. I know that I need it from time to time but at least I know that if I dream it’s all down to tat and I’m bit as bothered by the dream, I don’t sit all the next day trying to analyse it’ II.

5.6.6.1 View of change

Within this theme of adaptation is perhaps the ultimate option of change, namely the question ‘If you could choose to never dream again, would you want to stop dreaming?’ Only around 11% of participants replied that they would take that option, the overwhelming majority either didn’t want to stop or were unsure about stopping and yet many of those who wanted to continue dreaming were experiencing extremely distressing episodes on a regular basis:

> ‘I dream about demon possession, rape, and being chased’ OLQ
>
> ‘Dream a lot that i hve lost something i love and no matter how hard i try cant find them, such as my dog. once had a dream of my chest moving like the waves of the sea,wreird!!. being stabbed by a murderer etc. very vivid dreams all the time. once had a dream where just before i woke up i was going towards this light bright light and knew id died of cancer’ OLQ.

The response to this question was interesting. Other questionnaires and debates on online forums had rarely touched on this possibility and so it might be that this was a question that participants were not expecting or prepared for. Some of the responses were indicative of wanting time to consider this option and any potential consequences:

> ‘I'm not sure - it's weird, but despite the fact that the dreams are often dangerous and unpleasant, they often feel more real to me than my real life’ OLQ.
>
> ‘It's odd, but it really is a part of me, since i was very young’ OLQ
>
> ‘It's not something I have given thought to, I would need a long time to weigh up a decision that was as long-lasting as this’ OLQ
>
> ‘I don't know. Even though most of my dreams are scary, or unnerving at least, I wouldn't want to stop dreaming completely that just sounds odd to me. I think maybe my dreams are there because my subconscious is trying to tell

> me something, like stop being stressed all of the time! Or deal with that childhood trauma! Dreams must exist for a reason' OLQ.

This might reflect a fear of taking such a radical step and not knowing if the process of dreaming could be improved, it may be indicative of a faint hope that it might be, or it may be indication of a cluster of autistic preferences for resisting unplanned change and a desire for a preferred activity:

> I'm just gonna be honest. Change sucks. A lot. It's actually really scary; especially for people on the Autism Spectrum. I'm not entirely used to change yet; but I have most certainly gotten better at adapting to it. Change to me means to make or become different. For the most part, I don't want to change or become different; but all through my life I've been asked to because people aren't always comfortable with how people on the spectrum act.
>
> Autsin John Jones form the blog Autism and the resistance to change featured on the website The art of autism 20.2.2018.

This view of change also links into issues of self construal, of how the person would envisage themselves if not as a person who dreams. The participants had shown that they sufficiently motivated to contribute to the study and had demonstrated that they gave considerable thought and time to think about their dreaming activity, many since childhood, and it seems that this had become part of their identity, even those with the negative experiences so it as an area of activity that was part of the fabric of everyday life:

> 'That's a strange question and one that I haven't thought about before. I'm not at all sure to be honest. If I didn't dream then I would lose having dreaming to talk about. I would have to find other things to talk to my friends about and that might be difficult. I think that I would have a lot more time though' II.

Anxiety can have a great influence over how someone with autism may view change, for many heightened anxieties leads to resistance to change (Spiker, Enjey, Van Dyke & Wood, 2011). 'Stress' and 'anxiety' were amongst the most commonly used terms to describe the perceived origins or dreams and the impact that they have, these were used twice as much through the OLQ than positive descriptors of creativity, enjoy/ment/able/ing and happy. Stress and anxiety were seen to be both precursors to and arising from the dreaming process, whereas the more positively toned descriptors were related to more to dreaming outcomes.

Fergus Murray provides a personal account of how unsettling change can be:

> Stability is a basic human need, and life as a monotropic person in a polytropic world is often unstable. It is deeply destabilising to be pulled out of an attention tunnel, to be regularly surprised by people's actions, or to feel you are not being understood. Much of autistic behaviour can be seen as attempts to restore some kind of equilibrium.
>
> Fergus Murray from the blog Me and Monotropism: A unified theory of autism.

Anxiety is one of the greatest influencers in the production of dreams and its role in the well being of people with autism is well-established (Bjerot et., 2014; Black et al., 2017; Rzepecka et al., 2011):

> 'Think it would reduce my anxiety if I didn't dream and improve my sleep' OLQ
>
> 'If it has been a bad dream experience I can get depressed because I haven't slept well' OLQ.

Anxiety and reluctance to accept change can begin to spiral as the more someone invests in preserving the status quo then the greater the anxiety caused by threat of disruption becomes. Those experiencing negative dreams were also using more expressions and references to anxiety throughout the questionnaire so it is perhaps not unexpected that participants did not wish to add to their anxiety by jettisoning a constant feature in their lives to replace it with a very uncertain future experience.

5.7 The interconnectedness of the thematic diagrams

As discussed previously, the thematic diagrams are not discrete structures but rather interlinked and during the course of the research, particular relationships between organising themes became apparent, these causal relationships and impact on the findings of the project is discussed in the following section.

5.7.1 VALUING DREAMING and RECONCILING HEROES AND VILLANS

VALUING DREAMING is the precursor for RECONCILING HEROES AND VILLIANS, as there needs to an appreciation of the different effects of dreaming and the legacy that it leaves before the act of reconciliation can be attempted. For example, in assessment the positive or negative value that dreaming produces in areas of ENOYMENT, CREATIVITY, PROPHECY, NIGHTMARE and WELL BEING, will enable a judgement to be made about the contribution of the dreaming experience in the individual's life experience.

5.7.2 UNDERSTANDING DREAMING and PRE DREAMING ADAPTATION

UNDERSTANDING DREAMING is a prerequisite for PRE DREAMING ADAPTATION, as an individual needs to have an appreciation of the factors producing the dreams in order to frame some revision of them. When viewing the responses by participant the questionnaires which demonstrated that the participant had a well-developed understanding of the origins of their dreaming activity were, overall, the most positively toned ones.

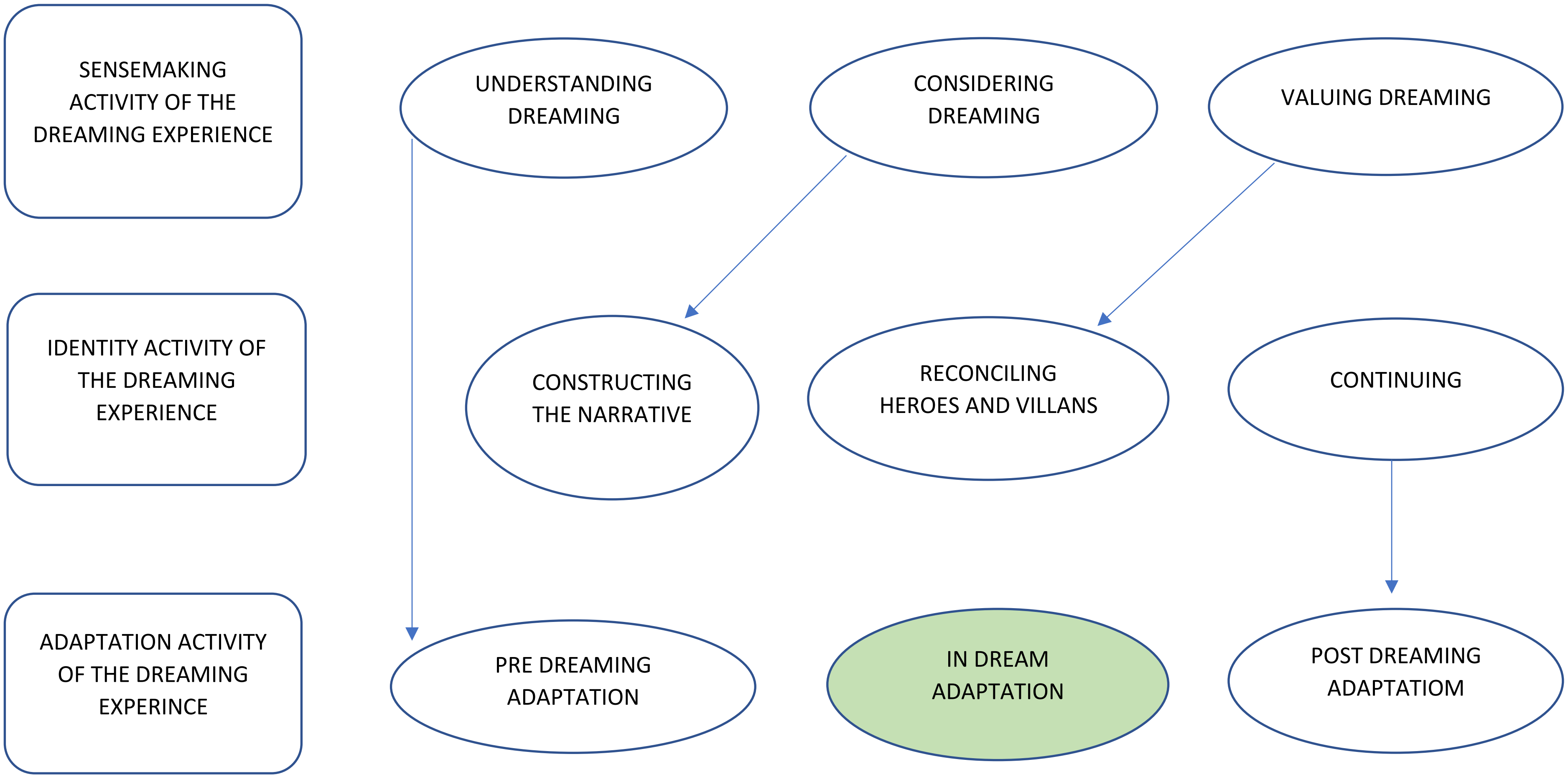
5.7.3 CONSIDERING DREAMING and CONSTRUCTING THE NARRATIVE

CONSTRUCTING THE NARRATIVE is that activity that follows on from CONSIDERING DREAMING. The process of CONSIDERING DREAMING allows an individual to make basic decisions about the experience and how they are able to relate to it, and in CONSTRUCTING THE NARRATIVE, these themes can be elaborated upon as they become an aspect of the individual's meta narrative.

5.7.4 IN DREAM ADAPTATION

IN DREAM ADAPTATION is rather different to the linked themes described above, in that the other organising themes have component themes that represent some element of difference (for example, UNDERSTANDING DREAMING is comprised of EXTERNAL FACTORS, PHYSICAL FACTORS and MENTAL AND EMOTIONAL), or stages in a process (as with CONSTRUCTING THE NARRATIVE, in which there are the stages of SEDIMENTATION and DEVELOPMENT). IN DREAM ADAPTATION has the singular aspect of some form of in dream direction whether it is described as lucid or not.

The diagram below shows the causal relationships between the organising codes of the thematic networks.


SENSEMAKING ACTIVITY OF THE DREAMING EXPERIENCE
UNDERSTANDING DREAMING
CONSIDERING DREAMING
VALUING DREAMING
IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE
CONSTRUCTING THE NARRATIVE
RECONCILING HEROES AND VILLANS
CONTINUING
ADAPTATION ACTIVITY OF THE DREAMING EXPERINCE
PRE DREAMING ADAPTATION
IN DREAM ADAPTATION
POST DREAMING ADAPTATIOM

Identity is a deeply existentialist concern (S & R)

5.8 Autism as a theme in the responses

Only three responses from the on line questionnaire either mentioned or alluded to autism specifically:

> 'I like that compared to my Neurotypical husband I can remember my dreams vividly' OLQ
>
> 'no, I'm autistic, not stupid' OLQ
>
> 'Sometimes there will be a theme for a few days, eg this week many of my dreams have featured autism' OLQ.

One of the respondents of the face to face interviews had rather more to say on their view of the impact that autism had on dreaming:

> 'I think that the dreaming is all tied in with my autism. I think that I get bogged down with things that other NTs seem to just shrug off, things to do with change and social interactions that I don't think I'm too good at anyway. And then my mood is not so good when I go to bed so I'm already doomed. I know that I'm going to take all the crap from the day into my dreams and then I worry about that more and that probably makes everything ten times worse. And then I have a nightmare and wake up and I spend loads of time mulling over it, ruminating, and then I make a mistake or misunderstand someone because I'm thinking about the dream and that carries on all day and then I'm worried about what dreams I'm going to have because of everything that has happened and it's not so much autism it's more like Groundhog Day' II.

As the emphasis of the SSIQ and subsequent on line questionnaire was about the dreaming experiences of autistic people rather than what they perceived to be autistic experiences and the questions were phrased to elicit information about dreaming, then this is not perhaps unexpected.

Topics covered in the responses to the initial interviews and questionnaire were largely these that may be seen as being linked to autism, such as anxiety, view of social interactions, views of change.

One response referenced alexithymia:

> ‘I have alexithymia, I don't know how I feel half the time!!’
> OLQ 79

The relationship between alexithymia and autism is still being established (Poquerusse, Pastore, Dellantonio & Esposito, 2018), and prevalence rates are felt to be very under reported in the population as a whole, currently estimated as being 5% in the general population and 50% in the autistic one (Kinnaird, Stewart & Tchanturia. 2019).

> To me, emotions are like storms at sea. They are mysterious and unpredictable. I feel like I can go from zero to furious in 0.4 seconds because I am unable to see all the intermediate shades of emotion along the route to furious, so when I finally arrive at that destination, it feels to me as if it came out of nowhere. I think it often seems that way to onlookers as well, because my Autistic style of emoting is not always very easy for people to understand.
>
> Max Sparrow from the blog Alexithymia; I don’t know how I feel. Unstrangemind 12.02.2017).

5.9 Conclusions

The experiences that participants reported largely followed the continuity model of dream production and effect (Schredl, Funkhouser & Arn, 2005), put simply, negatively toned days or events were linked to negatively toned dreams which then had negative impact the following day and the reverse for positive dreaming effect and production. This causal pattern was something that participants were aware of but appeared unsure About how or if this might be improved:

> ‘When a week is filled with intensive dreams I don’t feel rested and become more on edge and more sensitive to sensory overload, meltdowns and/or shutdowns’ OLQ.

Participants showed an appreciation for the benefits for of dreaming:

> ‘Need dreams help deal with things not dealing with when where awake’ OLQ
>
> ‘There's a reason we dream, I don't know why but there is’ OLQ
>
> ‘I feel it's a way of my mind exploring itself and all it encounters, like it's another level of processing and working things through’ OLQ

and overall those that found dreaming distressing did not want to be simply delivered from the debilitating experience; that the infrequent positive experience outweighed the negative:

> ‘Because sometimes I have really nice dreams’ OLQ
>
> ‘Some dreams are positive and it would be a shame to miss out on these’ OLQ.

What participants were hopeful was that a way forward could be found whereby they could maximise their positive experiences:

> ‘However, it would be more useful to alter my dreams so that they were more positive. Then I would perfectly happily dream each night’ OLQ.
>
> ‘would choose to carry on dreaming if I could have at least 75% positive dreams’ OLQ.

Further strategies for future research aimed at securing this improvement will be discussed in the final chapter.

Chapter 6 - Findings and discussion of findings of the IPA

6.1 Introduction

The IPA in some ways reflected the themes that had been identified in the TA but these coalesced throughout the interactions with the accounts into much deeper and more multi-faceted narratives with greater focus on concepts of identity. The themes of

1. The creation of a mystical identity
2. Dreams as a means of finding order and control
3. The experience of dreaming as a creation of a connected self

will be discussed in the following sections. The development of each theme will be shown with quotations and further discussion relating to broader literature. The quotations used will not be corrected for grammar or spelling in order to preserve the authenticity of these accounts.

Within each theme there is a discussion of the various components of the themes. These are more intended to reflect the different perspectives or lenses that the three themes were viewed from and through rather than being sub themes per se. These lenses are not mutually exclusive and are intended to highlight the point of interest, the initial the phrase or piece of information that led to the development of the hermeneutic process from the deep immersion in the narratives.

6.2 The theme of the creation of a mystical identity

The origins of this theme lay within the TA theme of DREAMS AS PROPHECY, however on re-reading the narratives it became apparent that there was a broader investment in a quality of ‘other worldliness’. Dreaming and thinking about dreaming is the creation of a private experience and one that cannot be wholly shared with or experienced by another, it is an intangible creation that cannot be replicated or manifest in physical form, but the mystical identity of dreaming was developed and extended in diverse ways by the participants. The following sections show the main themes of this development. On reading and re-reading the transcripts the language that was used was suggestive of a mystical identity: ‘realms’, ‘ocean of knowledge’, ‘kaleidoscopic rainbows’, ‘ethereal’, the references to the super heroes of film and fiction and the threats from faceless beings all intertwined to build a picture of these inner worlds.

reflections on cinematography and fiction

References to cinematography frequently occurred in the narratives. The construction of the film industry, of cinema and movies, is the construction of an arena in which fantasy can appear in a physical form. Place and narratives can be made ‘real’ in film form and so a reference to ‘the movies’ is an immediate short hand for worlds in which a myriad of other identities is possible. References to cinematography are used to reflect on how this other worldliness might be separate from the self and not confined by the same constraints upon the self, examples of refences to superheroes such as Spiderman would be an example of this. The otherworldliness of the theme is underpinned in the development that it is a phenomenon that can be observed and considered: ‘If it was a cool dream then I reflect on it kind of like when you've seen a good movie’.

Like the movies, references to books were another shorthand used to suggest mystical worlds: ‘like something out of a fantasy book. No idea where my brain gets the ideas but it comes up with entirely new universes’. The response suggests that the ideas for these ‘universes’ are beyond their perceived creative powers, that the dreams are not of their own thinking.

chronological mysteries

Timescales in dreams bear very little resemblance to standard hours and minutes, and have a variable quality that can make the experience far more intense. Participants often shared vivid recall of childhood dreams and that recalling these dreams for whatever reason could then trigger further dreaming episodes that were intense but bore no direct relationship to the original dreams. One respondent alluded to a telescopic quality of time and space: ‘they're often months apart and set in the same place with the same things/people’. There were some direct references to clock faces in dreams and these operated in ways that would not be possible in ‘real life’; clock faces ‘melted’, the hands of the clock in one response were small rodents. One respondent referred to an egg timer and the researcher was reminded of their frequent use in the classroom.

Temporal sensitivity is pervasive in the autistic community (Casassus, Poliakoff, Gowen, Poole & Jones, 2019) however it is perhaps a presentation that is

Impaired time perception is associated with autism and the rather nebulous representation of the clocks on dreams may be linked to that in some way.

sense of escaping reality

Within the theme of creating a fantasy world is that of escaping the ‘real’ one; for some participants this was a strategy to manage situations including depression: ‘When im depressed I try to sleep longer and dream because it's often better than real life’.

The language used in relation to this sub theme was poetic and evocative of these mystical settings: ‘mysterious’, ‘magical’ and ‘I enjoy the realms’.   There were some very descriptive and quite complex metaphors employed to convey the process: ‘It’s like my brain is trying to continue processing the ocean of information it has collected which results in the most prominent (however unrelated) details and information being smashed together to create a vivid ‘dream’’.

One participant reflected on the ritual around their dreaming activity; as a lucid dreamer they had found that certain pre sleep rituals would predispose them to autoscopic experiences, particularly ones involving flying. The very specific timings and order of the ritual was considered to be intrinsic to attaining states of lucid dreaming and so the escape from reality for this respondent was extended beyond the actual dream it started several hours previously with the conscious decision to have a dreaming episode. The commitment to their pre sleep ritual in itself induced a less stress state of mind and could begin to reverse the effects of challenging situations. For those respondents in the wider data capture who had developed lucid dreaming capabilities, there was not just a 'sense' of escaping reality but a confirmed belief that they would, quite literally do that.

the interpretation of the dream

The creation of a mystical identity is emphasized by the apparent need to decode them and to explore their inherent symbolism: 'I write down all my dreams in a journal to find patterns or symbolism, so I wonder as to the meaning'. The writing down of the dream, the separating of them from self to journal compounds the feeling of other worldliness that has been attributed by some to the dreamscapes. If there is a need to look for the meaning of the dream that is because the individual believes there to be further meanings to decode: 'it helps me to examine dreams and look for meaning within the symbolism. Sometimes they are straight forward or cryptic'.

This activity of interpretation is creating an identity of the individual as an expert or analyst, someone who contributes to the creation of a mystical world and then becomes proficient in interpreting it. One respondent reported that they had a large collection of books on dreaming, literally several hundred, and they enjoyed the forensic nature of de-coding not only their own dreams but that of others they had been able to extend their internal sleeping world into a waking hobby.

The parallel between dream interpretation and phenomenology was noted, the reading and re-reading, emersion on the narratives and piecing together a composite life view.

fore-telling and deja vu

The ability to predict the future has always been one of the main tenets of mysticism. That there exists and that there are people who are able to fore-tell a predetermined future is the subject of many an epic tale. Incorporating this into the process of dreaming gives a further layer of mysticality to the creation of this identity and success in this area can also lead to a degree of renown: ‘In the past I've had premonition dreams that feel very different from other dreams, they still haunt me years later, make me uncomfortable. My father also had premonition dreams, he was known for it’.

One participant reported that there was a difference in the nature of these dreams: ‘Other dreams can be prophetic and some are just nightmares or random. I can tell the difference by the intensity and feeling between normal dreaming and the prophetic kind, very different’.

This is not to say that the participants who experienced what might be termed premonition dreams would categorise them as such at the time of the dream but would with hindsight: ‘When I was 15 I had a dream that I now realise was showing me an underlying medical condition in a symbolic way. Had I known then what it meant it could have changed many paths and created a better life’.

final thoughts on the creation of a mystical identity

In the creation of these mystical places was the suggestion that the participants wanted to access these spaces, to escape from current localities into worlds which were not governed by the same temporal and other rules of existence, where different ways of being were possible. There seemed to be a continual dialogue in the narratives about if dreaming as an activity needed to be endowed with further mystical qualities or if the comparison to the worlds of fiction and film were ways of rationalising fantasy dream worlds and actually making them more real.

There was a sense that in giving the activity of dreaming a multi-faceted, many dimensional identity that the participants were adding to their own sense of identity as the creators of the dreams, that there was an interactive creation of identity in process with the development of one informing the development of the other: ‘I enjoy tapping into the otherworldly experience and writing about it. I have a rich inner world and dreaming adds to the layers within’.

There appeared to be a very complex interaction taking part within this theme, an interplay of language and description of the creation of impossible fantasy worlds with a desire to understand and make them wholly inhabitable, to pragmatize the exotic whilst maintaining its distinctive features.

6.3 The theme of dreaming as a means of finding order and control

Finding order and control to some degree is an existentialist act and most beings respond well to a stable and predictable environment with an element of freedom to explore and create. Finding order and control for autistic people is about finding ways to relate to the world, of decoding idioms and making sense of complex social situations and of building into any structure of order and control some safety valve of self-preservation so that they are not constantly camouflaging and this relates to the concept of autistic burnout that was discussed in the Literature Review.

exercising control over the direction of the dream

This element of controlling a dream was one that had emerged forcefully in the TA. Where participants had adopted proto-lucid or overtly lucid dreaming techniques, these were the narratives that tended to be more positively toned throughout and in which there was a sense that the individual felt empowered and in control; these were the narratives about dreaming in which the influence of the dreaming experience had been at least neutralised and had few adverse effects on waking well-being: ‘While I'm dreaming if i realise I'm dreaming then i can usually direct the dreams trajectory or make myself wake up if its scary’.

Exercising control in a dream is not the same as having control in waking life but for the participants it was as if success here could lead to success elsewhere in life; that it could be a key to greater success: ‘it feels so good when I start flying in my dreams, I feel like I can do anything’. Those participants that used overtly or proto lucid techniques in dreaming had far more positively toned responses throughout their online questionnaires; whether this was due to the removal of unhelpful dreaming experiences through the use of these techniques or the empowerment felt by the creation of some degree of control over an area of life or a combination of the two is unknown, but for what ever reason there was a broad correlation between controlling dreaming experiences and a sense of satisfaction with life:

> Now that I can dream in this way using lucid tools to make my dreams less scary and far more like I wasn't them to be, like dreams I want to watch but all mashed up together. I'm really enjoying dreaming. I don't try to dream like this every night cos that would be tiring in the long run and cos I wouldn't want the novelty to wear off, for them to become ordinary. I took me quite a while to learn how to do it, even with all the on line stuff, lessons and YouTube video, but now that I can do it, I wonder what else I could learn to do. I might take up baking!

the predictability of the binary system

One of the manifestations of this theme was the link to a self that was more like a computer, without the 'complications' of feeling and reduced to a predictable binary system. Computer terminology such as 'file-dump', 'filing', 'hard drive', and 'storage' were used in several responses. These metaphors were used when describing how the dream could be used to process thoughts, suggesting that this was somehow not something that happened in waking life: 'file clearance dreams where every odd but of stuff in my head gets filed and tossed out via dream'.

For one participant Mr Spock from the Star Trek series and films was the epitome of a 'human computer', making logical deductions and showing no emotions. Spock has been 'claimed' as autistic by many and is a much used stereotype for autists, always calm in a crisis and with a thoughtful solution, Spock embodies order and control.

using dreams as rehearsal

This is a proactive application of finding order and control, it is a pre-emptive means to explore situations in what may be a relatively safe environment. Some participants were able to undertake these rehearsals quite deliberately using lucid dreaming techniques, for others, the rehearsal dreaming activity was triggered by social anxiety about a forthcoming event. The anxiety induced dreams tended to develop dream scenarios which had more negatively tones outcomes and so compounded the participants' anxiety about the event further:

> If I am going for an interview or something like that I cn start to have lots of dreams about it where I'm in the interview answering the questions but some faceless parent keeps pressing one of those uh-ooh buzzers like I ve got the answer wrong and then I worry about the dream of the interview as well as the interview and by the time I get to interview I am a wreck.

the inverse of finding order and control

Within this theme is the presence of the correlating negative them of the lack of order and control. This lack of control can be sensed in the language about being caught, trapped or in some way impeded either within the post dreaming aftermath of trying to rationalise the dream. Examples of the language used around this theme are 'cliniging', 'sticky', 'frozen', states of being that could make something more vulnerable, less likely to find escape from a threat, perceived or otherwise, unable to make progress in any sense.

The sense of vulnerability manifested itself in language around sickness and ill health. With bleeding being a frequently used leitmotif, eg 'the colours bleed', 'I don't like the way they bleed into my waking life'

Or in the sense of the entrapment within the dream that one of the participants dwelt upon:

> Entrapment took the form not only of being captured or physically confined as in the example above but also in the sense of paralysis and being unable to move: 'an inablilty to climb stairs oftern features in my dreams'

One of the respondents from the wider data capture had described feeling trapped with the dream, of waking from on dreaming state into another and then another and of a sense of sheer panic that they would not wake.

final thoughts on dreaming as a means of finding order and control

Sensory issues, reading social situations and understanding complex relationships are sources of great stress for people with autism and the Literature Review showed how not having an understanding or control of these can have adverse if not quality of life limiting impacts on this group. The promotion of ways to find order and control – using apps, accessing services, acquiring new skills are all seen as helpful to autistic people in making sense of the world around them and enhance their place in it. Those participants who had developed an understanding of their dreaming experience, what triggered or exacerbated it and had been able to act upon this knowledge to manage dreaming expressed more confidence and resilience in the abilities in waking life; these were the responses in which clients did not feel that they had to change their plans, they were not at the mercy of the dream but rather had confidence in continuing with their schedule, 'now that I don't have these weird dreams, I never have to change my plans around'.

For those participants who were not able to exert influence over dreams the narrative felt exhausted, overwhelmed, there was a sense of dreaming a series of event that felt like ever decreasing circles or something unravelling:

> it can make me not want to sleep which messes up my sleeping pattern and makes me more tired, which then makes everything else harder to cope with, increases sensory difficulties, etc.

The presence or lack of order and control in dreaming both interacts with and mirrors the presence or lack of order and control felt by participants in real life; the challenges posed by dreaming are a metaphor for the challenges posed by autism.

6.4 The theme of dreaming as the creation of a connected self

Being connected to people and places, a sense of belonging is a human aspiration and essential for good mental health, with this sense humans do not thrive. The Literature Review highlighted how this lack of a sense of connectedness or isolation has a potentially devastating impact on the quality of life for autistic people. Through reading and re-reding the transcripts and note making the theme of a sense of wanting to make connections on multiple levels was formed.

seeking connectedness

Making connections in dreams was a theme that many participants in the study valued; whether that connectedness was to a place, person or the dream itself through interaction, sharing and analysing, that ongoing connectivity and presence was felt to be important. Participants used language like ‘secure’ and ‘safe’ when referring to these connections: ‘some dreams have been a comfort when family members appear to me and make me feel safe‘.

Participants also reported that dreaming helped them to connect with areas of their own psyche which they found helpful: ‘potentially discovering the root thoughts and impressions that caused them. I find it quite fascinating as it gives me a view into my own subconscious’.

sharing dream experiences to create a connected self

Sharing the content or experience of a dream was seen to be a way to promote social interaction with others. Recounting dreaming was generally seen as a form of social lubricant amongst the adults in the project and overall, they had a sense of what to share and what not to: ‘Fine. I don't generally discuss embarassing dreams. Just the weird or cool ones’.

There was a suggestion that the participants had a sense of wanting to please or entertain through this sharing of dream and that the actively chose which ones would promote social connectedness: ‘I mostly only discuss really bizarre/random dreams that I think will make people laugh’.

The use of dreaming as an interest to talk to others about is reflective of an idea explained by Attwood (1997) namely that autistic people with gather around interests and discuss them, rather than gathering and making conversation (small- talk) and then finding mutual interests. Dreaming was something that the participants were interested in and which is generally accepted as being something that it is acceptable to discuss, with certain limits, so in these situations this was an autistic interest that would be shared with others but more in that conversational style. It is a more satisfying than polite conversation for the autist but sufficiently non challenging as a subject to be considered as small talk for a non-autistic person. These safe, cross-over subjects are the social lubricant for meaningful interactions that can be appealing to those involved

reconnecting with people

There were several accounts of seeing or meeting dead members of family and friends in the dream and this is not considered to be an unusual manifestation on dreams (Dam, 2016). However, one of the accounts referenced the significance of re-processing the death of the parent and having to communicate this to others in a way which seemed to be more related to social anxiety than to the manifestation of the father:

> In my dreams he's come back, but he's still dying and we have to go through the whole thing all over again. Or my family has finally adjusted to him dying but then he comes back and it's very confusing/uncomfortable and I have to try and work out how to explain it to other people'. Some of the relationships are not only revisited but are more developed through dreaming: 'dreams about relationships that are not active in real life but continue vividly in dreams.

dreaming as a barrier to the creation of a connected self

For some participants the nature of their dream content meant that it was problematic for maintain connections in the following days after a particular episode: 'If I've had a vivid dream about a work colleague I find it hard to interact with them because I get flashbacks of the dream'. One participant reported that they had been known to carry on an in-dream argument with their partner over several days even though the partner knew nothing about the original circumstance of the argument. In these examples it is the content of the dream that was such that it made specific personal interactions problematic, however unsettling dreams may be barriers to connection in other ways.

Feeling tired or anxious, or diverting energy to states of rumination as a result of dreaming is not conducive to outward acts of connectivity

the inverse of connectedness

Within the construct of this theme is the correlation of the lack of a connected self; of a self that is in some way disconnected, displaced or disavowed.

> I would dream about being treated as though I'm invisible, or being shouted at and argued with for no reason, being blamed for things I hadn't done. One dream I remember clearly after I left high school, I dreamt that I was back in school and I approached a large circular table with all of my friends/acquaintances around it wearing the school uniform. I kept trying to speak to them and they wouldn't answer me, it was as though they couldn't see me, like I wasn't there

If a dream cannot be discussed because of the potential embarrassment it may cause it has the potential to become something that is to remain hidden, even something to feel ashamed of:

> Sometimes I have dreams that I can't tell anyone about. Not because they would laugh at me or they are about sex or something but because they are so awful that I can't even say what happens in them. I don't know where these come from and I don't think that I like that my mind can produce these vile creations. It just makes me think that I am not a nice person deep down

final thoughts on dreaming as a means of creating a connected self

Dreaming represented concepts of connectedness on many levels, and could simultaneously connect participants with tradition, knowledge ritual and people:

> I have many dream dictionaries and books on symbolism and relate to this knowledge very well. i.e. if I dream of someone with a conch shell, an ancient form of communication, I know it means they want to contact me or someone. I have taken part in shamanic dream journeying which was very profound, moving and truly awe inspiring. It proved to me that some dreams are much more than just a brain mechanism, they take us beyond this reality, although I already knew this as a child, from my father.

The desire to make satisfying connection is innate in the human population. For autistic people it can be made more complex by the unpredictability of human interaction and the constant need to interpret language, no-verbal language, meaning and context. Whilst they can be problematic in situations that take place between autistic and non-autistic people, it is interesting that autistic people are creating communities of autistic only members or were there is an autistic lead. The proliferation in recent years of groups established to specifically explore autistic identity and to connect with other autists has been facilitated by the internet which is allowing virtual world wide communities to form around particular issues and interests and the number of autistic bloggers has also risen in response to people wanting to learn and connect more with like-minded autistic people.

6.5 Conclusions

Dreaming has been woven into the fabric of identity to such an extent that the thought of being without it is to jeopardise that concept of identity even if the presence of dreaming is not a positive experience for the individual.

The themes discussed above are not mutually exclusive, but rather overlap and intersect each other. For example, one participant described how dreams ‘give me a sense of connection to something else beyond our reality’.

As reading and re-reading took place in the analysis these three themes seemed to be more significant to participants than others, the search for a unique place in life, to be able to have some control of the environment and to feel connected to other. These are issues that have resonated throughout the Literature Review and the personal autistic accounts used in this report. They reflect the development of an autistic identity or voice that has been explored through forums such as #actuallyautistic and the Participatory Autism Research Collective. The creation of a connected self embraces concepts of connectedness that may be easily extended to the ways in which individuals connect with society through employment and the opportunities that exist for development. The publication of ‘A Future Made Together’ and the creation of the All Party Parliamentary Group on Autism are initiatives designed to improve the quality of life and outcomes for people with autism. They are meta-representations of the views seen in the responses that autistic people contributed to the study who want to claim a sense of place, to find a sense of order and control and to have those opportunities to connect as others do.

In dreaming, as in homelessness, relationship to law and order and mental health issues and a myriad of other concerns these are issues which repeatedly surface in autistic writing in its broadest sense.

The struggles that participants had with dreaming are metaphors for the difficulties that autistic people face in daily waking life, it would be most interesting to see if the metaphor might work in reverse; to investigate if those individuals who had mastered their dreaming felt that they had more power in waking life.

In the following, final chapter there will be a review of the finding of the study and an appraisal of its contribution and limitations, and suggestions as to what directions future research might adopt to further explore the phenomenon of autistic dreaming

Chapter 7 - Recommendations and Conclusions

7.1 Introduction

This final Chapter draws together the various strands of the study by:

- Summarising the findings of the study
- Considering the limitations of the study
- Considering the implications and contribution of the study
- Reflecting on the generalizability of the study
- Formulating recommendations for future research
- Listing final conclusions

7.2 Summarising the findings of the study

7.2.1 Introduction

The aims of the research are

1. to explore an area of lived experience and to assess the ways, if any, that this impacts upon the quality of life as perceived by the individual
2. to reflect critically upon these accounts and how they can be used to contribute to discussion around the subject; how that might inform directions for future research or shape further interventions

and from these aims the following questions were formulated:

1. How do people with autism perceive their dreaming experience?
2. How do people with autism think that this affects their well-being?
3. What adaptations have autistic people made to their dreaming experiences?

7.2.2 The overall findings

The Literture Review highlighted several of the challenges that autistic people face in terms of their quality of life and discussed how atypical sleep architecture and other presentations frequently associated with autism may act to trigger dreaming activity. The study does not draw any conclusions as to if autistic people dream more than non-autistic people, that was not an aim but it has demonstrated that for a group within the population the act of dreaming is a challenge which can persist through life and be greatly problematic. The Literature Review also demonstrated that whilst the dreaming activities of other groups who may be considered to be vulnerable for example anorexics, people with multiple sclerosis, those at risk of post-natal depression, little assessment had been made of the role that dreaming might play in terms of the autistic population

Overall, the outcome of the study is a picture of two very different experiences of dreaming: one in which participants see dreaming as a positive, creative or at least helpful event, enabling the mind to process information about recent events, allowing memory consolidation and providing a way to rehearse for situation whilst affording them some fantasy cinematographic like experience. An experience which is considered to be vital, and uplifting for participants.

Alternatively, it is an experience which can produce discomfort and elevated levels of uncertainty and compound anxiety which reverberates in waking life. In the latter instance, the dreaming experience can cause plans to be altered or abandoned and leave the individual feeling tired and emotionally challenged.

A key finding was that only a small number of participants would welcome the opportunity to never dream again, even those that gave account of vivid distress and disruption wanted to retain the ability to dream, many with the caveat that they would welcome support to make this a more positive experience.

7.2.3 The impact of the design of the study

One of the significant successes of the study was the decision to move to an online format for the questionnaires. This enabled the collection of narratives of lived experience from individuals in the UK, the Netherlands, the United States, Canada, Denmark, Ireland, Germany, Austria, Spain, South Africa, Hungary and Israel. From the respondent data generated by the hosting platform, it could be seen that several participants had used the ‘save now finish later’ feature as in some cases the time taken to complete the questionnaires had run across several days with the longest time taken being 92 hours.

The data collected through the online questionnaire was rich and it would not have been possible for a small-scale study to have obtained this through direct interviews, especially across such a ranges of countries, and even using ‘skype’ type software to host digital interviews may have posed logistical problems with time differences and rescheduling to continue interviews in cases where participants wanted a break. The autonomy that the online questionnaire offered participants may have been a factor in this successful data collection.

The lack of social intensity provided by the online data collection and the convenience to complete the questionnaire as and when it suited participants are features that should be considered by the designers of future projects not only in the sense of incorporating these features into the design of data collections but also for there to be some research with autistic people into research methods per se and how more autism friendly variants can be developed.

The change to an online questionnaire yielded far more responses than could be successfully be accommodated in an IPA study and the decisions was taken to use Thematic analysis, the opportunity to combine both following the model used by Spiers and Riley (2019) has allowed for a more holistic interrogation of the dataset and had produced results and discussion that is both descriptive and idiopathic.

7.2.4 The use of NVivo

The observations that follow are pertinent to the NVivo analysis tool as that was the system that was used in this study. Other tools are available to researchers such as QDA Miner Lite, RQDA and dedoose, however as the project’s remit was not a comparison of these tools the following discussion will focus on the impact of NVivo alone.

Upon reflection the use of NVivo was neither a major benefit or hindrance to the study. It may be argued that committing to using the tool, in conjunction with other data handling processes, required an investment in time for the researcher to familiarize themselves with the application and its various features that might have been better deployed elsewhere.

After using NVivo for some initial searches and word frequency assessments its continued use in the coding and grouping process became an additional and unnecessary layer between the researcher and the data. As other researchers have commented NVivo seemed to keep the data at an arm's length which didn't foster that almost intimacy that is required for phenomenological analysis.

> We become separate and distinct from our research. While we conduct our research, we are no longer part of it, for, like the data itself, we must "input" ourselves (our hunches, interpretations, and lines of thinking) as written responses, as "memos" into the computer that holds and that now *is* our research
>
> Goble, Austin, Larsen, Kreitzer and Brintnell (2012)

In the research design stage, there was a degree of susceptibility on the part of the researcher to the claims made for the programme and the fact that it was made available to researchers by the University seemed to almost endorse it for analytical processes

However, having that understanding of the operational possibilities of NVivo will aid future decisions about is use in future studies; for example, it may be of greater assistance where the researcher to be involved in a project with others that requires the project management capabilities of NVivo.

7.2.5 That the study has further developed multi methods research

Employing the idiographic lens of the IPA study to all 90 participants in the TA sample would have been unwieldy and overly time consuming, and it would have produced findings that were hard to present coherently' (Spiers and Riley, 2019 p285).

Combining the approaches of TA and IPA has used two phenomenologically congruent approaches to explore the data

We would suggest that TA and IPA work well together as methods to draw out multiple elements of a large qualitative dataset, and that future researchers may also consider adopting this combination of methods in a phenomenological study. The combination of pragmatic and existential lenses has the potential to satisfy to range of requirements …of a single dataset' (Spiers & Riley, 2019, p287).

7.3 Considering the limitations of the study

7.3.1 Representation

This study is not representative of the range of presentations included under the heading of autism. Originally the study was designed to address the area of the spectrum which had traditionally been associated with Asperger's Syndrome, a sub category of the autism spectrum for which the diagnostic criteria is a full-scale Wechsler IQ of more than 70 and no significant language delay pre three years of age, however this became increasingly problematic over time. The main diagnostic tools for autism are the World Health Organisation's International Classification of Diseases Issue 10 (ICD 10) and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders Version 5 (DSM-5). When DSM-5 replaced version 4 in 2013, the sub category of Asperger's Syndrome was removed. Currently, the less widely used ICD 10 criteria still has criteria for a diagnosis of Asperger's but is expected to follow the DSM-5 and remove it when ICD 11 is issued (currently estimated as sometime in 2020). In parallel with these diagnostic revisions, has been the growing awareness that Asperger was involved in some way with the Nazi regime and the publication of articles by Czech (2018) and Sheffer (2018) means that there is growing discomfort in using the term as a diagnostic label.

In terms of this project, it was not tenable to proceed on the basis that participants would have a diagnosis of Aspergers, a criteria which had effectively ceased to exist in 2013, and so the project was revised to include participants with a diagnosis of autism.

> The term *Asperger's* was becoming shorthand for hyper-focused, often precocious talent and a socially awkward personality—a potential lonely misfit or even
> Hanna Rosin from the blog Letting Go of Asperger's (2014)

It may be that the participants who did contribute to the project would meet the criteria for a diagnosis of Asperger's if that criteria had been applied or that the promotion, language and platform of the questionnaire meant that it was only available to those able to access these reasonably sophisticated events. The responses that were provided through the on line questionnaire, were indicative of a range of skills around coherent expression and proving thoughtful narrative with some indication of reflection in it, indicative of higher order thinking skills (Heong, Othman, Yunos, Kiong, Hassan & Mohamad, 2011), or at least well-developed literacy levels. There are people from other areas of the spectrum, especially those with reduced verbal abilities or learning difficulties who might not be represented in this study.

The removal of Asperger's Syndrome from the diagnostic manuals will have an impact upon research with autistic participants; had this study been undertaken with people with a diagnosis of Asperger's Syndrome then it would have been appropriate to generalise the findings to others with that particular diagnosis, as it is, it would be insecure to generalise the findings from this report to the autistic population overall.

All the participants in the study were volunteers and it could be argued that they represented a particular cohort or group with particular interests in the project. They may represent other individuals' lived experiences of dreaming as it is an idiopathic experience, whilst also acknowledging that their experiences are not representative of the experiences of all individuals. Definitive conclusion was not an aim of the research as this would not reflect the study's ontological and epistemological positions.

7.3.2 Self-identifying with a label of

Although there is a long running and intense debate on social media around the validity of self-identifying with a label of autism, this is something that has created division in the publicly active community. The hashtag #actuallyautistic has been used in a way that some have found uncomfortable, to promote the legitimacy of those with a diagnosis over those who identify with the presentation.

> The people I know who are self identified autistic took a long time to be confident in their conclusion. They researched, they read, they talked to people, they thought about it so much they felt overwhelmed, they stressed, they denied, they went back to the start and did it all again….. until they had to admit to themselves that there was no other option than to conclude they are autistic. And then they had to go through the process of telling other people, knowing that they would be criticised for it. You don't go through that unless you are sure.
>
> From the Blog Hello Michelle Swan; 5 reasons I am self identified as autistic (17.07.2017).

Swan identifies the five reasons why she believes self-identification should be accepted as being: the diagnostic process is expensive; the diagnostic process is flawed; the diagnostic process can be harmful; protection and defiance.

In terms of future research, it would be useful to have a study with an autistic group and a group who self identify with to see what differences in responses there might be and how valid it is to request that a person has a clinical diagnosis of autism in order to participate in a research project.

7.3.3 Participation or participatory (revised)

Earlier in this report there was consideration about the nature of participation and enabling more participatory processes in research. Fletcher-Watson et al. identified 'five topics relevant to building a community of practice in participatory research: Respect, Authenticity, Assumptions, Infrastructure and Empathy' (2019).

Participatory research is being promoted through a variety of groups and initiatives and recently Centre for Research in Autism and Education (CRAE) asked current researchers to send in examples of how they made their research more accessible and any letters or information sheets that were particularly successful so that these can be made available to future researchers in the form of a tool kit, to support further participation. Learning from the experiences of researchers about how they are able to engage with and make projects accessible for people with autism, will enable to future research to integrate these practices from inception.

Participation-participatory is perhaps more of a continuum than distinct entities and this project has at various points represented one more than the other in terms of its operations. There have been aspects of this project that have been indicative of participatory elements such as the revision of the data collection to an online model and the original formulation of the research area. When the data collection of the project was revised, this rather worked against the participatory stance in that participants provided their information remotely and anonymously, and then effectively retired from the study rather than being an ongoing and consistent presence. Although there was a conscious aim to make the project as accessible and inclusive as possible, the design and scope of the operational process was to enhance the level of participation rather than create a fully participatory focus.

The report has followed on with the aim of the research to place the narratives of the participants as the central focus, and in using personal accounts from autists published on blogs to highlight particular issues has raised the contribution of the autistic population in shaping this report.

7.3.4 Reflection of autism language in research

There was some feedback from potential participants on the Twitter recruitment phase expressing some concern that the study had been promoted with the

#actuallyautistic, when the information and on line questionnaire used person first language interchangeably with the identity first language preferred by the group that uses #ActuallyAutistic. The position of this study outlined in the introductory chapter, was that the terms would be used interchangeably throughout the report and the research materials in order to respect the views of those who prefer person first or identity first language (Chown 2017) or at least to ensure that neither felt excluded or marginalised within the project. The comments about the language used from the potential participants reflect the very passionate positions that people hold upon this issue of autism language, understandably as it is an essential element of identity. However, in terms of research it is not helpful in creating seamless participatory projects, if significant numbers of potential participants are immediately uncomfortable with the terminology used.

Whilst the terminology to be used in future research is a topic worthy of further investigation, whether a position could be arrived at that would satisfy both the identity first and person first advocates might be more questionable; it might be an interesting academic exercise to undertake an investigation of the same research question using materials from both preferences to gauge levels of response and to assess any impact this might have on outcomes.

7.4 Considering the contributions of the study

7.4.1 Introduction

The following diagram was used to demonstrate where the ‘gap in knowledge’ was in the context of this project. It was an absence that was suggested by the cumulative presence of a series of issues around sleeping and dreaming, challenges faced by the autistic population and the research that had been undertaken with other populations.

7.4.2 Contribution in relation to the research questions

The study was recognised as being almost a reconnaissance activity into the dreaming experiences of autistic people and to gauge what the impact of this might be on their waking well-being. The initial Literature Review looked at the research linked in different ways to this experience and suggested that there was evidence to proceed with the exploration; in the case of other groups such as anorexics, anecdotal recounts had lead to studies into dreaming as being reflective of the severity of symptoms and so able to be used in support plans. Had the project found that dreaming was not a concern for a number of autistic people, then that in itself would have been indicative for further research projects.

As it was the project did highlight issues and an impact upon waking life, both positive and negative that should be explored further especially in light of the many societal challenges faced by the autistic community as outlined in the Literature Review especially the dream management techniques could be used to mitigate against the more extreme experiences.

7.4.3 Contribution in relation to participatory research

The project promoted the participation of autistic adults by offering a plurality of ways of providing information and in its response to the access preferences expressed. Throughout the report an autistic voice has been promoted through the use of narratives from blog and personal accounts to provide insight into autistic experiences. Whilst this is not a singular contribution that this study has made to knowledge, it has contributed to a wider development of research collaboration with the autistic community which is informing a wider contribution to knowledge.

7.4.4 Contribution in relation to methodological design

The development of the structure of the project into a multi method design builds upon the specific approach of Spiers and Riley (2019) in combining descriptive TA with idiopathic IPA. Again, the claim is not that this project has made an original contribution to phenomenological research design methods, but rather that in replicating this precedent, the proposal that Spiers and Riley made that the combination of TA and IPA would be 'crucial for disseminating key-findings and giving due recognition to precipitants' in-depth, complex and rich account of their meaning-making' (2019) may be tested. This contribution of this study to methodological research is that this combination has be revisited within a project and found to give a more detailed account of personal experience.

7.5 Reflecting on the generalizability of the study

In terms of the aims of the research, the data collection and analysis were not impaired by restricting participation to those who had a diagnosis rather than self-identified with a label of. No potential participant queried this, although one person did query how facile it would be to find a participant without a co-morbid diagnosis.

There were 91 responses to the questionnaire and 3 initial interviews, so the study did generate sufficient narrative and data to reveal a rich comprehensive portrayal of how dreaming impacts upon the well-being of people with autism.

The participants of this study might not be fully representative of the views of autistic people but they are representative of a group of communicative and articulate area of the spectrum, which may have been proposed as being that previously referred to as Aspergian before the revisions introduced in DSM-5 and the issues with Hans Asperger's war time associations.

Generalizability was not originally considered as an aim for this or any other study which aims to qualitatively assess an issue with the population covered by the description of autism; it is too diverse for that, and this was not envisaged as an aim for the project. According to Leung:

> Most qualitative research studies, if not all, are meant to study a specific issue or phenomenon in a certain population or ethnic group, of a focused locality in a particular context, hence generalizability of qualitative research findings is usually not an expected attribute
>
> (2015).

However, a recent study by Brett Smith (2018) suggests that there may be ways in which qualitative project such as this may be considered as being generalizable. Smith describes 4 types of generalizability and in the following sections each of these will be described and an evaluation made as to their applicability to this project.

7.5.1 naturalistic (representational) generalizability

In representational generalizability findings from one qualitative research project can be applied to other populations. These populations are often facing a broadly similar event such as that of the research by Lewis et al (2014) in which the experiences of a group of smokers who were trying to quit, in this instance the research might be naturalistically generalized to other groups quitting physically toxic and addictive habits:

> the research bears familial resemblances to the readers' experiences, settings they move in, events they've observed or heard about, and people they have talked to
>
> (Smith, p140, 2018).

In terms of this research naturalistic generalizability may take the form of taking the experiences from the autistic participants and applying them to groups with other neurodevelopmental conditions such as ADHD or ADD. It is difficult to see how this could be applied for example to conditions that were not life long and pervasive. There may be some commonality with some conditions such as dyslexia or dyspraxia to make this viable for a number of studies.

7.5.2 inferential generalisation (transferability)

> In contrast to how Lincoln and Guba (1985) defined it, the idea of transferability here is underpinned by the epistemological assumption that knowledge is constructed and subjective, reality is multiple, created and mind-dependent, and methods cannot provide theory-free knowledge. Transferability is also different here in that it is defined as occurring whenever a person or group in one setting considers adopting something from another that the research has identified.
>
> (Smith, p140, 2018).

There is perhaps real scope for this project to have inferential generalisation. Brett gives the example of a series of professionals from different backgrounds reading a report and asking if the content of the report can inform of shape their practice. In terms of this report, a practitioner might be prompted to sue the schemata from the TA to work through understandings and issues with clients from a variety of backgrounds; they may consider asking client groups what their experiences of dreaming are and simply being aware that it can range from a distressing to a rewarding experience with profound accompanying consequences will alter their view of the possibilities of dreaming.

7.5.3 analytical generalization

Also known as vertical or idiopathic generalizability, this is generalizability of the theory or concept and that these may have a wider applicability beyond the original study.

> in analytical generalisation it is the concepts or theories that are generalizable, not the specific context or populations. Moreover, conceptual or theoretical generalisations are not viewed as fixed, immutable, or to be asserted with absolute certainty
>
> (Smith, p141. 2018).

Pheonix and Orr (2014) have analytically generalised from a number of studies to develop concepts around pleasure in physical activity in older people. In terms of this research it would be feasible to apply the concepts and theories, especially those of the methodology and apply it to other studies, particularly in the case of the multimethod research design.

7.5.4 Intersectional generalizability

> That type of generalizability is also about producing 'work that tracks patterns across nations, communities, homes, and bodies to theorize the arteries of oppression and colonialism' (Fine *et al.* 2008, p. 174).
>
> (Smith, p141, 2018).

Parallels can be drawn with the 'arteries of oppression and colonialism' and the rejection of the medical model of autism by those who recognise autism as something beyond a non-autistic defined framework of symptoms and stereotypes. There are groups and affiliations who demand that there is a greater participation of autists in shaping research and policy at all levels to overcome non autistic hegemony and this project's ethos of promoting an authentic autistic voice or representation throughout would facilitate intersectional generalizability.

7.5.5 Conclusions

Generalizability was not considered as an original aim for this small-scale research project, although it has been academically interesting and quite satisfying from an early researcher perspective to see how this could be credibly claimed for aspects of the project. Awareness of the possibility of positioning generalizability as an aim for future projects, perhaps collaborative ones is certainly one that the researcher will consider.

7.6 Formulating recommendations for future research

7.6.1 Introduction

A review of the narratives of the participants was made to determine the areas of concern that they had shared. For the most part, the support that was sought was not about eradicating the dreaming experience but in re-framing it as a more positive activity, to lose the nightmare elements and retain those that produced the great sense of enjoyment and satisfaction that could be derived from a positive dreaming experience:

> ‘I like that most of my dreams are incredibly vivid and detailed, I enjoy the complete escapism of a good dream, I also believe that they help me to process and make sense of the world’ OLQ.

7.6.2 Raising awareness of the issue

The online questionnaire did suggest that a number of individuals considered their lives to be in some degree compromised by their dreaming experiences and it would be helpful for future research to gauge awareness of these issues amongst supporting or customer facing professions. At the moment, an internet search for autism and nightmares or dreaming yields very few results. This may lead people to think that there is no support for this or that is just a ‘normal’ part of their lives and something to be put up with.

A comparable development of awareness raising would be that of sleep latency and autism; between 2000 - 2005 there was an increase in research on sleep and serotonin imbalances in the autistic population, and sleep difficulties and autism began to emerge as an area of concern in the media. As a result of this raising of awareness, more families sought help and support, resulting in tenfold increase in the number of prescriptions issued for melatonin for people under the age of 55 and in behavioural programmes designed to promote better sleep habits and hygiene. It would be helpful to measure the levels of awareness of health practitioners to ascertain if they probe for issues around the impact of dreaming when an individual seeks support.

Further research could help people to see the patterns in their dreaming and how life events may influence it. Using a dream awareness questionnaire such as the Mannheim Questionnaire, or a modified version to accommodate more autism specific issues such as the interplay of sensory issues and dreaming, may help people to consider specific issues, enabling them to understand more and hopefully empowering them to address issues were possible.

A range of management strategies may be suggested at an early stage in the consultation process, such as sharing the dream, discussing it or keeping a dream diary or journal. An individual may be able to start to use these basic techniques to understand their dreaming processes and the impact it has on waking wellbeing and to gauge if further support or intervention was required.

> One of the most common suggestions I found for reducing nightmares was journaling. I've tried journaling in the past, unsuccessfully, because part of my brain spends the whole time going "why are we writing this if no one is going to read it?" But the underlying principle of using journaling to process my anxiety makes sense.
>
> Musings of an Aspie (24.11.2012).

7.6.3 The use of results from this study

It maybe that some of the outcomes and results of this study could be further explored, in particularly the use of the thematic diagrams of the superordinate themes.

The Thematic Network could be deconstructed into areas of discussion around the organising themes and then use the component themes as lines of questioning so that individuals might then work through and expand their understanding of the factors that affect their dreaming experiences and explore adaptations that might be particularly suitable for an individual to improve in their situation. An individual would be able to work through the thematic networks as part of an information collecting exercise before undertaking a more therapy-based intervention, or they may gain sufficient insight into dreaming processes that they do not require further follow on support.

The information that the individuals might generate from this exercise would enable them to formulate a personal checklist or questionnaire that would enable them to monitor their own wellbeing and take action as appropriate. For example, if an individual had been able to make a causal link between levels of anxiety and increased dreaming activity and a further link to increased dreaming activity to needing to alter plans in the immediate waking hours then they would be able to use change in any of these areas to check the impact on the other elements and to make some alteration or to investigate some intervention to ameliorate the anxiety.

An induvial would be able to use questioning tracking though the thematic diagrams to work through their dreaming processes to produce a personalised plan. The following flow chart represents the questions that might be asked at the various stages (in italics) with a rationale for why these have been included.

A The Audit

The Audit section of the process would involve fathering information on the causes and views of dreaming and discussions would follow the organising themes of the SENSEMAKING ACTIVITY OF THE DREAMING EXPERIENCE network.

What might trigger dreaming?

These might include medication, temperature, position, food and drink, health, stress, events

Anything else?

The person undertaking the audit would have some examples to consider to scaffold their thinking and it may be helpful for them to give a value of importance for each of the triggers they identify, on a scale of 1 to 10 so that the most influential causes can be identified.

When thinking about dreaming do you

Wonder if it was real or imaginary?

Discuss it with anyone else?

Enjoy thinking about it? *Anything else?*

Again, a rating scale could be used to identify which element was considered to be the most important factor or which occurred often

Do you think that dreaming is enjoyable?

Does it help with problem solving or creativity?

Is it an unpleasant activity?

Just gaining an insight into these three areas of dreaming would scaffold a conversation about perceived cases and effects which could then be used to produce an agenda for change.

It may be that following such an exploration the individual feels clear about what changes they may wish to make and in what order, for example from the ratings they may chose a trigger with a low relevance score and build up to a more central, more highly rated trigger.

The action plan would follow considering the three organising themes of the ADAPTION ACTIVITY OF THE DREAMING EXPERIENCE network, scaffolding discussion on what alterations might be made before after and during dreaming.

Inclusion of work around the IDENTITY ACTIVITY OF THE DREAMING EXPERIENCE may not be required to ensure a positive outcome for the intervention, but if was felt that this would be a beneficial addition, the thematic network could be used to scaffold and prompt discussion around this.

Using the networks in this way could be tailored to accommodate an individual's preferences, for example, if someone wished to work through this privately without the support of a practitioner, the scheme could be transferred to an interactive on line format, using skip logic to move through the different stages so that the work remain relevant to the individual. This structure would be similar to the data collection method used, which several participants had requested.

7.6.4 Lucid Dreaming Techniques

Lucid Dreaming should be an area for further investigation, as a way to manage the excesses of nightmares or as a way to promote positive dreaming experiences.   Its role in improving the experiences of populations who struggle with the dreaming phenomena has begun to be explored in diverse populations such as those with post-traumatic stress disorder (Gerlind, Brownlow, Ross & Barrett, 2016), narcolepsy (Dodet, Chavez, Leu-Semenescu, Golmard & Arnulf, 2.15), and its effects on the motor skills of darts players has been evaluated (Schadlich, Erlacher (Schredl, 2017) and it has been used in conjunction with other therapies (Holzinger, Klosh & Saletu, 2015).

Participants made links between stress and anxiety and dreaming. Those who were able to influence the production or direction of the dream appeared to have a more positive relationship with dreaming; some participants had achieved this through consciously engaging with the process of Lucid Dreaming and some through other adaptations such as avoiding stimulants or negatively toned activities before sleep. It may be helpful to trial the effectiveness of Lucid Dreaming with a group to determine of this could be a way to manage the adverse impact of dreaming on waking wellbeing.

It might be that individuals would not need to embrace a completely Lucid approach to see some improvements: to recap the experience of one of the initial interview participants:

> I just try to look at a clock face, so either the watch on my wrist or a larger clock on a wall or somewhere. And that tells me immediately if I am in a dream. Once I know that I'm dreaming then I'm not as frightened about things happening in the dream because it's not real. And I think that because I'm not frightened in the dream any more that the dreams have become happier or more positive, so I'm not as anxious when I'm awake or asleep because of dreams II.

This simple technique has enabled this participant to recognise when they are dreaming and so any negative influences in the dream content are undermined or minimised because they are understood to be elements of the dream. Understanding that it is impossible to switch a light on or off (Hearne, 1981) or to read an analogue clock (LaBerge, 2000) might be all that is required to allow anyone struggling with dreaming and its consequences to immediately start to improve their experiences.

My own experience with the reality checks was quite organic and transformative; I had read about pressing a finger into the palm of the other hand and then several months later in the course of a dreaming episode I tried it and when the finger passed through the hand I knew that I was dreaming and this reduced the perceived threat of the dream. Once I had made that initial reality check, I was able to repeat it as many times as I needed to in a dream to convince myself that I was in a dream situation and that disabled any perceived threat from the dream.

The reality checks form the initial stages of developing lucid dreaming techniques and for many they may be all that is required to hugely improve the quality of dreaming for individuals compromised by the process. Further research might be to explore the impact and satisfaction rates of introducing reality checks as a way of managing dreaming, or to investigate the experiences of autistic people who have become lucid dreamers, to see what the impact is in more detail.

7.6.5 Imagery Rehearsal Therapy

Imagery Rehearsal Therapy is a form of cognitive behavioural therapy and is often recommended for sufferers of post-traumatic stress disorder (PTSD) who are struggling with nightmares related to the source of their PTSD (Casement & Swanson, 2012). It is usually a fixed rather than open ended course of therapy and one in which the dreamer, supported by the practitioner, starts with one dream and re-scripts the ending to a more positive outcome. The new script is them rehearsed repeatedly until the new script usurps the older less helpful dream narrative. Traditionally the therapy begins with reformulating a dream that is more peripheral to the PTSD rather than a dream that is more dominant in the PTSD narrative (Lu, van Male, Whitehead & Boehnlein, 2009).

Whilst this therapeutic approach has been demonstrated as being effective for sufferers of PTSD (Davis & Wright, 2007; Krakow et al, 2000), other studies have concluded that it can be effective in the treatment of chronic nightmare type dreams arising from other conditions (van Schagen, Lancee, Spoormaker and van den Bout, 2016; Thunker & Pietrowsky, 2012).

Given the links between autism and PTSD discussed previously in this report this might be a pertinent therapy to assess and further research may undertake a study with a group to assess the impact of Imagery Rehearsal Therapy on a group of autistic people experiencing difficulties with dreaming.

The principles of Imagery Rehearsal Therapy could be used in conjunction with the lines of questioning generated from the thematic networks to develop a tailored, person centred approach to support someone who is finding dreaming challenging.

7.6.6 Eye Movement Desensitization and Reprocessing (EMDR) Therapy

EMDR was developed by Francine Shapiro, an American clinical psychologist (Shapiro, 1989). It involves the processing of an upsetting or traumatic memory using some form of bilateral stimulation of support the process, usually eye movement from side to side. Traditionally the therapy has been associated with the treatment of post traumatic stress disorder but is being developed to support other conditions. It may be an appropriate therapeutic intervention to consider where there were strong patterns of repeating dreams or in cases where dreams have similar themes. As with Imagery Rehearsal Therapy, there is a re-scripting of the negative experience to provide a more positive conclusion and this is supported by the bilateral movement. A recent Dutch study has shown that this can be an effective therapeutic intervention for adults with autism (Lobreght-can Burren, Sizoo, Mevissen & de Jongh, 2018) and this may be because EMDR is an intervention that does not rely on extensive verbal communication with the therapist unlike most psychotherapy modalities (Guina & Guina, 2018). The scaffolded approach of EMDR and its lack of dependency upon extensive verbal interaction may make it a preferred therapeutic intervention for autistic people who may find social interaction problematic in intense situations such as counselling sessions.

Future research could follow the experiences of a group of autistic people through a course of EMDR therapy to gauge how helpful it may be in re-framing or re-directing dreaming activities, using a measurement questionnaire to assess the pre and post therapeutic intervention condition of the individual.

7.6.7 From a totally different perspective…

7.6.7.1 Promoting wellbeing

Peter Vermeulen, addressing the Good Autism Practice in Belgium, commented that ‘it is remarkable that emotional wellbeing and the pursuit of it, although being highly valued for every human being, has received so little attention in research on the autism spectrum’ (2014). The presentation highlighted the findings of Frederickson and Joiner (2002) that positive feelings increase cognitive functioning, flexibility and adaptability, and that overall happier people are more likely to be successful in life (Lyubomirsky, King and Dier, 2005) contrasting this with the more problem orientated research in the autism domain. Promoting wellbeing or happiness as a way to attain more pleasing dreaming outcomes would fit with the continuity model of dreaming (Schredl, Funkhouser & Arn, 2005), although this might be more problematic to prove in practice if an individual’s mood in waking life is lowered by their dreaming experiences.

More generally, positive psychology programmes have been explored with people with autism (Zager, 2013; Bellini & Mcconnell, 2010), and it might be that these could be further refined using a framework like that of the PERMA model.

Vermeulen suggest that using a structure such as the PERMA model (Seligman, 2018; Iasiello, Bartholomaeus, Jardem & Kelly, 2017) to raise enjoyment:

P	Positive emotions
E	Engagement
R	positive Relations
M	Meaning
A	Accomplishments

Rongaglia has recently completed a study using the PERMA framework a work with an individual on the spectrum (2018) which reported positive outcomes in terms of the young person’s engagement with activities and academic progress, so this structure might be a tool to consider to support any future studies to promote wellbeing and happiness to secure improved dreaming outcomes.

More generally, positive psychology programmes have been explored with people with autism (Zager, 2013; Bellini & Mcconnell, 2010).

7.6.7.2 Autistic measures

Many of the assessment tools which have been used around diagnostic process and for assessing quality of life have been written without consultation with or meaningful participation with the autistic population. These assessment tools and measures are framing judgements about a population without necessarily reflecting its views and values. It would be invaluable in terms of understanding and producing truly participatory research if autistic measures could be produced:

> Success is not necessarily the same as quality of life, though it is related. For non-disabled people, it often is the same. At least, all the research I read defining quality of life for disabled people – and I assume the research is written from a non-disabled perspective -, determines quality of life through success. More so, it defines quality of life by success in areas important to non-disabled people. Common examples of measures of quality of life are employment, independent living and a long-term relationship.
>
> BloggingAstrid from the blog Deriving quality of life from success 26 June 2014.

7.6.8 Conclusions about future directions for research

There are a number of on line resources, videos, to support such any future studies, or these might be undertaken in conjunction with one of the sleep charities or units to enable other forms of assessment such as with polysomnographic equipment. Future studies could be undertaken in a range of formats such as through a diary study (Schredl & Noveski, 2018) or through an online platform (Mata-Rolim et al., 2013).

Future research could use a dream questionnaire such as the Mannheim Questionnaire in conjunction with a quality of life questionnaire to establish the pre and post intervention condition of the participant with the participants own views and estimation on the success or otherwise of the intervention.

The future research directions proposed, might, with the exception of EMDR, be designed so that participants might work in small groups to explore their dreaming experiences or may first begin with individual case studies and then integrate group work.

Raising awareness that dreaming is an activity that can be problematic for individuals is key to providing meaningful support. Just as awareness of mental health issues amongst young men in particular is being raised across social media and through training for public facing services such as health, education and police to spot the early sings of depression and other conditions, some publication of information around the impact that dreaming can have would provide these services with more insight in dealing with autistic people. Just as people facing mental health challenges may have become habituated to their condition, so autistic people may not realise the extent to which dreaming is adversely affecting their well-being and that there are strategies and interventions that may help support them with this. Understanding that dreaming can have a particularly adverse effect on an autistic person's well being may ensure that a practitioner includes this in a larger list of factors to rule in or out in the formulation regarding someone's presentation.

7.7 Final conclusions

This chapter has drawn conclusions from the study, including critical reflections on the implications for research and practice. The study has investigated how the experience of dreaming affects autistic people and any impact it may have upon their waking well-being. The narratives that were provided offered insights into private words that it was a true privilege to be granted and it is hoped that the careful analysis through the TA and IPA reflects this. The 'gap' in knowledge around the relationship between autism and dreaming has been both highlighted and affected by this study. It is hoped that further inquiry and research will take place at some point so that autists may be more fully supported if they are finding this a challenging issue and that that research is formulated in ways that further develop good practice when working with autistic participants in co-constructed research.

Appendices

Appendix 1 - Confirmation of Ethical Approval

Sheffield
Hallam
University

Our Ref AM/RKT/D&S-313
3 April 2017

Sally-Ann Pindar
Sheffield Institute of Education
Development of Society
Sheffield Hallam University
Howard Street
Sheffield
S1 1WB

INTERNAL

Dear Sally-Ann,

Request for Ethical Approval of Research Project

Your research project entitled "**Autistic Dreaming: A phenomenological study of dreaming and well-being**" has been submitted for ethical review to the Faculty's rapporteurs and I am pleased to confirm that they have approved your project.

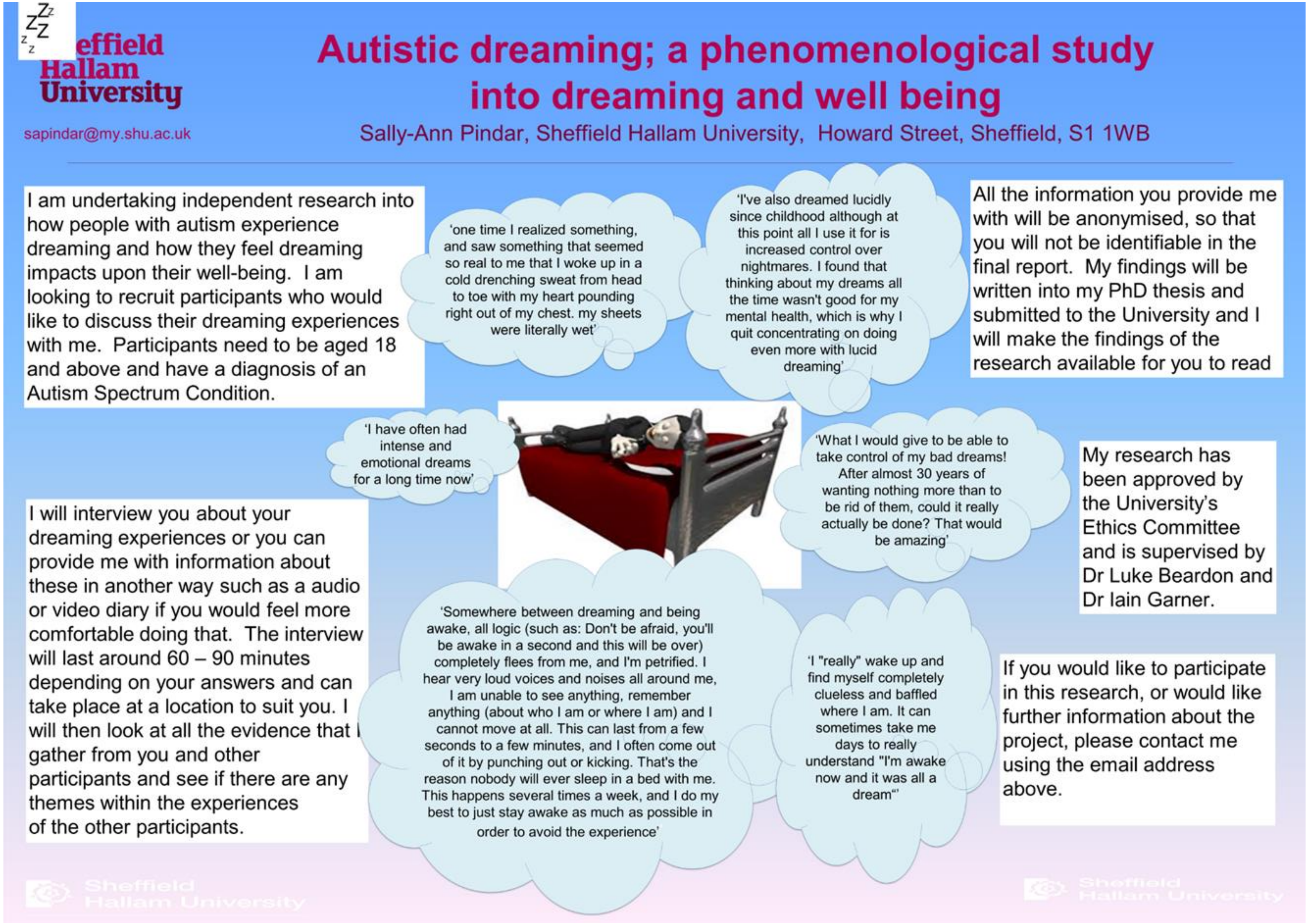
I wish you every success with your research project.

Yours sincerely

Ann Macaskill

Professor A Macaskill
Chair
Faculty Research Ethics Committee

Appendix 2 - Participant Recruitment Poster



sapindar@my.shu.ac.uk

Autistic dreaming; a phenomenological study into dreaming and well being

Sally-Ann Pindar, Sheffield Hallam University, Howard Street, Sheffield, S1 1WB

I am undertaking independent research into how people with autism experience dreaming and how they feel dreaming impacts upon their well-being. I am looking to recruit participants who would like to discuss their dreaming experiences with me. Participants need to be aged 18 and above and have a diagnosis of an Autism Spectrum Condition.

'one time I realized something, and saw something that seemed so real to me that I woke up in a cold drenching sweat from head to toe with my heart pounding right out of my chest. my sheets were literally wet'

'I've also dreamed lucidly since childhood although at this point all I use it for is increased control over nightmares. I found that thinking about my dreams all the time wasn't good for my mental health, which is why I quit concentrating on doing even more with lucid dreaming'

All the information you provide me with will be anonymised, so that you will not be identifiable in the final report. My findings will be written into my PhD thesis and submitted to the University and I will make the findings of the research available for you to read

'I have often had intense and emotional dreams for a long time now'

'What I would give to be able to take control of my bad dreams! After almost 30 years of wanting nothing more than to be rid of them, could it really actually be done? That would be amazing'

My research has been approved by the University's Ethics Committee and is supervised by Dr Luke Beardon and Dr Iain Garner.

I will interview you about your dreaming experiences or you can provide me with information about these in another way such as a audio or video diary if you would feel more comfortable doing that. The interview will last around 60 – 90 minutes depending on your answers and can take place at a location to suit you. I will then look at all the evidence that I gather from you and other participants and see if there are any themes within the experiences of the other participants.

'Somewhere between dreaming and being awake, all logic (such as: Don't be afraid, you'll be awake in a second and this will be over) completely flees from me, and I'm petrified. I hear very loud voices and noises all around me, I am unable to see anything, remember anything (about who I am or where I am) and I cannot move at all. This can last from a few seconds to a few minutes, and I often come out of it by punching out or kicking. That's the reason nobody will ever sleep in a bed with me. This happens several times a week, and I do my best to just stay awake as much as possible in order to avoid the experience'

'I "really" wake up and find myself completely clueless and baffled where I am. It can sometimes take me days to really understand "I'm awake now and it was all a dream"'

If you would like to participate in this research, or would like further information about the project, please contact me using the email address above.

Appendix 3 – Participant Consent Form (direct interviews)

PARTICIPANT CONSENT FORM

(direct interviews)

Autistic Dreaming: A phenomenological study of dreaming and well-being.

Please answer the following questions by ticking the response that applies

YES NO

1. I have read the Information Sheet for this study and have had details of the study explained to me. [ ] [ ]

2. Any questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point. [ ] [ ]

3. I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, ithout giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher. [ ] [ ]

4. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet

5. I wish to participate in the study under the conditions set out in the Information Sheet. [ ] [ ]

6. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes. [ ] [ ]

Participant's Signature: ______________________________ Date: ____________

Participant's Name (Printed): _______________________________________

Contact details: ____

Researcher's Name (Printed): ______________________________________

Researcher's Signature: ____

Researcher's contact details:
(Name, address, contact number of investigator)
Please keep your copy of the consent form and the information sheet together.

Appendix 4 - Participant information sheet – online survey and interviews

Thank you for your interest in this study which is a PhD study exploring how people with autism experience dreaming and any impact that they feel it has upon their well-being.

I will ask you to provide information about your dreaming experiences. The information you give will be in the form of your desriptions of your dreaming experience and how the dream may have affected your well being in the following waking hours - how it made you feel, and if it had any impact on your ability to carry out your usual activities. Please note that I am not able to offer therapeutic support for any sleep difficulties that you may be having.

The data that you provide in this questionnaire will be held in a password protected cloud, this data is traceable to your IP address in case you wish to withdraw from the project. Then, two weeks later the data will be removed from the cloud and anonymised, it will be stored in password protected files on an encrypted computer system. Personal information will be confidentially destroyed once the PhD report has been verified and other data used in the research will be anonymised, transferred and kept for 10 years with the University's secure systems and may be used to support other research during this period. Any information that is used in the final report such as quotes or statistics will be anonymised so that you will not be able to be connected or identified with what is recorded or reported.

This survey will be available for completion until it closes at noon on Tuesday 30th April 2019. The whole study is likely to take until the middle of 2019 to complete. I can send you a copy of the preliminary findings and a report of the study if you contact me by email. Participation in the study is completely voluntary and you are free to withdraw at any time if you change your mind and you will be able to request that your data be destroyed and not used in the study for up to 2 weeks following your completion and submission of the questionnaire.

If you have any questions you can contact me at sapindar@my.shu.ac.uk

Appendix 5 - Participant Consent (on line survey)

PARTICIPANT CONSENT

I have read the Information Sheet for this study.

I am over 18 years of age with any diagnosis related to the autism spectrum.

I do not have a co-morbid diagnosis (for example ADHD, ADD; please contact me if you have any questions about this - sapindar@my.shu.ac.uk)

I understand that I am free to withdraw from the study within the time limits outlined in the Information Sheet, without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher.

I wish to participate in the study under the conditions set out in the Information Sheet.

I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other academic research purposes.

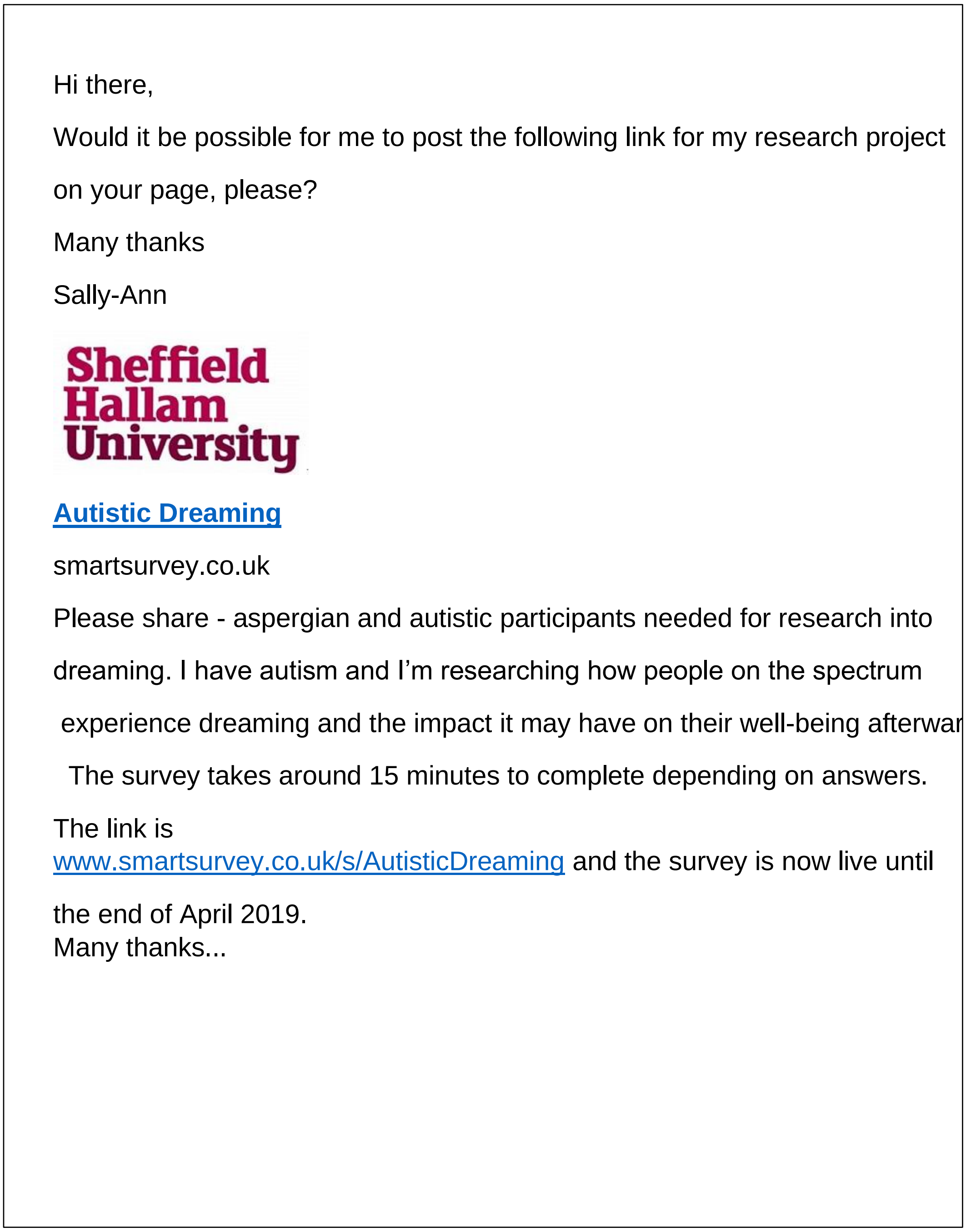
- ○ I have read the above and consent to participate in this project

Appendix 6 - On line survey questions

Where ‘skip logic’ was applied for a negative answer this is indicated as *

- Do you recall your dreaming experiences? *
- How would you describe the tone of your dreams (tick all that apply)?
  - Positive
  - Vivid
  - Unsettluing
  - Disturbing
  - Bizarre
  - Exciting
  - Other (please describe)
- What impact does this have on your waking life?
- Do you record your dremas? *
- How does that make you feel about your dreams?
- Do you discuss your dreams? *
- How do these conversations make you feel about your dreams?
- Have you ever sought support to cope with the effects of dreaming? *
- How successful was this?
- What might increase your chances of dreaming?
- Would you use this knowledge to increase of avoid dreaming?
- Is there anything that you can do to alter your dreaming experience either in the dream state or before falling asleep?
- What impact does dreaming have on your mood?
- Would a dreaming experience ever cause you to change your plans?
- How would you change your plans?
- Do you think that dream advserley affects your well-being? *
- Please describe how you think dreaming affects your well being?
- If you could choose to never dream again, would you want to stop dreaming?
- Why?
- Is there anything else that you would like to tell me about your dreaming experience and the impact it has upon your waking life?

Appendix 7 - Request for post on a group page



Hi there,

Would it be possible for me to post the following link for my research project on your page, please?

Many thanks

Sally-Ann

Sheffield Hallam University

[Autistic Dreaming](www.smartsurvey.co.uk/s/AutisticDreaming)

smartsurvey.co.uk

Please share - aspergian and autistic participants needed for research into dreaming. I have autism and I'm researching how people on the spectrum experience dreaming and the impact it may have on their well-being afterwar

The survey takes around 15 minutes to complete depending on answers.

The link is
www.smartsurvey.co.uk/s/AutisticDreaming and the survey is now live until the end of April 2019.
Many thanks...

Appendix 8 - Debriefing materials (on line survey and initial interviews)

Debriefing materials

The aims of this study are to investigate how people with autism experience dreaming and the impact that it has upon their well-being.

If you wish to contact me we any further questions or, if for any reason, you wish to withdraw you data once you have left (within 2 months of our most recent contact), I can be contact via my Sheffield Hallam University email sapindar@my.shu.ac.uk

You will be able to obtain a summary of the results of the study by contacting me via the email address above and an electronic copy of the summary can be sent to you.

If this study has raised personal issues that you are not comfortable discussing with the researcher now, you might wish to contact the Ieso Online Talking Therapy Service , you can refer via your GP of self refer - www.iesohealth,com/eastriding or telephone 01954 230 066. You will need to access internet connection to use this service.

If you have any concerns about this study or the way in which it was conducted you can contact my Supervisors, Dr Luke Beardon and Dr Iain Garner (L.Beardon@shu.ac.uk and I.Garner@shu.ac.uk respectively).

Thank you for participating in this research project.

Appendix 9 - The Mannheim Dream questionnaire (MADRE)

Dream Questionnaire (MADRE)

This questionnaire aims at obtaining a good overview of different aspects of dreaming. It takes about 5 to 10 minutes to complete. Please take your time and answer all questions carefully and completely.

Age: _____ years

Gender: ○ male ○ female

Occupation / Study discipline (students): ________________________

1. How often have you recalled your dreams recently (in the past several months)?

almost every morning ○ several times a week ○ about once a week ○
two or three times a month ○ about once a month ○
less than once a month ○ never ○

2. How intense are your dreams emotionally?

Not at all intense ○ Not that intense ○ Somewhat intense ○
Quite intense ○ Very intense ○

3. What is the emotional tone of your dreams on average?

Very negative ○ Somewhat negative ○ Neutral ○
Somewhat positive ○ Very positive ○

4. How often have you experienced nightmares recently (in the past several months)?

Definition: Nightmares are dreams with strong negative emotions that result in awakening from the dreams. The dream plot can be recalled very vividly upon awakening.

several times a week ○ about two to four times a year ○ about once a week ○
about once a year ○ two to three times a month ○ less than once a year ○
about once a month ○ never ○

5. If you currently experience nightmares, how distressing are they to you?

Not at all distressing ○ Not that distressing ○ Somewhat distressing ○

Quite distressing ○ Very distressing ○

Continued ...

Appendix 9 (continued_

6. Do you experience recurring nightmares that relate to a situation that you have experienced in your waking life?
Yes ○ No ○

7. How many of your nightmares are recurrent ones (in percent)?
_____ %

8. How often did you experience nightmares during your childhood (from 6 to 12 year of age)?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

9. Please list the topics of your childhood nightmares:
____

10. How often do you experience so-called lucid dreams (see definition)?
Definition: In a lucid dream, one is aware that one is dreaming during the dream. Thus it is possible to wake up deliberately, or to influence the action of the dream actively, or to observe the course of the dream passively.
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

11. If you have experienced lucid dreams, how old were you when they occurred the first time?

____ years

12. Attitude towards dreams

	Not at all	Not that much	Partly	Somewhat	Totally
How much meaning to you attribute to your dreams?					
How strong is your interest in dreams?					
I think that dreams are meaningful					
I want to know more about dreams					
If somebody can recall and interpret his/her dreams, his/her life will be enriched					
I think that dreaming is in general a very interesting phenomenon					
A person who reflects on her/his dreams is certainly able to learn more about her/himself.					
Do you have the impression that dreams provide impulses or pointers for your waking life?					

Continued …

Appendix 9 - (continued

13. How often to you tell your dreams to others?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

14. How often do you record your dreams?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

15. How often do your dreams affect your mood during the day?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

16. How often do your dreams give you creative ideas?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

18. How often do your dreams help you to identify and solve your problems?
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

19. How often do you experience Déjà vus (see definition)? Definition: During a déjà vu experience one is convinced one is reliving real-life situation that was already experienced in a dream.
several times a week ○ about two to four times a year ○ about once a week ○ about once a year ○ two to three times a month ○ less than once a year ○ about once a month ○ never ○

20. Have you ever read something on the topic of dreams? [Books or magazine articles]
No ○ One to two times ○ several times ○

21. Did the literature about dreaming / dream interpretation help you to better understand your dreams?

Not at all ○
Not that much ○
Somewhat ○
Quite ○
Very much ○

Appendix 10 - Discover Criteria for Aspie by Attwood and Gray (1999)

A. A qualitative advantage in social interaction, as manifested by a majority of the following:

1. peer relationships characterized by absolute loyalty and impeccable dependability
2. free of sexist, "age-ist", or culturalist biases; ability to regard others at "face value"
3. speaking one's mind irrespective of social context or adherence to personal beliefs
4. ability to pursue personal theory or perspective despite conflicting evidence
5. seeking an audience or friends capable of: enthusiasm for unique interests and topics;
6. consideration of details; spending time discussing a topic that may not be of primary interest
7. listening without continual judgement or assumption
8. interested primarily in significant contributions to conversation; preferring to avoid 'ritualistic small talk' or socially trivial statements and superficial conversation.
9. seeking sincere, positive, genuine friends with an unassuming sense of humour

B. Fluent in "Aspergerese", a social language characterized by at least three of the following:

1. a determination to seek the truth
2. conversation free of hidden meaning or agenda
3. advanced vocabulary and interest in words
4. fascination with word-based humour, such as puns
5. advanced use of pictorial metaphor

C. Cognitive skills characterized by at least four of the following:

1. strong preference for detail over gestalt
2. original, often unique perspective in problem solving
3. exceptional memory and/or recall of details often forgotten or disregarded by others, for example: names, dates, schedules, routines
4. avid perseverance in gathering and cataloguing information on a topic of interest
5. persistence of thought
6. encyclopaedic or 'CD ROM' knowledge of one or more topics
7. knowledge of routines and a focused desire to maintain order and accuracy
8. clarity of values/decision making unaltered by political or financial factors

D. Additional possible features:

1. acute sensitivity to specific sensory experiences and stimuli, for example: hearing, touch, vision, and/or smell
2. strength in individual sports and games, particularly those involving
3. endurance or visual accuracy, including rowing, swimming, bowling, chess
4. "social unsung hero" with trusting optimism: frequent victim of social
5. weaknesses of others, while steadfast in the belief of the possibility of genuine friendship
6. increased probability over general population of attending university after high school
7. often take care of others outside the range of typical development

Appendix 11 – List of Facebook pages and groups to which request were sent for permission to promote the survey on their pages

Autism Spectrum Late Diagnosis Support & Friendship
AUTISM AND SPECIAL NEEDS ACTION GROUP
Autism East Midlands
Adults with Aspergers and High-Functioning Autism - Support Group
The girl with curly hair
Aspergers Adult Support
Dorset Aspergers group
Autism Friendly UK
Aspergers/Autism Young Adults 16+
Women on The Spectrum | ASD & Aspergers | Support Group: No Drama
Aspergers Awareness
Autism Speaks
American Autism and Asperger's Professional Society
Asperger's syndrome and autism spectrum disorders support group
Asperger Syndrome Awareness
Autism aware UK
Autistic strategies
Asperger's Syndrome awareness worldwide
Adult Aspergers Support Community
Autism Association of Western Australia
Autism Spectrum Australia (aspect)
Adult Autistic Spectrum community
Autistics worldwide
Positively Autistic
The don't look autistic

Appendix 12 – sample transcript of initial interview

The whole thing was so vivid and had so many components of dreaming that I don't think that I've experienced before and certainly not with such clarity. I could see colours and feel textures and temperatures and there was also a sense that I had some degree of choice in my actions in the sense of flying the plane and looking at the clock and trying the switch. But there was also this totally terrifying sense of not having any control in that the plane crashed and I was not able escape from the dream.

Do you have any sense of how long you were dreaming for?

These events can't have gone on for very long but felt like they were never ending and inescapable.

How did you feel when you woke up?

I felt absolutely drained when I woke up. Just emotionally drained and exhausted. I had to ring in sick and take the morning off just to start to process the dream and to recover from it. One of my problems is that I have a ridiculous memory – photographic and aural and borderline hyperthymic so I can replay the dream, not quite with the same intensity but still in a very vivid form and even now I can see the settings in which the dream took place. I think that the dream was really startling because of all the elements that combined within it that I might not usually experience, so the flying and the waking from a dream into a dream and the sitting next to myself and the trying to do things in the dream. The sense of threat and violence in phases of the dream.

This an unusual sort of dream for you?

Usually my dreams are less clear, more sensations or feelings rather than actual cinema like views. Mostly these involve some form of threat or escaping or running away from things. I can recall dreams but this tends to be as archetypes, compilations of dreams rather than the absolute clarity of this particular dream.

Have you been able to find any triggers for your dreams?

If I can find a reason for the dream or link it into something that I’ve done or eaten then I don’t feel to upset or disrupted by it. The catastrophic one did make me feel really ill and drained and I think has continued to bother me as there were just so many things in it that I’ve not experienced in dreaming before or since and although I have come to realise that it was a response to a really stressful situation developing over months it was just such a light bulb/watershed moment that has never repeated itself which is strange as my dreams do tend to have recurring themes.

Appendix 13 – Sample of Initial Coding list

food
exhausted
tired
shaking
sweating
afraid
apprehensive
careful
concerned
distressed
fearful
angry
sad
nervous
film
repeating
violence
uptight
sick
cold
moon
medication
anxious
ill
laying on front
physical position
clothing
others
pets
tv
cinema
flying
falling
threat
embarrassment
prophecy
re-living
lost
attack
lucid
unsettling
childhood home
light switch
past
Freddie Mercury
arguments
underwater
stairs
bus
superman
intruders
thoughtful
inadequate
melancholy
positive
bizarre
movement
talking
snoring
crying
trauma
family events
work
special interests
rehearsal
social situations
heights
future
school
understanding
naked
enjoyable
sex
decipher
alexithymia
vivid
remember
therapy
reality
taking up time
less functional
burglars
harry potter
danger
random
odd
perplexed
pain
feeling of difference
abstract
neutral
risk
effect of sleep patterns
disheartened
stress
wellbeing
control
relaxing
awareness of being in a dream
blue light
melatonin
sad family dream
masking
avoiding people and events
problem solving
paranoid
horror film
creativity

Appendix 14 – Consolidation of codes

From the initial list of codes, those that were similar or related to that which was emerging as a basic component, in this case PHYSICAL FACTORS, were highlights and then amalgamated under that heading.

food
exhausted
tired
shaking
sweating
afraid
apprehensive
careful
concerned
distressed
fearful
angry
sad
nervous
film
repeating
violence
uptight
sick
cold
moon
medication
anxious
ill
laying on front
physical position
clothing

others
pets
tv
cinema
flying
falling
threat
embarrassment
prophecy
re-living
lost
attack
lucid
unsettling
childhood home
light switch
past
Freddie Mercury
arguments
underwater
stairs
bus
superman
intruders
thoughtful
inadequate
melancholy

positive
bizarre
movement
talking
snoring
crying
trauma
family events
work
special interests
rehearsal
social situations
heights
future
school
understanding
naked
enjoyable
sex
decipher
alexithymia
vivid
remember
therapy
reality
taking up time
less functional

burglars
harry potter
danger
random
odd
perplexed
pain
feeling of difference
abstract
neutral
risk
effect of sleep patterns
disheartened
stress
wellbeing
control
relaxing
awareness of being in a dream
blue light
melatonin
sad family dream
masking
avoiding people and events
problem solving
paranoid
horror film
creativity

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