

**Citation for published version:**

P. Maloret, and T. Scott, 'Don't ask me what's the matter, ask me what matters: Acute mental health facility experiences of people living with autism spectrum conditions', *Journal of Psychiatric and Mental Health Nursing*, Vol. 25 (1): 49-59, February 2018.

**DOI:**

<https://doi.org/10.1111/jpm.12438>

**Document Version:**

This is the Accepted Manuscript version.

The version in the University of Hertfordshire Research Archive may differ from the final published version.

**Copyright and Reuse:**

© 2017 John Wiley & Sons Ltd.

This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#).

**Enquiries**

If you believe this document infringes copyright, please contact the Research & Scholarly Communications Team at [rsc@herts.ac.uk](mailto:rsc@herts.ac.uk)

DR PAUL MALORET (Orcid ID : 0000-0003-2184-0642)

Article type : Original Article

## TITLE PAGE

'Don't ask me what's the matter, ask me what matters: acute mental health facility experiences of people living with Autism Spectrum Conditions'

## AUTHORSHIP

### Corresponding author

PAUL MALORET MA, BA (Hons), PGDip, PGCE, Dip HE, RNLD

Principal Lecturer, Nursing and Midwifery, School of Health and Social Work, University of Hertfordshire, Hatfield, United Kingdom AL10 9AB

Email: p.b.maloret@herts.ac.uk Tel: +441707283312

### Co-author

Dr TRICIA SCOTT PhD, BA(Hons), DipN, CertEd, RGN, RMN

Principal Lecturer, Centre for Research in Primary and Community Care, University of Hertfordshire Hatfield, United Kingdom AL10 9AB

Email: p.scott3@herts.ac.uk Tel: + 441707281029

## (1) Conflict of Interest

No conflict of interest is declared by the authors

## (2) Ethical Statement

Ethics Committee approval was obtained on 26 August 2015 from the NRES Committee London - South East reference number HSK/PG/NHS/00284.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jpm.12438

This article is protected by copyright. All rights reserved.

### **(3) Funding Source in the order given here**

No funding source is declared by the authors

### **(4) Clinical Trials Registry and Registration number**

This is not a clinical trial

**(5) Acknowledgments.** Where no information is available, the headings (1)-(3) should still be used with "None", or "Not applicable" used.

All authors should have made substantial contributions to all of the following:

- (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data,
- (2) drafting the article or revising it critically for important intellectual content,
- (3) final approval of the version to be submitted.

Please confirm that they have agreed to publication and put in brackets the way in which they have contributed:

**MALORET (1, 2, 3)**

**SCOTT (1, 2, 3)**

Abstract

Background

This qualitative study explored how mental health inpatients with autistic spectrum conditions experience and cope with anxiety when admitted to an acute mental health inpatient facility in the UK.

Anxiety is a common characteristic for people who live with autistic spectrum conditions and whilst a plethora of studies on anxiety in this population are published which correlate anxiety with mental health service experience, little is known about the actual triggers of anxiety and its manifestations.

This study adds to a body of evidence which considers anxiety experienced by people with autism.

The rationale for this paper includes the need to heighten mental health practitioners' understanding,

of the responses, motivations to engage and support required to overcome fears and anxieties when admitted to a mental health inpatient unit.

#### Method

The study used a qualitative naturalistic research design, to explore the emotional and psychological experiences of being a mental health inpatient living with an autistic spectrum condition. During 2015-2017 audio-recorded semi-structured interviews captured the experiences of 20 adults from the East of England who were former psychiatric inpatients with an established diagnosis of autistic spectrum condition. Interpretative phenomenological analysis enabled the identification of broad themes which explained in rich detail, participant reflections regarding the situations and events within the acute care mental health facility that triggered their anxiety, manifestations of anxiety and, responses to their anxiety.

#### Findings

Broad response patterns were identified that could be associated with their anxiety i.e. isolating themselves from others, including patients and staff, ceasing to eat and sleep adequately and all too often self-harming or exhibiting aggressive and violent responses.

#### Conclusions

The anxiety caused by the physical environment appears to be overlooked by mental health practitioners so attention to anxiety inducing encounters is needed when planning acute care mental health service improvement and research is required to clearly understand the experiences of this vulnerable group.

#### KEYWORDS

Autistic spectrum conditions, communication, anxiety, acute mental health admission.

#### Relevance statement

Growing numbers of people living with an autistic spectrum condition find themselves in mental health inpatient units within the UK. It is largely the opinion of the participants of the study that the services in which they find themselves are woefully ill-equipped to deal with their different needs and that frontline staff in mental health units could learn from mistakes made in the past and gain greater awareness and knowledge of how the core features of autism coexist with mental health issues.

### **Accessible Summary**

#### **What is known on the subject**

- There is a growing body of evidence that many people with an Autism Spectrum Condition suffer anxiety in their daily life and a realisation among practitioners that admission to a mental health unit for this population is usually a negative anxiety inducing experience.
- Anxiety is driven by the intolerance of uncertainty i.e. being unsure of what is going to happen, how long the uncertainty will exist and the insistence of sameness which, when compromised, can be anxiety provoking. Equally, confusion in understanding personal emotional responses and those of others is a source of anxiety.

#### **What this paper adds to existing knowledge**

- This paper builds upon existing understanding of anxiety as a causative factor of mental ill-health for people with an Autism Spectrum Condition.
- Specifically, this paper explores the potentially anxiety-inducing experience of mental health unit admission; how anxiety is felt, triggered, expressed and managed.

#### **What are the implications for practice**

- As many different anxiety responses could be exhibited during hospitalisation, including violent acts and self-harming, for mental health practitioners working in the inpatient units it is essential that the thoughts, feelings and responses of the patient with an ASC are better understood and that support offered during their stay in a mental health facility, is from an informed position.

## Introduction

According to the National Autistic Society (2017) an Autistic Spectrum Condition (ASC) is a lifelong developmental disability that affects how people perceive the world and interact with others. People living with autism see, hear and feel the world differently and live with this condition throughout their life. Autism is not an illness or disease and therefore, cannot be 'cured'.

People with ASC are particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life. It is well documented that hospital admission to meet the mental health needs should be a last resort however the evidence suggests that admissions are increasing (Narendorf et al, 2011). Howlin (2005) notes that the mere thought of an inpatient admission for a person with ASC can cause an acute escalation of the severity of their mental health condition, the desire for sameness can be seriously compromised when someone with ASC is placed in unfamiliar surroundings.

Ghaziuddin et al (1998) found that as many as 65 per cent of patients with Asperger Syndrome presented with symptoms of psychiatric disorder. More recently Bakken et al (2010) found that 53% of people with autism and intellectual disabilities suffered from a psychiatric disorder. Joshi et al. (2013) found significantly higher levels of psychiatric comorbidity in ASC populations when compared with non-ASC populations including major mood/depressive disorders, bipolar disorder and psychosis. Particularly high comorbidity concerned multiple anxiety disorders including phobias, separation anxiety disorder, agoraphobia, social phobias, obsessive-compulsive disorder, post-traumatic stress disorder and generalised anxiety disorders (Magiati et al, 2016). Mannion et al (2013) found that 46% of individuals with ASC had a psychiatric comorbidity, with this number rising to 79% if individuals also had an intellectual disability. High prevalence of psychiatric comorbidity in ASC is largely due to the constant anxious state of mind in which many live their lives. People with ASC will go to great lengths to minimise stress and create a predictable world in which they feel confident and may adequately function. This may involve long periods of isolation to detach from the most unpredictable element of society; people, with a significant impact upon their mental wellbeing. Additionally, most people with ASC fail to eradicate stress from their lives consequently, over a sustained period this can cause acute and chronic mental illness. Simonoff et al. (2013) estimated a figure as high as 70% among 12

year old children with ASC who met the criteria of at least one psychiatric disorder; 40% had two or more additional disorders.

It is crucial to understand the aetiology of anxiety within ASC populations and a great deal of anxiety experienced can be linked to the core features of the condition itself. A meta-analysis undertaken by Van Steensel and Bogels (2012) suggested 40% of young people with ASC met the criteria for an anxiety disorder and Magiati et al. (2016) suggested that people with greater ASC symptomatology i.e. more effected by the core features of autism, are more vulnerable to anxiety related difficulties. The Intolerance of Uncertainty (IU) is defined as a broad dispositional risk factor for the development and maintenance of clinically significant anxiety (Carleton 2012). IU is regarded as the main driving force behind the high anxiety levels experienced by this group (Maisel et al., 2016; Boulter et al., 2014; Wigham et al., 2015). Lidstone et al. (2014) suggest that repetitive motor behaviours and insistence on sameness can be seen as a marker for anxiety which can become noticeably more frequent with increased intensity when anxiety heightens. Equally, they can act as a buffer to alleviate distress and a mechanism for dealing with anxiety. Rogers et al. (2012) investigated the responses of children diagnosed with ASC, whereby those living with higher anxiety had more repetitive responses than those without. Agitation, aggressive and self-harming responses can also be a marker and an alleviator of anxiety within ASC populations (Rodgers et al., 2012; Lidstone et al., 2014). Additionally, emotional responses or confusion experienced by the person with ASC and their attempts to read and understand other people's emotional responses, alexithymia, difficulty in identifying and describing internal emotional states, also play a considerable part (Maisel et al., 2016; Boulter et al., 2014).

Historically, service provision for this client group has been problematic and at times dangerously elusive. The Autism Strategy (Department of Health, [DoH], 2010) demanded higher quality services, particularly for those who experience difficulty accessing services to meet their needs. Personalising services i.e. making services fit everyone's needs, not just those people who fit certain criteria was essential. Legislation to support the mental health care needs of people with ASC is still relatively new to the political horizon in England, but is beginning to have a gradual impact upon services. Despite best efforts by some services and excellent examples of person-centred care and reasonably adjusted services, with staff teams enjoying heightened awareness in autism, an experience of mental health inpatient care for someone with autism is described by many of the voluntary candidates in this

study as being poor. From an international perspective, the World Health Organisation (2013) reported on a global consensus to address an urgent need to strengthen strategies for comprehensive and integrated mental health services to care for people with ASC, in line with the WHO Comprehensive Mental Health Action Plan 2013-2020.

On this basis, there is a clear need to consider more closely what exactly is happening in the early hospital admission encounter and how best to minimise the stress experienced. This paper explores how patients with ASC experience and cope with their anxiety whilst in an inpatient mental health setting.

#### Research aim

The principal research aim was to explore how admission to a mental health unit impacts on the psychological well-being of adults affected by ASC. The primary aim was to explore commonly reported feelings of anxiety and stress among these patients who are away from their comfortable and familiar home environments within a psychiatric unit where daily experiences may be unpredictable. The secondary aims concerned first, to explore the lived experiences of adults affected by ASC who had been admitted to a mental health unit and second, to unearth how adults make sense of their thoughts and feelings having been treated as an inpatient. From these it was possible to determine the issues that heighten stress experience among the participants and their coping strategies.

#### Method

As the chief investigator I came to this research with my own experiences, values, ethics, attitudes and assumptions. My interest in this field has been informed by my experiences as a Registered Nurse Learning Disability, an academic specialising in learning disability nurse education and, a trainer in autistic spectrum conditions. I have witnessed first-hand the intensely poignant and powerful impact that admission to hospital can have on a person with a diagnosis of an ASC. As I paused to reflect on these experiences and my own personal reactions, it raised numerous questions regarding

the causes of heightened states of anxiety which are highly prevalent for these patients. It is this reflexive internal conversation and my relationship with others which, I believe, has led me to identify strongly with the subject matter of the current study and to pursue this research.

## **Design**

The study is concerned with how patients with ASC experience inpatient episodes and how they spend their time. Qualitative naturalistic research was used as a framework in combination with interpretative phenomenological enquiry (Smith 2013). Social constructivism (Berger and Luckmann, 1966) informed the study approach by referring to our psychological (cognitive) processes and structures at an individual level. In other words, how we perceive the world as individuals, collaboratively creating a small culture of shared artifacts with shared meanings (Cresswell, 2009). The Heideggerian phenomenological approach (Crowell, 2013) enabled me to get as close as possible to the participants' perception of events and to understand how people with ASC experience inpatient episodes and spend their time in the unit. Heidegger introduced the notion of the hermeneutic circle, which values our pre-understanding of situations, and ourselves as already in the world (Crowell, 2013). The hermeneutic circle has been developed in this study by reflecting upon my prior assumptions of the phenomenon, understanding how these assumptions can impact upon the interpretation of the participants' views, challenging these assumptions and gaining a more in-depth understanding sourced from the data. To truly understand the thoughts and feelings of a person with ASC, my prior knowledge and experience as a learning disabilities nurse and educator was invaluable to the research design, interviewing techniques and inductive data analytical process.

Elwin et al., (2012) and Narendorf et al., (2011) reported a poor uptake and unwillingness to meet for a face-to-face interview among people with ASC. Additionally, Bakkena et al. (2010) and earlier Jones and Meldal (2001) noted that when conducting semi-structured interviews with this group it was difficult to obtain the richness of data required, interviews often being short-lived with limited responses. Therefore, to maximise feedback on their experiences, great care and attention was paid to the interview approach and conditions.

## **Participants**

The national profile of people with ASC who need psychiatric inpatient care and who are without intellectual/learning disability is described as a group who are potentially vulnerable to exclusion from health and social care services (Department of Health, 2014). Consistently within this population people live largely independent lives, many live on their own, undertake employment or education opportunities, with support networks albeit family members or advocacy/support groups. Many are not known to health and social care professions until a mental health crisis occurs. Generally the autistic diagnosis for this group would be Asperger's Syndrome or High Functioning Autism (HFA). The mental health diagnosis is varied, but most prevalent within this group is an additional diagnosis of generalised anxiety disorder, depression and/or substance misuse. The majority of this group who have an existing diagnosis of ASC are male.

## **Inclusion criteria**

The inclusion criteria comprised participants over the age of 18 at the time of interview, capacity to consent, a minimum two week inpatient admission period and at the time of the interview they had a confirmed diagnosis of ASC. Additionally care was taken that the participants were well enough to be interviewed, this was established by having an open dialogue with the participants to this effect. Those who had been identified by the local Asperger's support team were only put forward where the team felt that they were well enough to participate.

## **Sample and recruitment**

Purposive sampling (Crotty, 2013) was used to identify former mental health unit patients with an established diagnosis of ASC therefore participants who volunteered into the study were already aware of their diagnosis. Recruitment was evidently easier and felt safer for the participants if the study had been recommended to them by the Manager of the local Asperger's Team. A small group of participants were identified and approached by the Manager of the Asperger's Team in the first instance, given contact details and information regarding the study. The potential participant then contacted me, to volunteer in. A snowball sampling technique (Crotty, 2013) was then used, whereby those initially sampled proposed other participants who had similar experiences and who they thought may be willing and able to share them. During invited sessions with the Autism/Asperger's Social Group I distributed the Participant Information Sheet explaining the nature of the research. The

reaction was positive as a number had experienced mental ill-health and subsequent admission to a unit and they expressed how they wanted their voice to be heard. A number of individuals wanted to learn more about the study before giving consent so my multiple visits were welcomed. On initial contact there would be an open discussion about the methodology and the research process and how the information would be used secondly, the semi-structured interview was explained. Following discussion, and answering of questions thinking time was facilitated to consult family and friends. Due to the higher male to female ratio in ASC diagnosis nationally a male-dominated sample was likely.

Although each of the 20 participants had an individual presentation, the participant's profile in **Table 4**, provides a representative example of all participants. Names used have been changed to protect anonymity.

#### **Table 4 Patient profile**

##### **Ethics**

Favourable opinion was granted by the National Research Ethics Service Committee London South East on 26<sup>th</sup> August 2015 (HSK/PG/NHS/00284). In line with the core principles relating to consent within the Mental Capacity Act (2005), attempts have been made to help the participants to make an informed decision about whether to participate. Reasonable adjustments and time allowances were made for individuals who potentially could have difficulty understanding relevant and importance information due to ongoing mental health problems or intellectual impairments. Equally it was important that the persons were not treated as unable to make a decision and capacity to consent was assumed unless established otherwise (National Research Authority, 2017).

To minimise distress when asked to recall their mental health unit experiences I explained to the type of questions they would be asked in advance, that they may take a break if they wished, especially if they became upset and that they could refuse to answer particular questions or withdraw from the study at any time without repercussion. A debrief followed each interview in which I asked participants their opinion of the process then offered a debrief sheet outlining support available to them.

## **Data collection**

Pilot interviews were undertaken with two volunteers with ASC to ensure that the questions asked were accessible for a recipient with autism. Minor amendments were made to the interview schedule so that it got to the core of the matter promptly. Additionally, greater effort was needed from me to bring the interviewee back to the questions when they seemed to be going off track. Eighteen 60-90 minutes face-to-face digitally-recorded semi-structured interviews were conducted over nine months. Interviews were carried out at a location chosen by the interviewee where they would feel comfortable e.g. their own home, day centres and colleges. Data was transcribed and I became familiar with the content and inflections within the data and used NVivo Version 11 software to organise the data into codes and superordinate themes each comprising distinct sub-themes.

## **Data analysis**

Data analysis was facilitated and for the most part completed by me, the Chief Investigator. However, to allow for robust intercoder reliability, the research supervisors also read and coded transcripts. Additionally, a member of the local council Asperger's Team and an expert by experience, who had a diagnosis of ASC, reviewed a number of transcripts and identified a number of emergent items for discussion which previously had not been considered.

Interpretive Phenomenological Analysis (IPA) was used to gain the depth of analysis required when interviewing people whose perception of events may be quite different from the interviewer. NVivo qualitative data analysis software was used to establish two superordinate themes comprising 'anxiety' and 'coping strategies'. It became clear that anxiety existed in many guises and situations during their period of hospitalisation and influenced their various associated responses to manage their stress.

Descriptive comments from the transcripts identified key words, phrases or explanations of relevance which structured the participant's thoughts and experiences. Subsequently, linguistic comments were made about the participants' tone or whether or not they had expressed humour, the degree of fluency, hesitancy and ability to articulate their thoughts. Further, data interrogation identified conceptual comments (Smith et al 2013) often represented as a shift in my focus on the questioning of the initial thoughts and interpretation of the data. To establish a reliable coding framework all

participants consented to a follow-up meeting or email/telephone conversation, to ascertain whether the points they made during the interviews had been interpreted correctly.

## Findings

Participants (n=20) were demographically diverse as outlined in **Table 1**. The majority (75% n=15) were recruited via the local Autism/Asperger's Support Group in the East of England. The sex ratio was 60% male (n=12) with a good representation of female participants (40% n=8). The average age was 35.5 years, and the time in which all the participants had spent in hospital as mental health inpatients was 6.3 years. More than a third (35% n=7) had at least one additional medical diagnosis and 95% (n=19) were taking psychotropic medication during admission. The participants were mostly diagnosed with psychotic disorder (25% n=5) or mood disorder (25% n=5), whilst 15% (n=3) reported other problems such as physical abuse or property destruction prior to admission. A total of 65% (n=13) were sectioned under the Mental Health Act (Department of Health, 1983) either before or during their admissions.

The findings present a range of themed quotations and observations linked to anxiety experienced by the participants during their time in the inpatient services, as well as a variety of coping strategies with the aim of dealing with existing anxiety and stress or pre-empting situations where increased levels of stress can be predicted. **Table 2** outlines the superordinate and sub-themes identified and expanded upon below.

The following findings outline two superordinate themes: 'anxiety' and, 'coping strategies'. In summary, the key findings include the causes of anxiety, the perpetual feeling of being afraid and uncertain of what is going to happen, the responses and coping strategies which can be explained when greater understanding is placed upon the anxiety experienced at the time. Participants described in detail how sensory differences can complicate and cause further anxieties, including sensory difficulties in eating.

### Anxiety

The interviews emphasised the presence of anxiety organised in the following sub-themes: fear, unpredictability, mistrust of people, lack of routine and structure, sensory profile of the unit, food and,

timeline and each will be discussed below. Anxiety as a superordinate theme mostly relates to the causes and comprised of the most spoken about subject in the interviews.

## Fear

Often when fear and anxiety become exhaustive, participants resort to violent acts towards other people and the nurses were very much in the firing line. Severity varied from shouting, swearing and screaming to physical aggression causing injury. Most of the violence reported would appear to be short-lived and limited to an outburst rather than a sustained attack. However, even a short-lived violent outburst, caused by a build-up of anxiety in patients with autism, can be destructive and serious. Indeed, Rodgers et al. (2012) also described responses witnessed in their study to be short and explosive, a way of coping with anxiety quickly. In this current study one participant explained how the sensory conditions of the physical environment coupled with a nurse talking to him simply overloaded his capacity to absorb more information. Once breached, he was impelled to stop the source of the information and attack the nurse causing serious injury resulting in attendance at an accident and emergency department. Numerous incidents of aggressive responses emerged from the data the following example is from a participant who would normally describe herself as passive so she was shocked to learn she was capable of such a response.

*“I remember the fear and anxiety within me and how it pushed me into a rage. I felt very paranoid about the people around me and considered that it was them against me. I remember on numerous occasions being very loud and aggressive and on less frequent occasions physically violent towards the members of staff. I don't think I've ever tried to hurt anybody in my life and I am sorry for how I behaved, but this was undoubtedly the most anxious time of my life and I felt completely out of control.” (Participant 5)*

## Lack of routine and structure

Many people manage their anxiety through daily routine. Much of the interview discussions were based upon a fear of not being able to re-establish beneficial routines whilst in their new environment and this shaped how they spent their time on the unit. Rodgers et al. (2012) and Lidstone et al. (2014)

recognised that the need for sameness and repetition is never more apparent than at times of significant anxiety. As one participant explained:

*“After the first four to five days of my admission period, my stress levels began to decrease as I began to understand what I was there for and how I should spend my time. I used the activities available to me to help establish a routine, for example I undertook a yoga session, always on Tuesday mornings and then a group session would follow in the afternoon. Once I established a pattern or routine, I started to manage my anxiety much better.” (Participant 3)*

Whilst another participant explained how routines and structure are an important aspect of his *Energy Bank* concept explained below:

*“The Energy Bank is like any other bank, in that it receives deposits and withdrawals and when the bank is in the red I feel physically and mentally drained, at this point my ability to control what is happening around me reduces, then my world becomes more unpredictable and then the anxiety increases. It is then that I feel at most risk of mental illness.” (Participant 11).*

*The identified Withdrawals and Deposits outside of a mental health inpatient unit, by this participant are detailed in Table 3 below. The concept was then explored with the participant when he was admitted to a mental health unit, at which point the ‘Withdrawals’ far outweighed the ‘Deposits’ and as a consequence, he lost control of many aspects of his daily life causing unpredictability and ultimately, high levels of anxiety.*

Sensory profile of the unit

Specific aspects of the physical environment were perceived as problematic and therefore a source of anxiety to include the excessively bright lighting, the overpowering smell of strong cleaning products, the continually loud air conditioning system and, the taste, smell and texture of the hospital food. One

participant articulated the impact that suffering from sensory processing disorder can have upon the experience of a hospital admission:

*“I know that I am sometimes hyper and hypo sensitive to certain things, but often it is not until afterwards when I sit down and think about it that I realise that the sensory issues have caused me problems and mostly anxiety. On the unit I found it extremely difficult to sleep, the buzzer on the door of the unit used to really irritate me and sounded really loud, but it didn’t seem to affect anybody else. The beeping noise of the fire alarms will keep me awake at night. I found myself in a situation where every night I spent in hospital my sleep was broken. There is also a constant humming noise, that when I felt anxious it sounded louder than it did when I wasn’t feeling so anxious, I think it might be the air-conditioning or the heating system, not too sure. The medical room was near to my bedroom and if the fridge was left open too long it would buzz, again not a problem for anybody else seemingly apart from me’.* (Participant 15)

Another participant explained the difficulty she faced with her personal hygiene which caused much conflict with the care team, who were very keen on her to maintain cleanliness:

*“I had problems with my personal hygiene on the unit because I did not like the water in the shower, it fell harder than the water I had at home and it was actually quite painful to have a shower or bath or even wash, so much of the time I chose not to.”* (Participant 12)

From the staff perspective one nurse was described as “...a proper chatterbox...” because she would talk quickly without pausing, this was a problem as the information could not be processed without time to think and a person with a sensory processing disorder would always be trying to catch up in the discussion. The participant explained:

*“I could keep up with the nurse for one or two sentences at the most and then I felt that my brain could take no more, I would stop trying to follow what she was saying and simply close down. I remember hearing nothing, but still see her mouth going up and down.”* (Participant 6).

## Food

Weight loss was reported by eight of the 20 participants. It was originally assumed that this had happened because the food was unappetising or the participant's perpetual state of anxiety whilst pacing up and down the unit burned calories or, they were purely feeling too anxious to eat. The expert by experience explained the possibility that this could be related to sensory processing disorder and the desire for sameness in their taste and diet. As this line of enquiry was missed during the initial interviews, the interviewer contacted the eight participants who had reported weight loss, to analyse this theory in more detail. It became clear that this was indeed related to sensory processing disorder. One participant explained:

*“Additionally, I had problems with the food. I didn't like the texture or the taste and certainly not the smell of some of the foods that came from the hospital kitchen. I normally eat the same food at home every single day, food that I prepared myself and know exactly how it can taste, I do it that way so I can predict how my food will taste and there's no surprises. I eat shepherd's pie at home, shepherd's pie was on the menu in hospital at least twice a week, however it wasn't my shepherd's pie and I couldn't eat it. Needless to say, I lost a lot of weight in the eight weeks I was on the unit.” (Participant 17)*

## Coping strategies

Recent studies identified a number of strategies employed to deal with anxiety quickly, including self-harming, physical and verbal aggression, repetitive motor behaviours and sameness behaviours (Wigham et al., 2015; Lidstone et al., 2014; Rodgers et al., 2012). Of note, in this study a number of participants explained in detail their anxiety avoidance strategies. Some were quite creative, whilst others would be considered dangerous, involving self-harm and violent responses. Broadly, the participants were aware of specific situations when their anxiety might become unmanageable and would try to be proactive to avoid escalation. Predicting these occasions was less likely during the admission phase and more likely when the participants became more experienced and alert to potential moments of anxiety on the units. The interviews emphasised the presence of coping strategies organised in the following sub-themes, isolation, stopped eating and self-harm.

## Isolation

Participants needed to isolate from others to cope with rising anxiety levels, as one participant explained:

*“In my normal living environment I have my flat, which is my own space which I have designed to meet my needs. The key component of this design is that there is nobody else in it! I know that I can find solitude and quietness, I can listen to my music, watch my own television or play on my PlayStation. Additionally, over a long period of time I have been able to eliminate all of the sensory aspects of my living space which could cause me stress. On the unit finding a quiet area was impossible, even the areas which were called ‘quiet areas’ were always quite busy and I can never find time just to be on my own. There was four beds in my dorm ...even with the curtain round my bed I was never alone. I found this unbelievably difficult to deal with and as a consequence I spend my entire time on the units on the edge of my nerves.” (Participant 20)*

## Stopped eating

A number of participants said they had no desire to eat during their time on the units as outlined earlier. While the main reasons were due to sensory processing disorder and the food being prepared by the hospital kitchens and therefore different in taste, smell and texture and as a result, unpalatable.

This unpredictability about the nature of the food caused anxiety. One participant explained:

*“I was feeling so worried all of the time, I simply didn’t have an appetite. The nursing staff would always be on at me to eat. They would watch me at mealtimes and record how much I had eaten. I didn’t want to annoy them so I would force myself to try and eat something at least, but this seemed to cause me digestible problems. I have been out of hospital now for just over a year, but my appetite is still not as it was and I don’t think it will be.” (Participant 8)*

## Self-harming

Unfortunately self-harm is a common strategy to deal with acute anxiety and these acts vary considerably in severity (Lidstone et al., 2014). One participant reflected on an extreme response where he would bang his head against walls. His aim, quite literally, was to ‘knock the fear and

anxiety out of his head'. Others reported cutting their bodies, most were superficial cuts at various anatomical locations. Whilst one participant articulated fluently the need for so many people with autism to regularly hurt them self:

*"I use a short sharp pain to interrupt my anxiety and my worries. I call it my worry cycle and I have a couple of techniques that I know work for example, I flicked my earlobe really hard which gives me a sharp pain and it makes me think about the pain very quickly and sometimes I forget what I was worried about in the first place! Another thing I do is to wear an elastic band around my wrist and I snap it against my more sensitive underside of the wrist or I would just pinch myself hard. The little pain episode interrupts the train of thought enough to have to start thinking about it again from further back. In hospital I was constantly trying the strategies but none of them worked. That's mental illness, pure and simple, the stark difference between anxiety relating to the core features of autism and something that is much harder to control." (Participant 13)*

Box 1 Ask me What matters?

## **Discussion**

The purpose of this study was to understand the stress and anxiety experienced by mental health unit in-patients with ASC, to understand the manifestations of their anxiety and coping strategies. The participants were all very different in the way they presented during the interviews therefore I constantly evaluated the interview technique and approach to ensure that their individual needs were being met. Some participants could recall and articulate their thoughts and feelings during the time of admission, whilst others found this a profoundly painful process and some struggled to remember what it was like and what they were thinking at the time. A small number of interviewees found the subject matter of the interview challenging and despite my efforts to focus, continually diverted the conversation towards the subject they felt more comfortable talking about.

The themes emerging from this study are common to ASC populations and many fit with what is understood to be the core features of ASC. For example, the intolerance of uncertainty, the need for routine and sameness and fear of unpredictability, issues with relationship building and trusting those who are employed to care for them, issues with the sensory profile of the physical environments in which they find themselves.

### *What this study adds to the evidence*

This study contributes to the growing evidence on the experience of adults who live with autism who are admitted to a mental health facility. Despite growing acknowledgement that admission to acute mental health facilities should be a last resort, reported admissions continue to rise (National Institute for Health and Care Excellence, 2014). The overarching theme of this current study is anxiety, and their experience of and strategies employed to deal with or avoid it in the first instance. Many of the participants drew comparisons upon their day-to-day lives outside of the inpatient unit and how they are successful in managing potentially stressful situations and consequentially containing their anxiety. Detachment from their regular routine and inability to access personal coping strategies is the root cause for the feeling of being out of control, the inevitable anxiety that follows and the responses to the anxiety which are a consequence of their situation. Some participants were able to re-establish a structure and routine within the inpatient units which helped immensely with their day-to-day survival. A small number reported that they had become so comfortable with their routines i.e. three mealtimes a day with activities or therapeutic sessions in the morning and afternoon, that they found it difficult to leave them behind and discussion of discharge plans were to be avoided because the thought of losing the routine exacerbated their anxiety once again. It has been noted in previous studies that exercising control over an immediate situation or an environment is critical to minimising anxiety for many people with ASC. Intolerance of uncertainty (IU) is regarded as one of the main driving forces behind the high levels of anxiety experienced by patients with ASC (Maisel et al, 2016; Boulter et al 2014; Wigham et al 2015).

Engagement in activities especially involving going out from the unit, appeared to be a positive aspect and service users expressed how they particularly value those activities which promoted independence, choice and control. However, difficulties in providing predictability and routine in relation to activities in the units were described, which often resulted in disappointment and frustration for the service user including outings were postponed or in some cases cancelled due to lack of staff. Service user views of themselves and their relationship with staff, carers and other service users influenced how they experienced admission. The current study reports that service users experienced difficulties in relating to staff and other service users thereby isolating themselves on occasion. A number of participants reported they felt different to other service users without ASC and that they

could observe better relationships between the care team and those in patients without ASC. Maisel et al (2016) suggest that the poor emotional recognition experienced by people with ASC, can lead to the confusion and mistrust of relationships. Howlin (2005) also observed that even on the units where the inpatients are extremely unwell, there will generally be relationships formed between the staff and patients, 'some displays of good humour and sharing of experiences were common place'. However, a patient with ASC is unlikely to take part in these interactions and their general lack of response in social situations are a continual source of irritation to both staff and fellow patients alike.

Relationships with family were also significant to the service users during the admission. The traumatic experience of being admitted to an inpatient unit may partially be attributed to service user experiences of being separated from their family which some perceived as rejection and being separated from family contributed to feelings of distress and loneliness. Maintaining and increasing contact with family and friends were therefore important. Interestingly, the participants experiencing longer admission periods reported a disconnection with family and friends and were more likely to maintain regular contact during the early periods of the admission, as they were in the latter period. This was explained by one participant that maintaining relationships with people within their current environment, seems more important than preserving contact with people whom they see very seldom and are not part of their day-to-day lives.

It is important to consider how interactions, relationships and patterns of behaviour between service users, staff and other service users influence the construction of meaning, understanding and experience within the context of the inpatient units. Indeed, many different systems and relationships can be seen to have contributed to the service user's experiences. These can be observed within two relational concepts of '*sense of agency*' and '*creating safety and protection*'. These elements represent important factors in how service users make sense of their experience within the context of the inpatient environment and the cultural milieu or, their relationships with others. Relating according to Johnson et al, (2011) is an essential part of our human experience and it is at the core of our emotional and social abilities. Therefore, when a psychiatric patient is experiencing distress and pain the need for another person to provide compassionate care and reassurance becomes increasingly needing. The factors affecting service users '*sense of agency*' relate to a sense of responsibility and control over what happened during their admission and feelings of involvement and inclusion which

were also highlighted as being generally negative throughout participant narratives in this study. Within the concept of '*creating safety and protection*' participants described a number of issues regarding their vulnerabilities and need for protection and those strategies employed to ensure their safety. It is clear that incidents of verbal and less commonly physical aggression reported in this current study, contributed to the difficulties in the relationships between service users and the participants acknowledged being drawn to other patients who were quieter and less likely to cause impact upon their stress levels.

### **Implications**

Partnership and collaboration in the care process may offer incremental building blocks such as items, people, activities that matter to people with ASC which can enhance their motivation to take back control of their lives and recovery from mental illness. Instead, much of the formulation of care is considered within existing mental health care pathways, which appeared to be inappropriate, with poor outcomes. It is essential that services be co-produced and the views and experiences of inpatients with ASC be at the forefront of changing services to improve outcomes for this group whose need for appropriate mental health care is imperative and services need to be designed in partnership with the people who use them. This paper offers new evidence which can assist mental health nurses and other practitioners to understand the issues which impact upon the patient with ASC, to encourage a motivation to engage and to provide the support they need to overcome their fears and anxieties. As one participant explained, '...it's the small big things that count' (Participant, 9).

### **Conclusion**

This study provides an in-depth analysis and considered interpretation to arrive at a greater understanding of the significant impact of hospitalisation for the patients living with ASC and acute exacerbation of mental health comorbidities. Most highlighted issues that impact upon their mental well-being which could be perceived by mental health unit staff as small, even trivial. Nevertheless, despite the perceived scale of the issue, anxiety and need for sameness can be a significant problem for them. To some extent the above comments reveal why people with ASC adopt extreme responses in this situation. There is no doubt that some of these responses can be particularly challenging to

mental healthcare professionals, but with greater insight as to the root cause, practitioner responses could be more sensitive and understanding.

### **Limitations**

As this study had a relatively small sample and participant reflections may be limited to this group. It is questionable whether further research of this nature would glean greater insight. Perhaps this would be restricted to gaining knowledge of the types of stressors and range of coping strategies. It is however, important that practitioners consider their own practice setting by encouraging staff to assess needs and implement strategies to reduce the anxiety burden for this cohort.

### **References**

- Bakkena, T., Helverschoua, S., Eilertsenb, D., Heggelundc, T., Myrbakkc, E., & Martinsenb, H. (2010). Psychiatric disorders in adolescents and adults with autism and intellectual disability: A representative study in one county in Norway. *Research in Developmental Disabilities*, 31(6), 1669–1677.
- Berger, P. & Luckmann, T. (1966). *The social construction of reality*. New York: Anchorbooks.
- Boulter, C. Freeston, M, South, M & Rodgers J. (2013). Intolerance of Uncertainty as a Framework for Understanding Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Journal of Autism Development and Disorder*, 44, 1391–1402. doi:10.1007/s10803-013-2001-x
- Carleton, R. N. (2012). The intolerance of uncertainty construct in the context of anxiety disorders: Theoretical and practical perspectives. *Expert Review of Neurotherapeutics*, 12(8), 937–947. doi:10.1586/ern.12.82.
- Cresswell, J. (2009). *Research Design, Qualitative, Quantitative and Mixed Methods Approaches*. London, Sage.
- Crotty, M. (2013). *The Foundations of Social Research*. London: Sage.
- Crowell, S. (2013). *Normativity and Phenomenology in Husserl and Heidegger* Cambridge University Press.

Department of Health. (1983). Code of practice: Mental Health Act London, Department of Health.

Department of Health. (2009). The Autism Act. London: Department of Health.

Department of Health. (2010). The Autism Strategy - 'Fulfilling and rewarding lives'.

Elwin, M., Ek, L., Schröder, A., & Kjellin, L. (2012). Autobiographical accounts of sensing in Asperger syndrome and high-functioning autism. *Archives of Psychiatric Nursing*, 26(5), 420-429.

Ghaziuddin, E. et al. (1998). "Comorbidity of Asperger syndrome: a preliminary report." *Journal of Intellectual Disability Research* 42(4): 279-283.

Howlin, P. (2005). *Autism and Asperger Syndrome - Preparing for adulthood* (2nd ed.). London: Routledge.

Johnson, S., et al. (2011). "Inpatient mental health staff morale: a national investigation." from [http://www.nets.nihr.ac.uk/\\_\\_data/assets/pdf\\_file/0020/64532/FR-08-1604](http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0020/64532/FR-08-1604).

Jones, R. & Meldal, T. (2001). Social Relationships and Asperger's Syndrome A Qualitative Analysis of First-Hand Accounts. *Journal of Intellectual Disabilities*, 5(1), 35-41.

Lidstone, J. Uljarevic M. Sullivan J. Rodgers, J., McConachie, H., Freeston, M. Leekam, S. (2014). Relations among restricted and repetitive behaviours, anxiety and sensory features in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8, 82–92.

Magiati I. Ong, C. Xin Yi Lim Wen-Li Tan, J. Yi Lin Ong, A. Patricia, F. Shuen Sheng Fung, D. Min Sung, Poon, K. and Howlin, P. (2016) Vol. 20(3) ). Anxiety symptoms in young people with autism spectrum disorder attending special schools: Associations with gender, adaptive functioning and autism symptomatology. *Autism*, 20 (3), 306–320.

Maisel, M. Stephenson K. South, M. Rodgers, J. Freeston, M. & Gaigg, S. B. (2016). Modelling the Cognitive Mechanisms Linking Autism Symptoms and Anxiety in Adults. *Journal of Abnormal Psychology*, 125(5), 692–703.

Narendorf, S., Shattuck, P., & Sterzing, P. (2011). Mental health service use among adolescents with an autism spectrum disorder. *Psychiatric Services*, 62(8), 975-978.

National Autistic Society. (2017). What is Autism? Retrieved from <http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx>

National, Development, Team, for, & Inclusion. (2012). Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities.

Department of Health (2014). THINK AUTISM: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update. London: DoH.

Rodgers, J., Glod, M., Connolly, B., & McConachie, H. (2012). The Relationship Between Anxiety and Repetitive Behaviours in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 42:, 2404–2409. doi:10.1007/s10803-012-1531-y

Smith, J. A., Flowers, P., & Larkin, M. (2013). *Interpretative Phenomenological Analysis - Theory, Method and Research*. London: Sage.

Simonoff, E., Jones, C., Baird, G., Pickles, A., Happe', F. and Charman, T. (2013). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 54(2), 186-194.

Van Steensel, F. J. A., Bögels, S. M., & Dirksen, C. D. (2012). Anxiety and quality of life: Clinically anxious children with and without autism spectrum disorders compared. . *Journal of Clinical Child & Adolescent Psychology*, 53(41), 731–738. doi:<http://dx.doi.org/10.1080/15374416.2012>

Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The Interplay Between Sensory Processing Abnormalities, Intolerance of Uncertainty, Anxiety and Restricted and Repetitive Behaviours in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45, 943–952. doi:10.1007/s10803-014-2248-x

World Health Organization (2013). *Autism spectrum disorders & other developmental disorders*. Retrieved from Geneva:

“I don't think I'm the only autistic person who finds it challenging to understand my feelings and emotions, I very often find it difficult to understand feelings of anxiety, fear, happiness, sadness. On the unit I was constantly asked 'How are you feeling today'? I could never work out the answer. Did I feel depressed? If so do I feel more depressed or less depressed than I did yesterday? I feel, when working with people with autism, it is more important to instead of asking us

'What's the matter?' Ask us 'What matters?'.’

Box 1 Ask me What matters?

<b>Patient Characteristics</b>		<b>N=20</b>
		<b>N%</b>
<b>Psychiatric Diagnosis</b>	<b>Anxiety Disorder</b>	<b>35.5%</b>
	<b>Psychotic Disorder</b>	<b>27.3%</b>
	<b>Mood Disorder</b>	<b>25.3%</b>
	<b>Depression</b>	<b>10.3%</b>
	<b>Eating Disorder</b>	<b>5.2%</b>
	<b>Substance Abuse</b>	<b>4.5%</b>
<b>Gender</b>	<b>Male</b>	<b>60%</b>
	<b>Female</b>	<b>40%</b>

<b>Length of admission (average if more than one admission)</b>	<b>Under one month</b>	<b>42 %</b>
	<b>1-3 months</b>	<b>21%</b>
	<b>4-6 months</b>	<b>10.5%</b>
	<b>7-12 months</b>	<b>8.6%</b>
	<b>13 -24 months</b>	<b>6.7%</b>
<b>Employment</b>	<b>Yes</b>	<b>30%</b>
	<b>no</b>	<b>70%</b>
<b>Age</b>	<b>18 – 24 years</b>	<b>10%</b>
	<b>25 – 35</b>	<b>40%</b>
	<b>36 - 50</b>	<b>40%</b>
	<b>Over 50</b>	<b>10%</b>

**Table 1 Participant demographics**

<b>Superordinate themes</b>	<b>Sub-themes</b>
Anxiety	Fear Lack of routine and structure Sensory profile of the unit Food
Coping strategies	Isolation Stopped eating Self-harming

**Table 2 Demonstrates two superordinate themes and associated sub themes**

Energy Bank	
Withdrawals	Deposits
Socialising Change Making a mistake Sensory sensitivity Daily living skills Coping with anxiety Over analysing Being teased or excluded	Solitude Special interest Physical activity Animals and nature Computer games Meditation routines Nutrition Favourite food

**Table 3 Participant's notion of the Energy Bank**

#### Participant profile

Liz was first admitted to a mental health unit and she was only 16 years old, she is now in her early 50s and in total has been admitted to psychiatric care on eight separate occasions. Seven of those admissions were without a diagnosis of ASC. Instead of the identification of the core features of autism, Liz has been treated for schizophrenia, depression and substance misuse. Due to her consistent misdiagnosis Liz has been prescribed ten different types of antipsychotic medication.

After her formalised diagnosis and a period of time getting used to the idea of being autistic, Liz decided to seek support from her local Asperger's support team. The Asperger's team have been helpful to Liz in providing counselling to help come to terms with her diagnosis, supporting her with important networks and helping her re-establish her place in employment. From a mental well-being perspective Liz is in a much better place and willing and able to talk about her experiences. Similar to many other participants in this study, Liz was recruited via the Asperger's support team and appreciates the importance of her experience being shared for the benefit of improving service provision for people with ASC who are admitted to mental health units in the future.