Health professionals' experiences and attitudes regarding diagnoses that challenge mental health services

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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Contents

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List of abbreviations

ACT	Acceptance and Commitment Therapy
ADSHQ	Attitudes towards Deliberate Self-Harm Questionnaire
ANOVA	Analysis of Variance
APA	American Psychiatric Association
APDQ	Attitudes to Personality Disorder Questionnaire
ASD	Autism Spectrum Disorder
ASSIA	Applied Social Sciences Index and Abstracts
BPD	Borderline Personality Disorder
BPDQ	Questionnaire on Borderline Personality Disorder
BPS	British Psychological Society
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DBT	Dialectical Behaviour Therapy
DoH	Department of Health
DSH	Deliberate Self-Harm
EBE	Expert by Experience
HAQ	Helping Alliance Questionnaire
IPA	Interpretative Phenomenological Analysis
KUF	Knowledge and Understanding Framework
MDT	Multi-Disciplinary Team
NAS	National Autistic Society
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIMHE	National Institute for Mental Health in England

PD   Personality Disorder

PDAQ   Personality Disorder Attitudes Questionnaire

PD-KASQ   Personality Disorder – Knowledge, Attitudes and Skills

            Questionnaire

PRISMA   Preferred Reporting Items for Systematic Reviews and Meta-

            Analyses

RCT   Randomised Controlled Trial

RMN   Registered Mental Health Nurse

SDS   Social Distancing Scale

STEPPS   Systems Training for Emotional Predictability and Problem-

            Solving

SU   Service User

UK   United Kingdom

USA   United States of America

Acknowledgements

Declaration

This thesis has been written in partial fulfilment of the requirements for the Universities of Coventry and Warwick Clinical Psychology Doctorate Programme. It has not been submitted for a degree at any other institution.

This thesis was carried out under the academic and clinical supervision of Jo Kucharksa (Clinical Director, Coventry University) and Tim Lacey (Counselling Psychologist, Worcestershire Health and Care NHS Trust). A colleague who is familiar with Interpretative Phenomenological Analysis checked the validity of qualitative coding in the empirical paper. The named supervisors offered advice regarding the analysis and read drafts of the chapters. Apart from the collaborations stated, all the material presented in this thesis is my own work.

Summary of chapters

This thesis comprises three chapters exploring health professionals' experiences and attitudes regarding diagnoses that challenge mental health services.

The first chapter is a systematic literature review investigating the impact of training on staff attitudes towards personality disorder. Eleven articles were reviewed and critically evaluated. Despite inconsistencies in the data and a number of methodological concerns, there is evidence to suggest that training is effective in improving staff members' cognitive and affective attitudes towards personality disorder, and their therapeutic engagement with service users. Clinical and research implications are discussed in relation to developing staff training packages regarding personality disorder.

The second chapter is a qualitative study of mental health nurses' experiences of caring for adults with autism spectrum disorder (ASD) in acute inpatient services. Semi-structured interviews were conducted with seven nurses and the transcripts were analysed using Interpretative Phenomenological Analysis. The two major themes that emerged from the data indicated that nurses felt confused and unable to make sense of autistic presentations, but were able to overcome these challenges by focusing on their core nursing values and providing person-centred care. Overall, the findings highlight mental health nurses' lack of knowledge about ASD. Clinical implications are discussed in relation to developing staff members' skills and confidence in working with this client group.

In the third chapter, personal reflections on the research process are discussed, with a particular focus on stigma and stereotyping in mental health services. These include the evolution of my own perspective and a consideration of the role of clinical psychologists in supporting staff.

Overall word count: 19,919

Chapter 1: Literature Review

The impact of training on staff attitudes towards personality disorder:

a systematic review of the literature

In preparation for submission to *Clinical Psychology Review* (see Appendix A for

author instructions)

Overall chapter word count (excluding tables, figures and references): 8,082

1.1. Abstract

Negative attitudes towards personality disorder (PD) are common amongst mental health professionals and can have a detrimental effect on the quality of care service users receive. In the United Kingdom, the publication of two key policy documents (*'No Longer a Diagnosis of Exclusion'* and *'Breaking the Cycle of Rejection'*) has reformed the way mental health services cater for people diagnosed with PD, emphasising the need for staff training to address negative attitudes. The current review explored the findings of studies investigating the impact of training on staff attitudes towards PD. Six databases were searched for relevant literature published before April 2015. Eleven articles met the inclusion criteria. Despite inconsistencies in the data and a number of methodological concerns, there is evidence to suggest that training is effective in improving staff's cognitive and affective attitudes towards PD, and their therapeutic engagement with service users. A number of recommendations for future research directions are highlighted, including the need for randomised controlled trials to determine the relative efficacy of different types of training interventions.

Key words: staff attitudes, personality disorder, training, review

1.2. Introduction

Personality disorder (PD) has been described as, *"problematic ways of coping with everyday life and dealing with self, others and the world which result from the interplay between genetic and environmental factors and disrupted early development"* (Department of Health (DoH), 2009, p. 9). The two main diagnostic classification systems are in broad agreement with regard to the subtypes of PD (World Health Organisation, 1992; American Psychiatric Association (APA), 2013). The diagnosis most commonly researched and discussed in the literature is borderline personality disorder (BPD), which is characterised by persistent instability in; interpersonal relationships; self-image and mood; and behaviour (APA, 2013). People diagnosed with BPD are at high risk of deliberate self-harm (DSH) and suicide, and frequently present to mental health services in crisis (National Institute for Mental Health in England (NIMHE), 2003a).

1.2.1. Personality disorder in context

It is estimated that 5-13% of the population in the United Kingdom (UK) experience difficulties that would meet the criteria for a diagnosis of PD (Coid & Yang, 2006). Unsurprisingly, the prevalence is much greater amongst mental health service users (SUs) and is estimated at 30-40% for psychiatric outpatients, rising to 40-50% for inpatients (Casey, 2000). Despite high prevalence rates, a diagnosis of PD carries tremendous stigma, attracting negative judgements from professionals (Aviram, Brodsky & Stanley 2006).

People with PD have been poignantly described as, 'the patients psychiatrists dislike' (Lewis & Appleby, 1988).

As a result of negative perceptions, people diagnosed with PD have often struggled to access support from health and social care services, leaving them even more vulnerable to mental health crises. These issues were brought to light by the publication of '*Personality Disorder: No Longer a Diagnosis of Exclusion*' (NIMHE, 2003a), which outlined recommendations for improving services for people diagnosed with PD in the UK. Central to this guidance was the education and training of mental health professionals at all levels. It emphasised that negative attitudes must be challenged in order to develop services founded on acceptance and therapeutic optimism. Subsequently, a capabilities framework was developed, describing qualities required for working confidently and compassionately with SUs with PD ('*Breaking the Cycle of Rejection*'; NIMHE, 2003b).

1.2.2. Staff attitudes towards personality disorder

Staff attitudes towards PD have been widely researched. Stigmatising beliefs are a common theme in the literature, with clients being considered 'difficult', 'manipulative', 'attention-seeking', 'threatening' and even 'dangerous' (Markham, 2003; Newton-Howes, Weaver & Tyrer, 2008; Woollaston & Hixenbaugh, 2008; McGrath & Dowling, 2012). The interpersonal difficulties and destructive behaviours associated with a diagnosis of PD can evoke feelings

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of incompetence (Cleary, Siegfried & Walter, 2002), or negative emotions towards clients (Bodner, Cohen-Fridel & Iancu, 2011). Deans and Meocevic (2006) noted that a third of their sample of 65 psychiatric nurses reported feeling angry when working with SUs diagnosed with PD. Such reactions may be influenced by a widely held view that people with PD have control over their behaviour (Markham & Trower, 2003; Forsyth, 2007). Aviram *et al.* (2006) suggest that many staff view these clients' problematic behaviours as moral failings, rather than symptoms of illness. If professionals do not consider PD to be a legitimate mental health problem, they are likely to hold cynical beliefs about its treatability. Research has demonstrated staff's lack of optimism about the potential for change in clients with PD (e.g. Markham & Trower, 2003; Black *et al.*, 2011).

Negative attitudes towards SUs have a direct impact on staff's clinical practice. Compared with schizophrenia, nurses are less likely to express empathy for clients with PD and more likely to give belittling responses (Gallop, Lancee & Garfinkel, 1989). The desire to maintain social distance from clients with PD is considerably greater than with other SUs (Hinshelwood, 1999; Markham, 2003). Wright, Haigh and McKeown (2007) argue that professionals' therapeutic boundaries are more conservative when working with PD; rather than setting safe limits for collaboration, these act as a "protective line of separation" (p. 242). This creates a self-fulfilling prophecy; when staff reject clients by withdrawing emotionally, they unwittingly invite the manipulative and self-

destructive behaviours they expect (Aviram *et al.*, 2006). Negative attitudes are therefore a major barrier to building positive therapeutic relationships, which are critical to achieving successful outcomes for people diagnosed with PD (DoH, 2009).

1.2.3. Addressing staff attitudes

The widespread belief that people with PD are more difficult to care for than other SUs appears to be rooted in a lack of confidence and knowledge (National Institute of Clinical and Health Excellence (NICE), 2009). Despite negative attitudes, staff accept that they have a role to play with this client group and are willing to engage in further training (Cleary *et al.*, 2002; Woollaston & Hixenbaugh, 2008). Having a framework for understanding behaviour has been found to promote positive attitudes and improve the quality of interactions with clients (Stroud & Parsons, 2013).

'The Personality Disorder Capabilities Framework' offers guidance on educational activities that could help *"interrupt the cycle of rejection that is deeply implicated in the development of personality disorders and which is compounded by the negative and rejecting attitudes and practices of many agencies"* (NIMHE, 2003b, p. 6). The framework can been used to design staff training programmes aimed at challenging negative perceptions of PD and promoting an attitude of recovery. One such programme is the Knowledge and Understanding Framework (KUF; Institute of Mental Health, 2013), which was

developed by a national partnership of NHS and UK government bodies, and is delivered within local services via a 'train the trainer' model. Local evaluations of this initiative are being carried out to demonstrate its effectiveness and ensure continued funding.

1.2.4. Rationale for the current review

Negative attitudes towards PD are common among mental health professionals and can have a detrimental effect of the quality of care SUs receive. Literature in this area highlights the need for training to address staff attitudes and programmes are being delivered based on recommendations outlined in clinical guidance (NIMHE, 2003a; NIMHE, 2003b; DoH, 2009; NICE, 2009). It is important to consider the effectiveness of training interventions, in order to inform future service development.

1.2.5. Aims

The aims of this paper are to:

- Systematically review and summarise findings from all studies investigating the impact of training on staff attitudes towards PD;

- Consider the utility of these findings in developing services for people with PD;

- Assess the quality of the research reviewed and make recommendations for future research.

1.3. Method

1.3.1. Systematic search strategy

A systematic literature search was completed in March 2015, using databases that provided access to literature in the field of psychiatric healthcare: PsychINFO (including Applied Social Sciences Index and Abstracts (ASSIA), PsychARTICLES, Social Sciences Abstracts & Sociological Abstracts), Medline (OVID), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus and Web of Science. The Cochrane Database of Systematic Reviews was also searched to ensure the current review was original.

Search terms were informed by the research question, *'What is the impact of training on staff attitudes towards PD?'* The terms were developed based on published literature in the field and combined using the Boolean operator 'AND' to target all components of the question:

- "personality disorder"

- "attitude*"

- "staff" OR "clinician*" OR "professional*"

- "training" OR "education" OR "workshop"

N.B. * represents truncation to capture variations in the terminology

1.3.2. Selection criteria

Table 1.1 details the inclusion and exclusion criteria used for assessing the relevance of retrieved articles. The decision to exclude forensic population studies was taken because previous literature indicated that staff's feelings and attitudes regarding clients' offending behaviour is likely to be a confounding variable (Bowers, McFarlane, Kiyimba, Clark & Alexander, 2000).

Table 1.1. Inclusion and exclusion criteria

Inclusion criteria	Published in a peer-reviewed journal
	Evaluated the impact of a training intervention on clinicians' attitudes towards PD
	Included participants who had professional contact with people diagnosed with PD
	Included either a quantitative measure of attitudes or a qualitative exploration of attitude change
Exclusion criteria	Paper is a review, commentary, book chapter, conference abstract or discussion piece
	Not written in English
	Did not include registered mental health professionals in the sample
	Conducted in forensic services only

1.3.3. Search results

Figure 1.1 illustrates the study selection process, in accordance with guidance outlined in the PRISMA statement (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009). The initial database searches generated 249 results, from which 80 duplicate records were removed. The titles and abstracts of the

remaining 160 records were then examined against the selection criteria; 124 of these were considered not relevant to the review. The full texts of the remaining 36 articles were examined for eligibility and 24 were excluded. The reference lists of the remaining 12 articles were hand-searched, revealing three potentially relevant articles, which were examined in full; however, none of these met the selection criteria. Initially, 12 articles were therefore eligible for inclusion in the review.
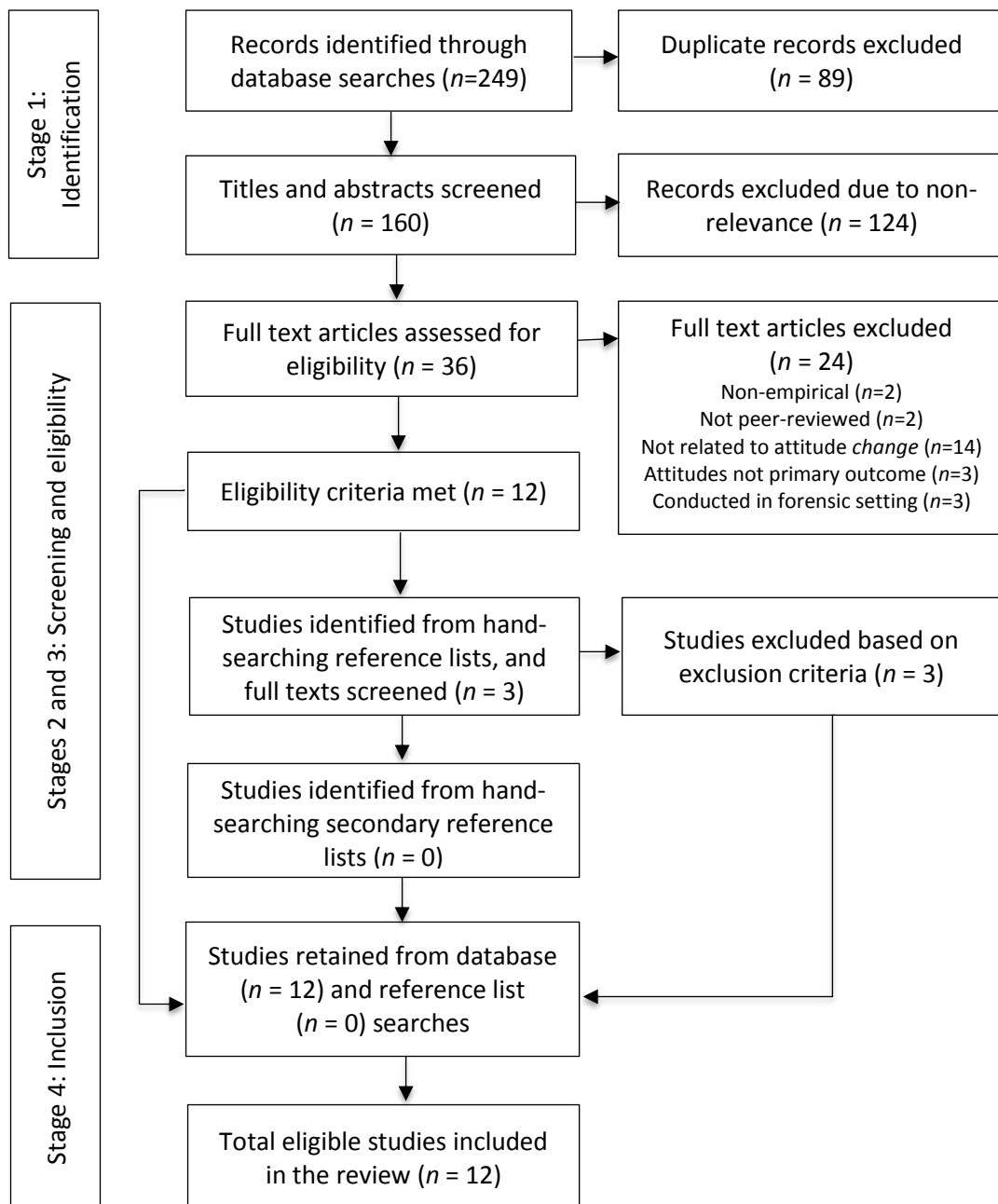
Figure 1.1. PRISMA flow diagram of the study selection process

1.3.4. Quality assessment

The 12 eligible articles were assessed for quality using a checklist based on that of Caldwell, Henshaw and Taylor (2011). This framework was chosen for its consideration of both quantitative and qualitative research paradigms, as both

methodologies were identified in the articles. Adaptations were made to account for studies that employed a mixed method design; these studies were subject to both checklists outlined by Caldwell *et al.* (2011). Guidance for completing the checklist was referred to closely to ensure consistency (see Appendix B).

Studies were rated against each quality criterion and given a score of: 0 – criterion not met; 1 – criterion partially met; or 2 – criterion met. A total was calculated out of 36 for single method studies and 48 for mixed method studies. Total ratings were converted to percentages for ease of comparison. The quality of studies ranged from 42% to 89%, with a mean of 73% (see Appendix C). One study was excluded based on its low quality rating (28%), as it employed a subjective methodology and had poor clarity of outcomes (Rigby & Longford, 2004). The remaining 11 studies were included in the review.

1.3.5. Data synthesis

Both quantitative and qualitative studies were included in the current review. In order to integrate both types of evidence, a qualitative approach to data synthesis was adopted (Dixon-Woods, Booth & Sutton, 2007). A thematic analysis was conducted to identify recurring themes in the data (Braun & Clarke, 2006).

1.4. Results

1.4.1. Overview of studies

The main characteristics of each of the 11 included studies are summarised in Table 1.2. Five of the studies were conducted in the UK, with staff employed by the NHS and other public organisations. Four studies were conducted in Australasia and two were from the United States of America (USA). All of the training interventions evaluated in the studies provided psycho-education about the diagnosis, aetiology and treatment of PD, but varied in their focus.

Three studies investigated the impact of general psycho-education workshops. Two of these reported on local implementations of the national KUF initiative, an awareness course that is co-facilitated by people diagnosed with PD, or 'experts by experience' (EBEs) (Davies, Sampson, Beesley, Smith & Baldwin, 2014; Lamph *et al.*, 2014). The third study presented findings from a series of workshops for professionals working in health and criminal justice services in Essex (Schafer, McGrath, Kent, & Nightingale, 2013).

Five studies evaluated psycho-education workshops about the diagnosis of BPD specifically (Krawitz, 2004; Hazelton, Rossiter and Milner, 2006; Commons-Treloar and Lewis, 2008; Commons-Treloar, 2009; Rogers and Acton, 2011). Two of these were concerned with clinicians' attitudes towards DSH in this client group, rather than the clients themselves (Commons-Treloar and Lewis, 2008; Commons-Treloar, 2009). Two of the BPD workshops were centred on

principles of Dialectical Behaviour Therapy (DBT; Linehan, 1993) (Hazelton, Rossiter and Milner, 2006; Rogers and Acton, 2011). One study sought to compare the impact of two programmes, informed by DBT and psychoanalytic principles respectively (Commons-Treloar, 2009).

Two studies evaluated staff training about specific treatment approaches for PD. One of these was about a cognitive-behavioural group for people with BPD called Systems Training for Emotional Predictability and Problem-Solving (STEPPS) (Shanks, Pfohl, Blum & Black, 2011). Another study compared the impact of two training workshops, based on Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) and DBT respectively (Clarke, Taylor, Bolderston, Lancaster & Remington, 2014).

Finally, one study examined the effectiveness of a self-instructional workbook about BPD, rather than a group workshop (Miller and Davenport, 1996).

The thematic analysis of findings revealed four major themes: cognitive and affective attitudes; therapeutic engagement; personal and professional development; and staff factors. Findings related to each of these themes are presented, followed by a general methodological critique of the included studies, based on findings from the quality assessment checklist. For studies where effect sizes were not reported, Cohen's *d* (Cohen, 1992) has been calculated using the means and standard deviations.

Table 1.2. Summary of included studies

Authors, year, country and aims	Quality	Sample and training intervention	Design, measures and analysis	Key findings
Clarke *et al.* (2014) UK To directly compare ACT- and DBT-based training interventions in improving staff attitudes towards patients with PD	83%	Health and social care staff providing services for patients with PD, recruited from state-funded or charitable organisations Random allocation to 2-day training workshops: ACT (*n*=53) vs. DBT (*n*=47)	Mixed method Quantitative: randomised controlled trial (RCT) – between-subjects design Self-report measures completed pre- and post-intervention and at 6-month follow-up: • Attitudes to Personality Disorder Questionnaire (APDQ) • Helping Alliance Questionnaire – Therapist Version (HAQ-II) • Social Distancing Scale (SDS) Statistical analysis: Linear Mixed Models Qualitative: Thematic analysis of 3-month follow-up interviews	Quantitative analysis: Staff attitudes, quality of therapeutic relationship and social distancing improved after both types of training. Improvements were maintained at 6-month follow-up. Qualitative analysis: ACT participants emphasised the emotional impact of working with patients with PD and reported greater awareness of their personal thoughts, emotions and action urges. DBT participants emphasised service responses to patients with PD and reported a sense of reassurance about their professional role.
Commons-Treloar & Lewis (2008) Australia & New Zealand To examine the effect of education on clinicians' attitudes towards working with DSH in BPD	81%	Registered health practitioners (*n*=99) working in emergency medicine (33.3%) and mental health (66.7%) settings All participants attended a 2-hour clinical education session on BPD	Quantitative within-subjects design Self-report measure completed pre- and post-intervention: • Attitude Towards Deliberate Self-Harm Questionnaire (ADSHQ) Statistical analysis: *t*-tests	Attitude ratings for both groups improved following clinical education. Equivocal levels of improvement were found across different service settings and occupational fields. Prior completion of training on BPD had no effect on attitudinal change.

Authors, year, country and aims	Quality	Sample and training intervention	Design, measures and analysis	Key findings
Commons-Treloar (2009) Australia & New Zealand To compare education programmes using cognitive-behavioural and psychoanalytic frameworks in changing clinicians' attitudes towards DSH in BPD	69%	Registered health practitioners (*n*=65) working in emergency medicine (26%) and mental health (74%) settings Random allocation to 2-hour education sessions on BPD: cognitive-behavioural (*n*=18) vs. psychoanalytic (*n*=25) No intervention control group (*n*=22)	Quantitative between-subjects design (RCT) Self-report measure completed pre- and post-intervention and at 6-month follow-up: • ADSHQ Statistical analysis: *t*-tests	Attitude ratings improved immediately after both education programmes. At 6-month follow-up, small improvements were maintained for the psychoanalytic group only. No significant changes were observed for the control group.
Davies *et al*. (2014) UK To present audit findings with regard to the KUF level 1 PD awareness training	71%	Staff members employed by a NHS mental health Trust (*n*=162) All participants attended a 3-day KUF PD awareness programme. Training was co-facilitated by experts by experience (EBEs).	Mixed method Quantitative: within-subjects design Self-report measure completed pre- and post-intervention and at 3-month follow-up: • Personality Disorder – Knowledge Attitudes and Skills Questionnaire (PD-KASQ) Statistical analysis: *t*-tests Qualitative: Thematic analysis of post-intervention feedback questionnaires	Quantitative: Levels of understanding, emotional reactions and capability efficacy improved immediately after training. Understanding and emotional reactions remained improved at follow-up, while capability efficacy regressed to pre-training levels. Qualitative: The KUF course received positive feedback overall. There was mixed feedback regarding the co-delivery model.

Authors, year, country and aims	Quality	Sample and training intervention	Design, measures and analysis	Key findings
Hazelton *et al.* (2006) Australia To assess the impact of an introductory DBT workshop on staff's knowledge of and attitudes towards BPD	44%	Staff members working in a mental health service in semi-rural areas (*n*=94) All participants attended a 2-day DBT workshop	Mixed method, within-subjects design Quantitative: self-report measure completed pre-intervention and at 1-month and 6-month follow-ups • Questionnaire not named; based on Cleary *et al*. (2002) Qualitative: Discourse analysis of focus groups conducted at pre-intervention and 1-month follow-up	Quantitative data was subjected to descriptive analysis only. The percentages of participants who perceived clients with BPD to be difficult to manage were equivocal at the various time points. Qualitative analysis: A shift in the meaning staff associated with BPD was noted; from 'pervasive pessimism' at pre-training to more optimistic outlooks at 1-month follow-up.
Krawitz (2004) Australia To assess the effect of a training workshop on clinicians' attitudes towards working with people with BPD	78%	Staff members working in public mental health and substance abuse services (*n*=418) All participants attended a 2-day training workshop on BPD	Quantitative within-subjects design Survey completed at pre- and post-intervention, and 6-month follow-up • Questionnaire not named; participants rated 6 facets of their attitudes towards people with BPD on a Likert scale Statistical analysis: analysis of variance (ANOVA)	Improvements were found following training for all 6 items: willingness, optimism, enthusiasm, confidence, theoretical knowledge and clinical skills. Improvements were maintained at 6-month follow-up.

Authors, year, country and aims	Quality	Sample and training intervention	Design, measures and analysis	Key findings
Lamph *et al*. (2014) UK To evaluate the effectiveness of a local model of multi-agency KUF delivery over a 12 month period	72%	Multi-disciplinary staff working in various services (*n*=136): mental/general health (28%), criminal justice/substance misuse (19%), housing (31%), other (22%) All participants attended a 3-day KUF PD awareness programme, co-facilitated by EBEs.	Quantitative within-subjects design Self-report completed pre- and post-intervention and at 3-month follow-up: • PD-KASQ Statistical analysis: Wilcoxon signed-ranks tests	Levels of understanding, emotional reactions and capability efficacy improved immediately after training. Only scores on the understanding subscale remained improved at follow-up.
Miller & Davenport (1996) USA To examine the effect of a self-instructional programme on nurses' knowledge of and attitudes and behavioural intentions towards patients with BPD	89%	Convenience sample of registered nurses working on inpatient psychiatric units of general hospitals Experimental group (*n*=19) received education in the form of a self-instruction module on BPD. Control group (*n*=13) received no intervention.	Quantitative between-subjects design Self-report measure completed pre- and post-intervention • The Questionnaire on BPD (BPDQ) Statistical analysis: ANOVA	The experimental group showed increased knowledge and improved attitudes following the intervention. No significant changes were observed for the control group.
Rogers & Acton (2011) UK To determine whether general awareness training is effective in improving staff attitudes towards PD	42%	Staff members working on inpatient units for comorbid PD and learning disabilities (*n*=35) All participants attended a 1-day PD awareness training event, with an emphasis on DBT	Quantitative within-subjects design Self-report measure completed pre- and post-intervention: • Personality Disorder Attitudes Questionnaire (PDAQ) Statistical analysis: *t*-tests	Empathy levels improved following training. There was no difference in levels of antipathy.

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Authors, year, country and aims	Quality	Sample and training intervention	Design, measures and analysis	Key findings
Schafer *et al.* (2013) UK To evaluate the effectiveness of training workshops in challenging stigmatizing attitudes towards PD	89%	Multi-disciplinary staff working with people with PD in a range of health and criminal justice services (*n*=664) Participants attended between one and three 1-day workshops on PD. Training was co-facilitated by service users.	Qualitative 'illuminative evaluation' design Post-intervention evaluation forms and telephone interviews (*n*=16) were analysed using thematic analysis	Workshops challenged participants' beliefs about PD, promoting therapeutic optimism, understanding, and positive partnerships. Factors for achieving attitude change were identified as service user involvement and a team approach to training.
Shanks *et al.* (2011) USA To determine whether negative attitudes towards patients with BPD can be modified through education	75%	Mental health professionals (*n*=271) from a range of disciplines, including social workers (38.4%), counsellors (20.7%), psychologists (9.2%) All participants attended a 6-hour training workshop about the STEPPS treatment programme for outpatients with BPD	Quantitative within-subjects design Self-report questionnaire regarding clinicians' attitudes towards BPD (developed for the purpose of evaluating the STEPPS training) was completed pre- and post-intervention Statistical analysis: *t*-tests	After training, participants endorsed greater empathy for patients with BPD, greater awareness of their distress, and a greater desire to work with them. They were less likely to express dislike for BPD patients.

1.4.2. Cognitive and affective attitudes

1.4.2.1. Beliefs about personality disorders

Three studies examined the impact of training on stigmatising beliefs about PD (Hazelton *et al.*, 2006; Shanks *et al.*, 2011; Schafer *et al.*, 2013). The common perception that people with PD are more difficult to deal with than other SUs was found to be prevalent both before and after training in Hazelton *et al.*'s (2006) study, with 73% of participants endorsing this belief at six-month follow-up. However, there was a marked difference in qualitative data derived from focus groups at the different time intervals. The pre-training consensus was that people with PD are purposefully hostile; this was not mentioned in the post-training analysis, when participants took a more positive view of SUs (Hazelton *et al.*, 2006). Schafer *et al.* (2013) reported a similar shift, encapsulated in a theme entitled, *'From moral judgement to clinical problem'*. Participants reported re-evaluating their judgements about SUs being 'vindictive' or 'manipulative', instead coming to view their behaviour as understandable responses to traumatic experiences.

Another widely held belief highlighted in previous literature is the notion that PD is not a legitimate mental health problem. Shanks *et al*. (2011) noted a significant increase (p=0.005, d=0.45) in participants' agreement with the statement, 'BPD is an illness that causes symptoms that are distressing to the individual' after STEPPS training. This formed part of a nine-item questionnaire developed specifically to evaluate the programme.

1.4.2.2. Understanding and empathy

Five studies reported findings related to participants' understanding of and empathy for people with PD (Commons-Treloar & Lewis, 2008; Rogers & Acton, 2011; Schafer *et al*., 2013; Davies *et al*., 2014; Lamph *et al*., 2014). The KUF programme is evaluated using the Personality Disorder – Knowledge, Attitudes and Skills Questionnaire (PD-KASQ; Bolton, Feigenbaum, Jones & Woodward, 2010, cited in Lamph *et al.*, 2014), which comprises three subscales: 'understanding', 'capability efficacy' and 'emotional reactions'. Both of the KUF evaluation studies noted significant improvements on the 'understanding' subscale (Davies *et al*., 2014 ($p<0.001$, $d=2.99$); Lamph *et al*., 2014 ($p<0.05$, $d=2.56$)). Improvements were maintained at three-month follow-up. Davies *et al.* (2014) also gained qualitative feedback, in which staff reported having better insight into the importance of responding to this client group in a validating manner. Participants gave mixed feedback regarding the involvement of EBEs. A minority expressed concerns that their presence may restrict honest discussions about perceptions of PD (Davies *et al.*, 2014). However, many found hearing SUs' perspectives invaluable in enhancing their understanding, a finding that was echoed by Schafer *et al*. (2013). Qualitative findings in the latter study indicated a shift in staff's empathic attitudes, with participants describing having greater tolerance and acceptance of SUs' behaviour (Schafer *et al.*, 2013).

Rogers and Acton (2011) noted a significant, medium-sized improvement in empathy (p=0.0036, d=0.40) on the Personality Disorder Attitudes Questionnaire (PDAQ; Jones & Feigenbaum, 2003, cited in Rogers & Acton, 2011). However, there was no reduction in levels of antipathy. The authors concluded that staff hold conflicting attitudes towards patients with PD, which are likely too entrenched to be altered by a general awareness programme. However, the credibility of this result is questionable, as a number of methodological limitations were noted, which are discussed in section 1.4.6. This study received a low overall rating on the quality assessment checklist (42%; see Appendix C).

Finally, in a study of staff attitudes towards DSH in people with BPD, Commons-Treloar and Lewis (2008) observed minimal, non-significant changes in empathic attitudes following a psycho-education session on BPD (d=0.10). This was measured using the Attitudes towards Deliberate Self-Harm Questionnaire (ADSHQ; McAllister, Creedy, Moyle & Farrugia, 2002). Although participants were instructed to answer questions with regard to their experience of SUs with BPD, the chosen measure does not make specific reference to any diagnosis, which may limit the applicability of the findings in the current review.

1.4.2.3. Emotional responses

Both of the studies that evaluated training about specific therapeutic approaches found positive changes in staff's feelings towards people with PD.

Shanks *et al*. (2011) noted a statistically significant decrease in participants' endorsement of the statement 'I dislike BPD patients' following STEPPS training ($p<0.0001$, $d=0.49$). Clarke *et al*. (2014) compared two training programmes (ACT vs. DBT) using the Attitudes to Personality Disorder Questionnaire (APDQ; Bowers & Allan, 2006), which measures five dimensions of positive and negative feelings towards people with PD (e.g. 'acceptance vs. rejection', 'exhaustion vs. enthusiasm'). Both the ACT and DBT groups made statistically significant improvements in their emotional attitudes ($p<0.001$, $d=0.59$), which were maintained at six-month follow-up. Qualitative analysis of three-month follow-up interviews revealed that participants in the ACT group emphasised the emotional impact of their work with people with PD. They reported having a greater awareness of their thoughts and feelings about patients since engaging in ACT-based training. Emotional reactions were not highlighted as a theme for the DBT group (Clarke *et al*., 2014).

Significant improvements in participants' emotional reactions to a diagnosis of PD were found immediately after the KUF awareness workshop (Davies *et al.*, 2014 ($p<0.001$, $d=1.80$); Lamph *et al.*, 2014 ($p<0.05$, $d=1.01$)). A smaller, but significant improvement was maintained at 3-month follow-up in Davies *et al.*'s (2014) study ($p<0.01$, $d=1.70$). However, Lamph *et al.* (2014) observed no difference between pre-training and follow-up scores, suggesting the increase in positive feelings towards people with PD were not sustained.

1.4.2.4. Optimism

Two studies explicitly measured staff's optimism for people with PD (Krawitz, 2004; Shanks *et al.*, 2011). Both used novel questionnaires developed for the purpose of the evaluations. Krawitz (2004) observed significant improvements in optimism, which were maintained at six-month follow-up ($p<0.01$, $d=0.60$). Likewise, Shanks *et al.* (2011) demonstrated a significant reduction in hopelessness about the prognosis for people with BPD ($p<0.0001$, $d=0.79$). Participants were also moderately more optimistic about interventions for BPD following training; they felt more able to make a positive difference to patients' lives ($p=0.0041$, $d=0.40$), and were more positive about the effectiveness of psychotherapy ($p=0.0219$, $d=0.32$) (Shanks *et al*., 2011).

Two studies highlighted qualitative findings with regard to optimism (Hazelton *et al.*, 2006; Schafer *et al.*, 2013). Hazelton *et al.* (2006) conducted focus groups at three time intervals; pre- and post-training, and at six-month follow-up. The pre-training consensus was one of 'pervasive pessimism', participants being of the opinion that BPD was untreatable. A shift to more optimistic outlooks was observed following training; participants expressed hope about being able to work therapeutically with clients, guided by a DBT framework. Similar findings were reported by Schafer *et al.* (2013), who found that increasing staff's awareness of treatment options helped them feel encouraged and look for new ways of engaging with clients with PD.

1.4.2.5. Overall attitude change

Two studies did not refer to specific cognitive or affective components of staff attitudes in their analyses, instead presenting results with regard to overall attitude change (Miller & Davenport, 1996; Commons-Treloar, 2009).

Miller and Davenport (1996) employed the Questionnaire on Borderline Personality Disorder (BPDQ; Reece, 1988, unpublished study cited in Miller and Davenport, 1996) to examine the impact of a self-instructional workbook about BPD. Significant improvements in attitudes were observed for the experimental group ($p<0.01$, $d=1.01$), while a non-intervention control group made no change. However, the content of the BPDQ was not described in the article, therefore the nature of participants' attitude change is unclear.

Commons-Treloar (2009) employed the ADSHQ to compare the impact of two education workshops, informed by DBT and psychoanalytic principles respectively. Overall attitudes towards DSH in people with BPD significantly improved following both types of workshop (DBT $p=0.02$, $d=0.43$; psychoanalytic $p<0.01$, $d=0.53$). Improvement was maintained at six-month follow-up for the psychoanalytic group only, with a small effect size ($p<0.05$, $d=0.26$). Although the ADSHQ includes a subscale on 'use of an empathic attitude', the result was not reported in this study and therefore cannot be separated from the other subscales, which are concerned with staff's knowledge and confidence. This study is also subject to the same limitations as

Commons-Treloar and Lewis (2008), in that attitudes towards a PD diagnosis are not specified.

1.4.3. Therapeutic engagement

1.4.3.1. Social distancing

Three studies examined the impact of training on staff's desire to distance themselves from SUs with PD. Clarke *et al.* (2014) found significant improvements in scores on the Social Distancing Scale (SDS; Link, Cullen, Frank & Wozniak, 1987) following both ACT- and DBT-based training ($p<0.001$, $d=0.67$). Improvements were maintained at six-month follow-up. STEPPS training was observed to have a similar impact; there was a significant decrease in participants' agreement with the statement, 'If I had a choice, I would prefer to avoid caring for a patient with BPD' ($p<0.0001$, $d=0.83$) (Shanks *et al.*, 2011). In a similar vein, Krawitz (2004) noted significant increases in participants' willingness ($p<0.01$, $d=0.44$) and enthusiasm ($p<0.01$, $d=0.55$) in working with clients with BPD immediately after psycho-education and at six-month follow-up.

1.4.3.2. Therapeutic relationships

One study made explicit investigation into the impact of training on the quality of staff's therapeutic relationships with SUs with PD. Clarke *et al.* (2014) found significant improvements in scores on the Helping Alliance Questionnaire (HAQ-

II; Luborsky *et al.*, 1996) following both ACT- and DBT-based training ($p<0.001$, d=1.62). Improvements were maintained at six-month follow-up.

Schafer *et al.* (2013) reported qualitative findings with regard to therapeutic relationships. A major theme entitled *'From containment to therapy'* details participants' views that PD workshops helped them develop positive alliances with SUs. Staff reported being more able to listen to and engage with SUs since gaining a better understanding of their behaviours.

1.4.4. Personal and professional development

1.4.4.1. Knowledge about personality disorders

Two studies tested participants' knowledge of BPD before and after training. Miller and Davenport (1996) found a significant increase in psychiatric nurses' knowledge after they completed a self-instructional workbook about BPD ($p<0.01$, d=1.51). Furthermore, knowledge and attitudes were significantly positively correlated at both time points (pre-test $p<0.05$; post-test $p<0.01$), suggesting the two are related. Hazelton *et al.* (2006) administered a survey that incorporated general knowledge questions about BPD. However, the clarity of the results section in this article is poor. The frequency of positive responses to each question is listed, with no explanation as to the correct response, and no statistical analyses to compare results across the three time intervals (pre-workshop, post-workshop, and six-month follow-up). Hazelton *et al*. (2006) concluded that knowledge regarding detection and treatment of BPD

improved. However, such an effect is not evident in the data presented; if anything, the results appear to be equivocal at each time interval.

1.4.4.2. Perceived competence

Four studies noted a significant increase in participants' self-rated ability to work with people with PD immediately after training (Krawitz, 2004 ($p<0.01$, $d=0.29$); Shanks *et al.*, 2011 ($p<0.0001$, $d=0.80$); Davies *et al.*, 2014 ($p<0.001$, $d=1.35$); Lamph *et al.*, 2014 ($p<0.017$, $d=1.65$)). There were mixed results regarding the long-term impact of training on perceived competency. Krawitz (2004) found that improvements in theoretical knowledge, clinical skills and confidence were all maintained at six-month follow-up. This is in contrast with the KUF studies, both of which saw participants' capability efficacy ratings regress to pre-training levels after three months (Davies *et al.*, 2014; Lamph *et al.*, 2014). Similarly, Hazelton *et al.* (2006) found that the majority of participants reported being either 'moderately' or 'only a little' confident in working with people with BPD after training and at follow-up.

In qualitative exploration, Clarke *et al.* (2014) noted that staff who attended a training course on DBT reported a sense of reassurance about their role with clients. In contrast, staff who attended ACT-based training were more focused on personal than professional development (see section 1.4.4.3). These findings were considered to reflect the different foci of the training courses;

client-management skills in DBT vs. self-management techniques in ACT (Clarke *et al.*, 2014).

Finally, in a study of clinicians' attitudes toward DSH, Commons-Treloar and Lewis (2008) found that BPD training was associated with small to medium improvements in participants' confidence (d=0.43) and capability (d=0.30) in dealing with patients with BPD who self-harm.

1.4.4.3. Personal functioning

In addition to client-focused outcomes (i.e. attitudes, social distancing and therapeutic relationship), Clarke *et al.* (2014) employed three staff-focused measures to examine the impact of ACT- and DBT-based training on participants' personal functioning. There were no significant changes in distress, burnout or psychological flexibility for the DBT group. The ACT group showed worse outcomes (i.e. increased burnout and reduced flexibility) immediately after training, which were not sustained at follow-up. Clarke *et al*. (2014) suggest the intervention may have evoked strong emotions that were initially disruptive for participants. This notion was supported by qualitative follow-up interviews, in which staff described the ACT-based training as emotionally challenging, but helpful. Participants reported having a greater awareness of their own emotions, both in their personal lives and in their work with people with PD. Hazelton *et al.* (2006) reported a similar qualitative

finding, in that staff benefitted both personally and professionally from learning mindfulness techniques in their DBT-focused workshop.

1.4.4.4. Team building

Two qualitative studies made reference to the impact of training on team building (Schafer *et al.*, 2013; Clarke *et al.*, 2014). Schafer *et al.*'s (2013) participants placed a strong emphasis on the benefit of taking a whole team approach to training. They described how gaining a shared understanding of PD supported them to enhance communication and consistency amongst staff, and to promote a more positive and constructive attitude in the whole service. Clarke *et al.* (2014) also noted the benefits of group workshops, however, the nature of these differed depending on the training content. Staff who attended ACT-based training experienced a sense of humanity and community, which was fostered by the group ethos of personal disclosure. Staff who attended DBT-based training also experienced a connection with their colleagues, which was based on gaining a shared approach to clinical practice.

1.4.5. Staff factors

1.4.5.1. Occupational background and service setting

Where participants' occupations were reported, the majority were registered nurses (46-75%). Medics formed the smallest proportion of each sample (<5-11%). None of the studies provided an indication of whether these figures were

representative of the spread of professions in the workforce. Other occupational groups included allied health professionals, psychologists and social workers.

Two studies looked at the impact of participants' job roles and working environments on their attitude ratings. Krawitz (2004) reported that neither professional group nor work setting was associated with attitude change. Commons-Treloar and Lewis (2008) found equivocal levels of attitude change in both emergency medicine and mental health staff. Participants from all occupational backgrounds made significant improvements; these were of small to medium effect size for nurses (d=0.39) and allied health professionals (d=0.41), while a large effect size was observed for medics (d=0.79).

1.4.5.2. Prior experience, education and training

Very few studies collected data regarding participants' current levels of experience, education and training. Only two studies included calculations to investigate whether such variables had an impact on attitude ratings. Commons-Treloar and Lewis (2008) found that participants with undergraduate and postgraduate degrees made significant and medium-sized improvements in their attitude ratings (d=0.46), compared with their hospital-trained colleagues, who did not demonstrate significant changes. This implies that clinicians with a higher education level are more likely to benefit from group workshops on PD. However, this contradicts findings by Miller and Davenport (1996); while staff

members' formal education level was positively correlated with knowledge at pre-intervention, no such relationship was observed at post-intervention. Given their finding that knowledge and attitudes were positively correlated at both time intervals, this suggests the educational workbook enhanced participants' knowledge and consequently improved their attitudes, regardless of their formal education level.

Aside from education, Miller and Davenport (1996) found no correlations between attitudes and other demographic variables. Commons-Treloar and Lewis (2008) noted that clinicians with more than 16 years of clinical experience did not show significant attitude change, compared with their less experienced colleagues. Furthermore, those reporting daily to fortnightly contact with patients with BPD made significant improvements, whilst those reporting less regular contact made minimal changes. This is consistent with previous findings that frequency of contact is positively associated with attitude ratings (Black *et al.*, 2011; Egan, Haley & Rees, 2014).

1.4.5.3. Gender

Only five studies reported the gender of their participants (Hazelton *et al.*, 2006; Commons-Treloar and Lewis, 2008; Commons-Treloar, 2009; Shanks *et al.*, 2011; Clarke *et al.*, 2014). All five showed an overrepresentation of females, ranging from 60% to 79% of the overall sample. This reflects the typical composition of healthcare services; according to recent equality and diversity

statistics, females comprise 81% of the NHS non-medical workforce (Health and Social Care Information Centre, 2014).

One study compared gender groups; Commons-Treloar and Lewis (2008) noted a statistically significant and medium-sized improvement in female clinicians' attitude ratings following training (d=0.43), compared with minimal and non-significant improvements in males. However, as males made up only 25% of the sample, this calculation may have been underpowered.

1.4.6. Methodological critique

The quality assessment checklist revealed a number of common strengths and limitations in the included studies, which are discussed below. These were broadly related to study design; recruitment and participants; outcome measures; and quality of analysis.

1.4.6.1. Study design

It is important to note that approximately half the included studies fall under the category of service evaluation, rather than research (Hazelton *et al.*, 2006; Rogers & Acton, 2011; Schafer *et al.*, 2013; Davies *et al.*, 2014; Lamph *et al.*, 2014). Service evaluations seek to determine the effectiveness of interventions already in use, and therefore cannot benefit from the usual methods of controlling for bias, such as randomisation (Health Research Authority, 2013). Two of these studies received low ratings on the quality assessment checklist,

due to having unclear rationales and experimental hypotheses, as well as weak methodological controls (Hazelton *et al.*, 2006 (44%); Rogers & Acton, 2011 (42%); see Appendix C).

Five of the included studies employed a quantitative, within-subjects, pre-test/post-test design (Krawitz, 2004; Hazelton *et al.*, 2006; Commons-Treloar & Lewis, 2008; Rogers & Acton, 2011; Shanks *et al.*, 2011). None of these studies included a control group; therefore any changes cannot be reliably attributed to training alone. In contrast, Miller and Davenport (1996) adopted a between-subjects design with a non-intervention control group. Participants were not randomly allocated to experimental and control groups because the groups were recruited from different staff teams to reduce diffusion of experimental effects through interaction. However, efforts were made to match participants in terms of demographic characteristics. As a result, Miller and Davenport (1996) were able to present firmer conclusions about the effectiveness of their educational workbook, affording their study one of the highest overall ratings on the quality assessment checklist (89%; see Appendix C).

It is difficult to determine which *components* of the training interventions were most successful in bringing about attitude change. This restricts the possibility of directly comparing the programmes, which varied considerably. In order to research this quantitatively, more stringent methodological controls would be required, such as randomly allocating participants to distinct interventions.

Randomised controlled trials were conducted in two studies, both of which received reasonably good quality ratings (Commons-Treloar, 2009 (81%); Clarke *et al.*, 2014 (83%); see Appendix C).

In the studies reviewed, qualitative methods were arguably more useful in highlighting the effectiveness of specific training content. For example, the quantitative measures used in Clarke *et al.*'s (2014) study did not differentiate between ACT- and DBT-based training, while qualitative feedback indicated different processes in achieving attitude change. Clarke *et al.*'s (2014) study is an example of the way mixed method research can complement objective, generalizable findings (i.e. quantitative) with subjective, clinically meaningful findings (i.e. qualitative), to reduce the effects of corresponding methodological weaknesses (Abusabha & Woelfel, 2003). Qualitative data also enhanced Hazelton *et al*.'s (2006) study. Only frequencies were reported for the quantitative survey, with no statistical comparison of response rates at the three time intervals. However, discourse analysis of focus group data provided an insight into the emotional process of training, as well as highlighting elements that were particularly useful to participants, such as mindfulness training (Hazelton *et al.*, 2006). Qualitative methods proved similarly useful in highlighting the value of specific aspects of other programmes, such as SU involvement (Schafer *et al.*, 2013; Davies *et al.*, 2014) and team-based approaches (Schafer *et al.*, 2013).

Another common limitation is a lack of long-term follow-up data to indicate whether the effects of training were sustained (Miller & Davenport, 1996; Commons-Treloar & Lewis, 2008; Rogers & Acton, 2011; Shanks *et al.*, 2011). Three studies that did include a follow-up period highlighted that significant pre-test/post-test differences either disappeared or reduced in the months following the intervention (Commons-Treloar, 2009; Davies *et al.*, 2014; Lamph *et al.*, 2014). In contrast, both Krawitz (2004) and Clarke *et al.* (2014) highlighted that participants' attitudes towards PD remained improved six months after training. However, in all studies, follow-up data was collected via mail or email. The results are therefore biased towards participants who returned questionnaires. A high proportion of data sets were lost to follow-up, ranging from 40% (Clarke *et al.*, 2014) to 91% (Davies *et al.*, 2014).

1.4.6.2. Recruitment and participants

All of the studies reviewed used either convenience or purposive sampling methods. On the whole, participants were selected based on their occupation and/or work setting, and their interest in attending training. The results should therefore be treated with caution, as non-probability sampling techniques cannot be used to make inferences from the sample to the wider population of interest. Results may have been influenced by a self-selection bias; staff who opted to attend training may have been more committed to addressing their attitudes towards PD than those who were excluded from studies because they chose not to take up training opportunities. Indeed, it has been demonstrated

that staff who volunteer for training report higher levels of enjoyment, security, acceptance and purpose with regard to their work with SUs with PD than those who do not volunteer (Webb & McMurran, 2007).

Studies were conducted in a variety of service settings and with a number of occupational groups. In many cases, this information was not described in adequate detail. Four of the five UK studies recruited participants from a wide range of public services, including NHS Trusts, Social Services, housing authorities and the criminal justice system (Schafer *et al.*, 2013; Clarke *et al.*, 2014; Davies *et al.*, 2014; Lamph *et al.*, 2014). The generalizability of their results is therefore limited due to broad and/or poorly defined populations. Only two studies recruited participants from within a single service, increasing the homogeneity of their sample and thus the generalizability of their results (Miller & Davenport, 1996; Rogers & Acton, 2011).

1.4.6.3. Outcome measures

Several different instruments were used to quantitatively measure clinicians' attitudes towards PD. All were self-report questionnaires, which are subject to the effects of socially desirable responding. Blinding procedures were described in three studies, whereby participants completed outcome measures privately and were identified using a code (Krawitz, 2004; Commons-Treloar & Lewis, 2008; Clarke *et al.*, 2014). None of the other studies reported whether they took steps to ensure participants' anonymity.

There were vast inconsistencies between studies in terms of which facets of staff attitudes were measured. Three studies conducted comprehensive evaluations, encompassing aspects of each of the three main themes: cognitive and affective attitudes; therapeutic engagement; and personal and professional development (Krawitz, 2004; Shanks *et al.*, 2011; Clarke *et al*., 2014). In contrast, other studies either measured overall attitudes (e.g. Miller & Davenport), or focused on just one aspect. Rogers and Acton (2011), for example, limited their analysis to empathy and antipathy, reducing the complexity of staff attitudes to a rather dichotomous representation. It was acknowledged in the article that the sample in question were likely to hold particularly complex views, as the service they worked in catered for SUs with comorbid learning disabilities and PD. However, the authors made few references to the impact of clients' learning disabilities on staff attitudes, suggesting they did not account for this confounding variable. This is surprising given that people diagnosed with comorbid PD and learning disabilities are considered to be a particularly challenging client group (DoH, 2009; Lee & Kiemle, 2014). For these reasons, Rogers and Acton's (2011) study received the lowest overall rating on the quality assessment checklist (42%; see Appendix C). Their notions regarding the stability of staff's negative attitudes and the limited efficacy of training cannot be firmly concluded.

Two studies looked specifically at attitudes towards DSH in individuals with BPD (Commons-Treloar and Lewis, 2008; Commons-Treloar, 2009). Samples in both studies included staff from mental health and emergency medicine services. However, the ADSHQ was developed using a normative sample of emergency department nurses whose training and expertise lie in physical health (McAllister *et al.*, 2002). It may not be the most appropriate measure to assess the attitudes of mental health clinicians, who are likely conceptualise DSH differently to their emergency medicine colleagues.

Outcome measures varied in terms of their reliability and validity. The most robust measure was the 35-item APDQ, which was developed and validated in the UK using a large normative sample of forensic and mental health practitioners, and has good psychometric properties (Bowers & Allan, 2006). The APDQ was used by Clarke *et al.* (2014), which notably received one of the highest scores amongst the reviewed studies on the quality assessment checklist (83%, see Appendix C). Conversely, studies of lower quality utilised measures that had not been tested for reliability and validity (Krawitz, 2004; Hazelton *et al.*, 2006; Rogers and Acton, 2011; Shanks *et al.*, 2011). Several were developed or adapted specifically for the study in question. Hazelton *et al.* (2006), for example, report basing their survey questionnaire on that of Cleary *et al.* (2002) but offer no explanation of how this was amended.

1.4.6.4. Quality of analysis

1.4.6.4.1. Quantitative methods

In nine of the quantitative studies reviewed, general linear models (e.g. *t*-tests, analysis of variance) were used to compare means at different time intervals. Effect sizes for within-group differences were reported in four studies (Krawitz, 2004; Commons-Treloar & Lewis, 2008; Commons-Treloar, 2009; Rogers & Acton, 2011). None of the other studies provided an explicit indication of clinical significance; the *d*-scores reported in this paper were calculated by the reviewer. Furthermore, none of the reviewed studies reported power calculations and, in many cases, sample sizes were small. There is therefore a possibility of Type II errors (i.e. 'false negatives'), particularly in studies where a vast proportion of data was lost to follow-up (e.g. Davies *et al.*, 2014). Insufficient power also increases the possibility of Type I errors (i.e. 'false positives'), unless error corrections such as adjusted *p*-values are applied. Only one of the reviewed studies adjusted for Type I error (Lamph *et al.*, 2014).

A final issue is that of researcher bias. Hazelton *et al.* (2006) did not conduct statistical tests on their quantitative survey data, and drew unsubstantiated conclusions on the basis of descriptive statistics. Inflated interpretation can occur when researchers attempt to present findings favourably by reporting qualitative explanations of quantitative effects (Ioannidis, 2008). Bias resulting from inflation and selective reporting may be more common in service evaluation projects than in research, due to pressures on clinicians to

demonstrate the efficacy of their interventions in order to secure on-going resources. Indeed, Rogers and Acton (2011) also present relatively firm conclusions based on limited data.

1.4.6.4.2. Qualitative methods

Only one of the reviewed studies employed a solely qualitative methodology (Schafer *et al.*, 2013). A comprehensive explanation of the analysis was outlined, including quality control procedures for enhancing rigour, consistency and reflexivity (e.g. co-coding transcripts). The three mixed method studies provided less detail about their qualitative analysis, and efforts to reduce the effects of researcher bias are not reported (Hazelton *et al.*, 2006, Clarke *et al.*, 2014; Davies *et al.*, 2014).

1.5. Discussion

The aim of the current review was to summarise and critically appraise literature regarding the impact of training interventions on staff attitudes towards PD. The findings will be discussed, along with clinical implications and opportunities for further research.

1.5.1. Summary of findings

Despite inconsistencies between which facets of attitudes were investigated, there was broad agreement that training can have a positive impact on staff's

cognitions, emotions and behavioural intentions regarding people diagnosed with PD. The findings indicate that increasing clinicians' knowledge about PD helps to challenge stigmatising beliefs and to promote understanding, empathy and optimism for SUs. Training was also demonstrated to improve therapeutic engagement. These findings echo those regarding other training programmes about mental health problems (e.g. Endley & Berry, 2011; Caruso *et al.*, 2013) and DSH (Saunders, Hawton, Fortune & Farrell, 2012).

Substantial variations in the content and delivery of training interventions restricted opportunities for comparison; therefore it is unclear which components of each programme proved most successful in altering attitudes. Qualitative reports suggest participants' understanding was enhanced by SU involvement, the benefits of which have been demonstrated elsewhere. Hearing personal accounts from SUs in recovery has been shown to reduce nursing students' stigmatising attitudes towards mental ill health (Sadow & Ryder, 2008). Clinicians have also reported valuing the testimonies of people diagnosed with BPD during training workshops (Krawitz & Jackson, 2007).

Findings regarding personal and professional development were less consistent. Although training was associated with improvements in staff's perceived competence in working with SUs with PD, there is limited evidence to suggest such effects were sustained. Given the interpersonal difficulties inherent in the presentation of PD, staff will inevitably continue to face challenges in their work

with these SUs. Training may provide a foundation for challenging stigmatising attitudes, however, on-going support and supervision is essential for helping staff manage their experiences of countertransference (Aviram *et al.*, 2006). This may also be achieved by enhancing staff members' awareness of their own thoughts and feelings. In the current review, qualitative studies highlighted improvements in participants' self-awareness and self-management skills following mindfulness training. Razzaque, Okoro and Wood (2015) demonstrated that clinicians' mindfulness is associated with having a strong therapeutic alliance with SUs. There is also a growing evidence base for the personal benefits of mindfulness for staff; i.e. reducing stress and burnout and improving self-care (e.g. Brady, O'Connor, Burgermeister & Hanson, 2012).

1.5.2. Summary of methodological critique

The reviewed studies varied in quality and the findings summarised above should be treated with caution. Very few studies provided adequate descriptions of either their sample or the population of interest, while others described heterogeneous samples, limiting the generalizability of their findings. Small sample sizes and/or loss of data to follow-up were common limitations that lessened the statistical power of quantitative analyses. Several studies did not include a follow-up period to observe the long-term efficacy of training. Additionally, only two studies included a non-intervention control group. In several cases, this was because the articles reported on evaluations of existing services. Service evaluation projects do not attempt to test explicit hypotheses

or generate generalizable knowledge (Health Research Authority, 2013). The utility of their findings beyond the service in which they were conducted is therefore limited.

1.5.3. Limitations

The current review has a number of shortcomings. Firstly, only articles published in the English language were included; potentially relevant studies may therefore have been omitted. All of the included studies were conducted in Western countries (i.e. UK, USA and Australasia) and the findings may not be applicable to other cultures. The most significant limitation was the inconsistency between studies in terms of; the types of intervention evaluated; the backgrounds of staff recruited; and the assessment of attitudes. With regard to the latter, it was apparent that researchers' constructions of the concept of 'attitudes' varied considerably. This limits the depth of knowledge that can be gleaned from these papers, as well as the comparability of the studies.

All of the included studies relied on self-report measures, which are commonly biased by socially desirable responding. Given the socially sensitive nature of the topic, participants in the reviewed studies are likely to have presented a favourable image of themselves in order to conform to socially acceptable values, gain approval, or avoid criticism (van de Mortel, 2008). The results may therefore represent a skewed picture of staff members' attitudes towards

people with PD, and indeed the effectiveness of the training interventions evaluated. Furthermore, while attitudes are thought to predict behavioural intentions (Theory of Planned Behaviour; Ajzen, 1991), the current review provides little evidence for changes in staff members' treatment of people diagnosed with PD. It therefore cannot be presumed that attitude change resulting from the training interventions led to an enhanced patient experience.

1.5.4. Clinical implications

Despite limitations in the included studies and the review overall, some tentative suggestions can be made regarding implications for workforce development. Some of the most successful training programmes were those about specific treatment approaches, such as DBT, ACT (Clarke *et al.*, 2014), or STEPPS (Shanks *et al.*, 2011). This is line with guidance in the *'Personality Disorder Capabilities Framework'*, which states that all staff should *"be capable of applying theoretical perspectives to the treatment of PD, under direction"* (NIMHE, 2003b, p. 27). The findings of the current review further indicate that training may be enhanced by incorporating an experiential component (e.g. mindfulness techniques).

There is some evidence to support the inclusion of EBEs as co-facilitators in delivering training. Interacting with people diagnosed with PD in a different context to their caring role may help staff recognise SUs' positive attributes and promote a "re-engagement with common humanity" (Wright *et al.*, 2007, p.

236). Additionally, the findings indicate that taking a whole team approach to training can help foster a culture of positive attitudes within a service (Schafer *et al.*, 2013). Finally, the importance of on-going supervision in supporting staff who work with clients with PD is highlighted, to maintain positive, recovery-focused attitudes (NIMHE, 2003a; Aviram *et al.*, 2006).

1.5.5. Research implications

The evidence to date is limited by a lack of high-quality research with clearly defined variables. In the first instance, it would be advantageous to study the most appropriate way of measuring staff attitudes towards PD. This would require a detailed deconstruction of the concept of attitudes, in order to produce a valid measure that can be used as standard in future research. However, the complexity of measuring attitudes 'scientifically' has long been debated; many researchers argue the need to look beyond quantitative scales and consider the added value of qualitative methods (Shrigley & Koballa, 1984; Reid, 2006).

In the current review, qualitative evaluations were arguably the most illuminating in identifying the most useful aspects of training for achieving attitude change. As there is currently no conclusive evidence in this area, researchers may therefore wish to adopt a mixed method design, complementing measurable data with participants' perspectives. This issue may also be overcome by conducting randomised controlled trials to compare

the impact of different types of training interventions, such as those based on different theoretical frameworks. Non-intervention control groups should also be used to enhance the validity of any findings.

1.5.6. Conclusion

This review offers a preliminary indication of the potential for improving staff attitudes towards people diagnosed with PD through training. It is important not to lose sight of the intended purpose of such interventions, which is to improve the quality of care for SUs with this diagnosis. In addition to enhancing the methodological quality of research in this area, explicit investigation is required into the impact of training on clinical practice, to determine whether such programmes are actually effective in "breaking the cycle of rejection" (NIMHE, 2003b).

1.6. References

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Chapter 2: Empirical Paper

A qualitative exploration of mental health nurses' experiences of working

with adults with autism spectrum disorder

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2.1. Abstract

Adults with autism spectrum disorder (ASD) are vulnerable to mental health problems and consequent hospital admissions. However, ASD is poorly understood within mental health services. The current study aimed to explore staff members' experiences of working with adults with ASD in acute inpatient services. Semi-structured interviews were conducted with seven mental health nurses and the transcripts were analysed using Interpretative Phenomenological Analysis. Two superordinate themes emerged from the data: *'Out of our depth'* and *'Remembering the person'*. Nurses felt confused and unable to make sense of service users' presentations, which they perceived as incompatible with the environment and purpose of an acute ward. Focusing on their core nursing values of empathy, understanding and compassion helped them overcome these challenges and adjust their practice. Nurses coped with their uncertainty by finding a role for themselves in protecting vulnerable individuals. The findings highlight mental health nurses' lack of knowledge about ASD. Training and clinical supervision are crucial for developing their skills and confidence in caring for this client group.

Key words: Mental health nurses, autism, hospitalisation, Interpretative Phenomenological Analysis

2.2. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder, characterised by impairments in reciprocal social communication and interaction, and restricted patterns of behaviour, interests or activities (American Psychiatric Association, 2013). ASD manifests on a continuum of severity and occurs with or without accompanying intellectual impairment. Many people with ASD also experience sensory sensitivities. The vast majority of literature to date has focused on autism in childhood and adolescence; however, there is growing recognition of ASD as a lifelong condition, the effects of which persist throughout adulthood (Wright, Brooks, D'Astous & Grandin, 2013). This is epitomised by the passing of the Autism Act 2009, the United Kingdom's (UK) first disability-specific legislation, which was intended to make provision for meeting the needs of adults with ASD.

2.2.1. Late diagnosis

Brugha *et al*. (2011) estimate that ASD affects approximately 1% of the adult population in the UK, and that, *"adults with ASD living in the community are socially disadvantaged and tend to be unrecognised"* (p. 459). Those without intellectual impairments tend to fall through the gap between mental health and learning disability services and struggle to access specialist support (Griffith, Totsika, Nash & Hastings, 2011).

Barnard, Harvey, Potter and Prior (2001) proposed a 'common spiral' of events to highlight the possible consequences of being overlooked by services. Prior to diagnosis, adults with ASD are unable to access support, leaving them vulnerable to depression and other mental health problems, which may lead to breakdowns or suicide attempts. Those who require acute care are at risk of being misdiagnosed, which further prevents their needs being recognised. Other potential risks of late diagnosis include bullying, isolation and loneliness in the short-term, and, in the long-term, underachievement and prolonged dependency on parents (Portway & Johnson, 2005).

2.2.2. The mental health needs of adults with autism spectrum disorder

The prevalence and range of mental health problems in adults with ASD is greater than that of the general population (Ghaziuddin, 2005). Depression and anxiety are common experiences for this group (Ghaziuddin, Ghaziuddin & Greden, 2002; Kannabiran & McCarthy, 2009; Lugnegård, Hallerbäck & Gillberg, 2011). Their vulnerability is increased by factors intrinsic to ASD, such as communication difficulties and cognitive rigidity, as well as common experiences of people with ASD, such as loneliness, victimisation and family tension (Tantam, 2001; McCoy, 2012). Many people with ASD have high trait anxiety, which can lead to extreme agitation, suicidal behaviour, or aggression and conduct problems (Tantam, 2001).

Assessing mental health problems in people with ASD can be difficult, as even high-functioning individuals with adequate language skills often lack the emotional vocabulary to understand and express their feelings (Attwood, 2007; Kannabiran & McCarthy, 2009). Another challenge lies in disentangling the overlap between core features of ASD and other psychiatric symptoms, particularly when psychosis is apparent. Although comorbidity between autism and schizophrenia does occur (Hallerbäck, Lugnegård & Gillberg, 2012), the overlap between unusual perceptions and cognitions in these two conditions can result in misdiagnosis (Dossetor, 2007). For example, people with ASD may hold overvalued ideas (e.g. about a special interest), which can resemble delusions (Ghaziuddin, 2005). Severe anxiety may manifest as an exacerbation of autistic traits such as rituals or unpredictable behaviour (Tantam, 2001). Dossetor (2007) suggests that high levels of anxiety may lead to an increase in idiosyncratic preoccupations, which can appear bizarre or psychotic to professionals unfamiliar with ASD. Raja and Azzoni (2010) warn that misdiagnosis can lead to a general underestimation of the occurrence of ASD in adult psychiatric service users (SUs).

Given the prevalence and nature of mental health problems in adults with ASD, it is to be expected that some will experience crises that result in admission to a psychiatric hospital. Furthermore, it is likely that their autistic features will have been unrecognised or misdiagnosed (Barnard *et al*., 2001; Raja & Azzoni, 2001). This was exemplified by the diagnostic assessment of 141 inpatients in an

American psychiatric hospital (Mandell *et al.*, 2012). Ten per cent of SUs met the criteria for ASD; none had previously been diagnosed with autism and almost all had a current diagnosis of schizophrenia. The issue of over-diagnosing psychosis in people with ASD has also been highlighted by case illustrations (Perlman, 2001; Dossetor, 2007).

2.2.3. Autism spectrum disorder in mental health services

The issues people with ASD face when using mental health services are highlighted by a series of first-hand accounts collated in *'Aspies on Mental Health: Speaking for Ourselves'* (Beardon & Worton, 2011). A common theme in most of the stories is that a lack of understanding – on behalf of themselves or others – is a key factor in prolonging psychological distress. Those who were not diagnosed with ASD until adulthood describe the frustration of *"deal*[ing] *with a world that isn't designed for them"* (Shepherd, 2011; p. 104). The authors stress the importance of self-understanding, for which an accurate diagnosis is crucial: *"The truth is, the reason I can…appear so 'normal' is due to my diagnosis and the sense it enabled me to make out of myself, my life and the world around me"* (Goldthorpe, 2011; p. 160).

Several authors describe the added distress of having difficulties that were not understood by mental health professionals. Cornish (2011) outlines his experience of feeling let down by staff and having to *"justify my way of being, my existence"* (p. 84). Christmas (2011) describes the overwhelming sensory

experience of a hospital admission, where *"[neither she nor nursing staff] were in a position to ameliorate* [her] *extreme reactions to events as they occurred"* (p. 19). Goldthorpe (2011) recalls being perceived as uncooperative or untruthful in her years as a 'revolving door patient', in which multiple psychiatric admissions, diagnoses and medication changes served to intensify her distress.

These accounts indicate that a lack of understanding and empathy from staff can have damaging consequences for SUs. Olson and Hanchett (1997) emphasised the importance of empathy in all nursing care. They demonstrated a negative relationship between patient distress and nurse-expressed empathy (defined as the skill of understanding what a patient is saying and feeling, and communicating this verbally to the patient). There was also a negative relationship between patient distress and patient-perceived empathy (defined as a patient's feelings of being understood and accepted by a nurse). SUs with ASD report that empathy, understanding and acceptance from staff would be highly beneficial to their progress (National Autistic Society, 2009; Beardon & Worton, 2011). Unfortunately, mental health professionals' ability to convey such understanding may be hindered by their lack of specialised knowledge and issues of diagnostic confusion.

2.2.4. Rationale for the current study

Many adults with ASD do not receive the support they need, leaving them vulnerable to mental health problems and consequent hospital admissions. A general consensus in the literature is that ASD is poorly understood within mental health services. Recognition of these issues is growing and the education of frontline staff was identified as a key development need in the national autism strategy (Department of Health (DoH), 2010). Despite this, there has been no research into the experiences and perspectives of staff members themselves. It is important to consider how they make sense of these SUs' presentations, including how a diagnosis of ASD impacts on this understanding.

2.2.6. Aims and research questions

The current study aimed to explore the experiences of frontline staff working with adults with ASD in acute mental health services. A particular focus was on how staff members understand and respond to SUs receiving a diagnosis of ASD for the first time, and whether this new diagnosis impacts on staff members' work with these SUs. The following research questions were posed:

1. What are the experiences of staff members working with adults with ASD in acute mental health services?

2. What challenges do this group present and how do staff members make sense of them?

2.3. Method

2.3.1. Design and materials

As the research questions were exploratory, a qualitative methodology was adopted. Data collection and analysis were guided by the principles of Interpretative Phenomenological Analysis (IPA), which is one of the most commonly used qualitative methods in clinical psychology research (Smith, 2011). IPA seeks to discover how a phenomenon – in this case, ASD in mental health care – has been experienced, perceived and understood by particular individuals (Smith, Flowers and Larkin, 2009). The interpretative, or hermeneutic, aspect of IPA allows the researcher to analyse the *meaning* of participants' subjective accounts, and can therefore be said to benefit from an 'epistemological openness' (Larkin, Watts & Clifton, 2008), occupying a position between realism and social constructivism. IPA was considered to be the most appropriate methodology for the current study, as the aims were to understand and 'give voice' to participants' experiences (Larkin *et al.*, 2008). IPA is also appropriate for exploring new or under-researched phenomena (Smith, 2004), which was the case for the current study.

A semi-structured interview format is the most appropriate method of data collection in IPA research (Smith, *et al.*, 2009). DiCicco-Bloom and Crabtree (2006) argue that less structured interview techniques ensure that the interviewee is *"more a participant in meaning making than a conduit from which information is received"* (p. 314). An interview schedule was developed

by the researcher and research supervisors, drawing on previous literature (Appendix J). The questions were neutral and open, to encourage participants to share as much information as possible, unselfconsciously and in their own words. This also allowed flexibility for the participants to direct the conversation towards topics most meaningful to them (DiCicco-Bloom & Crabtree, 2006).

2.3.2. Participants

The population of interest was staff members who had experience of caring for adult SUs with ASD in acute mental health services. The sample was restricted to Registered Mental Health Nurses (RMNs) with similar qualifications and training, to increase homogeneity, in keeping with the requirements of IPA (Smith *et al*; 2009).

Participants were recruited from the staff teams of two acute psychiatric wards within a West Midlands NHS Trust, using a purposive sampling method. A participant information sheet (Appendix G) was disseminated to RMNs in these teams at staff meetings. They were asked to express their interest in participating either by contacting the researcher or giving permission to be contacted.

Seven participants were recruited, as per recommendations from Smith *et al.* (2009), who advise that four to ten interviews allow for a meaningful level of

analysis. There were four female and three male participants, with an age range of 22-49 years (mean = 34 years). All were qualified RMNs, whose level of nursing experience ranged from four months to ten years (mean = 3 years, 10 months). Minimal information about participants has been provided to preserve their anonymity.

2.3.3. Procedure

Semi-structured interviews were conducted with each participant in a private room at their place of work. Locations were chosen for the participants' convenience. Before the interview, they were shown the information sheet again and any questions or issues were resolved. They were informed of their right to withdraw from the study up until the completion of data analysis. Participants were then asked to sign the consent form (Appendix H) and complete a short demographic questionnaire (Appendix I), to provide information that gave a context to their experiences.

Interviews were recorded using a digital audio recorder. The interview schedule was used as a guide; however, the researcher endeavoured to follow the participant, encouraging them to share their experiences without leading them. The mean length of the interviews was 31 minutes 03 seconds (range 20.08–46.17). Participants were given written debriefing information after the interview (Appendix K).

2.3.4. Analysis

Interviews were transferred onto a password-protected computer and transcribed verbatim. To ensure anonymity, each participant was given a pseudonym and all personally identifiable information was removed. The transcripts were analysed using the step-by-step process for IPA outlined by Smith *et al.* (2009) (see Table 2.1).

Table 2.1. Process for IPA analysis (Smith et al., 2009, p. 82-101)

Analytical stages
1   Reading and re-reading
2   Initial noting
3   Developing emergent themes
4   Searching for connections across emergent themes
5   Moving to the next case
6   Looking for patterns across cases

Descriptive, linguistic and conceptual aspects of participants' transcripts were noted, analysis of which led to identification of emergent themes (see Appendix L for an example of coding a transcript). These concepts were then organised into clusters and connections between participants' accounts were identified, resulting in a master table of superordinate and subordinate themes for the entire sample (see Appendix M for an example).

2.3.4.1. Position of the researcher

The researcher is a female Trainee Clinical Psychologist who has no association with the NHS Trust in which the study was conducted. The researcher has prior

experience of supporting adults with ASD in an inpatient setting, but was not working in this capacity at the time of conducting the study. The researcher has an interest in understanding how individual staff members conceptualise ASD, which is akin to the idiographic, phenomenological and hermeneutic underpinnings of IPA (Smith *et al.*, 2009).

Interpretation in IPA is open to influence from the subjective position of the researcher, as their attempts to make sense of participants' sense-making creates a double hermeneutic (Smith *et al.*, 2009). To ensure data collection and analysis remained grounded in the experiences of participants, the researcher took steps to 'bracket' their existing preconceptions about the subject (Rolls & Relf, 2006). A reflexive stance was maintained throughout the research process, by recording any thoughts, feelings and impressions that might bias the analysis in a reflective journal (Tufford & Newman, 2010). These insights are discussed in a reflective paper in Chapter 3 of this thesis.

2.3.4.2. Validity and credibility

Yardley's (2000) criteria for assessing the validity of qualitative research were referred to throughout the research process. The four criteria are: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. Efforts to ensure transparency and reflexivity in the study are discussed in section 2.3.4.1. The analysis kept as close as possible to the original data, in order to maintain sensitivity to each participant's individual

narrative. To enhance the rigour of the analysis, a group of peers conducting IPA research read participants' transcripts and discussed emerging themes with the researcher. A peer familiar with IPA coded one transcript in full and their notes were compared with that of the researcher to identify themes that may have been overlooked. In the final stage, connections between emergent themes were explored alongside the researcher's academic supervisor, who is experienced in using IPA.

2.3.5. Ethics

This study was approved by the Coventry University Ethics Committee and the Research and Development department of the NHS Trust from which participants were recruited (see Appendices E and F for confirmation of approval). The study was conducted within ethical guidelines outlined by both Coventry University (based on guidance published by the UK Research Integrity Office, 2009 and the Research Councils UK, 2013) and the British Psychological Society (BPS, 2010).

2.4. Results

The compositional structure of themes from the IPA analysis is displayed in Figure 2.1. Two superordinate themes emerged from the data: *'Out of our depth'* and *'Remembering the person'*. These will be described qualitatively and illustrated with extracts from participants' transcripts. An ellipsis (…) appearing in quotations represents omitted text.

Superordinate themes

Subordinate themes

```
┌──────────────────────┐        ┌──────────────────────┐
│                      │        │   1.1. Utter confusion│
│  1. 'Out of our depth'│◄──────►└──────────────────────┘
│                      │
└──────────────────────┘        ┌──────────────────────┐
                                 │  1.2. Incompatibility │
                                 └──────────────────────┘

┌──────────────────────┐        ┌──────────────────────┐
│                      │        │   2.1. Empathy in     │
│  2. Remembering the  │◄──────►│   understanding       │
│     person           │        └──────────────────────┘
│                      │
└──────────────────────┘        ┌──────────────────────┐
                                 │  2.2. Protecting the  │
                                 │   vulnerable          │
                                 └──────────────────────┘
```
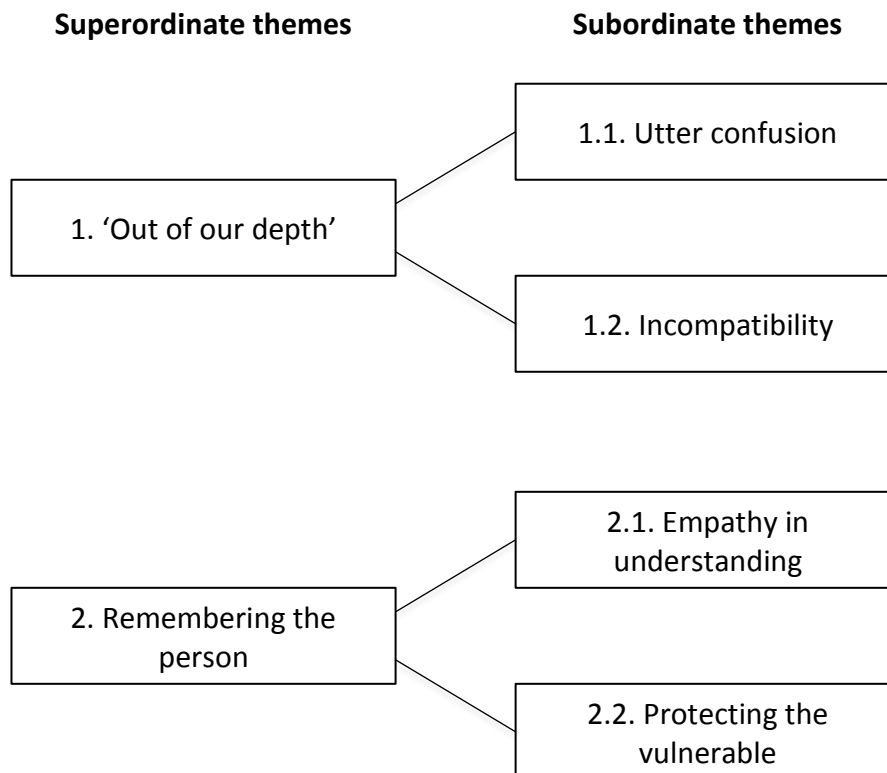
Figure 2.1. Compositional structure of themes

2.4.1. Superordinate theme 1: 'Out of our depth'

> *"What can I actually do for them? Is there anything we can do?"*
>
> (Natalie, line 42)

An overarching theme across all participants' accounts was being out of their depth in the task of nursing adults with ASD. Nurses described feeling confused and unable to make sense of these SUs' behaviours, which they felt were incompatible with the ward's environment and purpose. All participants commented that they needed more guidance.

2.4.1.1. Subordinate theme 1.1: Utter confusion

Confusion was a major theme in all nurses' accounts, and is highlighted by their descriptions of feeling baffled by people with ASD:

> *"We cannot make heads or tails of their presentation."* (Marie, line 231)

> *"I don't know if I've made sense of it at all…she's contradicting herself. But that could be…how she's wired…I don't know."* (Liam, line 193)

All participants cited SUs' communication difficulties as a barrier to understanding their crises. They noted that people with ASD have a limited ability to express their emotions and needs. Charlotte noted that mental illness is a subjective experience that cannot be fully assessed through observing the person:

> *"A lot of it you need to elicit from the patient and if you can't then it's hard to understand."* (Charlotte, line 142)

Six participants commented on the complicated task of trying to separate signs of mental illness from those of ASD. The issue of psychiatric comorbidity is highlighted in Liam's description of a male SU who was admitted to hospital presenting with active symptoms of psychosis:

> *"Very fixed thinking…that could be his schizophrenia blocking his thoughts, or it could be his Asperger's, so it's quite hard to determine which one is which."* (Liam, line 121)

A similar issue was that of 'diagnostic overshadowing', where SUs' autistic traits had been attributed to long-standing mental health diagnoses. Sally reflected on her initial conceptualisation of a female SU who went on to receive a diagnosis of ASD:

"She'd got a label of personality disorder, she was very disruptive…quite high risk. And it never occurred to me…that maybe there was something else going on as well." (Sally, line 167)

The experience of being confused about SUs' presentations was strongly related to some participants' confidence in building therapeutic relationships. Three participants (Sally, Paul and Gareth) had some knowledge of ASD from experiences in their personal lives. Paul felt that having relatives with autism helped him interact with SUs, but sympathised with his colleagues' anxiety:

"If I hadn't got personal experience…I'd probably be in a lot more of a panic state during those engagements." (Paul, line 299)

Nurses who were new to working with ASD seemed more emotionally affected by the experience. There was a sense of participants feeling unsettled by their patients' apathy. Marie expressed bewilderment at the lack of emotion a SU displayed when talking about his suicide attempt:

"He talked about suicide as if it was someone going to the shop and buying a box of chocolates. There was no emotion…he was

as calm as anything…which was very, very confusing." (Marie,

line 110)

The challenge of engaging people with ASD proved frustrating for less experienced nurses. The language of two participants suggests this frustration is related to their attributions about SUs' behaviour. Liam's global statements about a female SU suggest he sees these challenges as being internal, part of her nature: e.g. ***"She is** difficult."* (Liam, line 155). Charlotte's account of a patient's refusal (rather than inability) to connect with her implies attributions of control and choice:

*"**Won't** make any eye contact with you, **won't** sit down and tell*

you how they're feeling…so it's hard to understand them."

(Charlotte, line 96)

There was a strong sense of anxiety in these narratives. Five participants explained they were cautious about wording things 'correctly', as they felt unable to predict how their patient would react. Marie's account conjures an image of 'walking on eggshells':

"I used to have quite a lot of one-to-ones with [SU] *but I got*

stuck, when he asked me questions and you're thinking, 'God,

should I say this? How does he take that?'" (Marie, line 78)

Ultimately, nurses' confusion about ASD undermined their confidence to care for these SUs, as illustrated by Marie's struggle to communicate with family caregivers:

"[Families] come to us and want to ask questions, what do I tell

them? I'm not confident nursing their loved one. What do I tell

them to reassure them?" (Marie, line 195)

Underpinning this prevailing sense of confusion was a lack of knowledge about ASD. All participants reported having had no formal training on ASD, either pre- or post-qualifying. A lack of support and education was apparent in their attempts to educate themselves using public resources:

"If someone suggests it [autism]*, I go on the computer to check.*

That's how much I don't know." (Marie, line 7)

"We end up going on the Internet and looking at NHS

websites…It just doesn't seem very professional." (Natalie, line

78)

Participants also drew on the personal resources of more experienced nurses. They described their attempts to manage confusion by turning to their colleagues for support:

"You learn from working with your colleagues and they say, 'you

know he's doing that 'cause he's autistic?'" (Gareth, line 249)

"Just keep talking to each other. If you don't know something

you ask and somebody will know." (Sally, line 370)

All participants expressed a desire for guidance, either for their own learning or to support them as a team. They offered a variety of suggestions regarding

opportunities that would enhance their ability to work with SUs with ASD. The majority of participants believed training would be beneficial. Charlotte reported that she would appreciate information about the lived experiences and expectations of care of people on the autism spectrum. Gareth valued 'on the job' experience more highly than formal training and was of the opinion that RMN training courses should place greater emphasis on neurodevelopmental differences.

> *"I think it would be quite interesting to actually hear off…patients that live with autism on a day to day basis. Maybe we could have some talks or chats."* (Charlotte, line 224)

> *"I think experience…if student nurses were expected to do even a week working with people with learning disabilities or autism to get some insight."* (Gareth, line 468)

Three participants commented on the value of clinical supervision with a psychologist, which offers a space for reflection and problem solving. Sally's description of 'unpicking' themselves conveyed an image of the team as a whole having become tangled in a web of confusion:

> *"As much as you need to unpick the patient's problems, sometimes you just need to unpick yourself as a team as well."*
> (Sally, line 363)

2.4.1.2. Subordinate theme 1.2: Incompatibility

This theme reflects nurses' views about a mismatch between ASD and acute psychiatric services. All participants discussed SUs who they believed were inappropriately placed but had nowhere else to go:

> *"She came onto this ward because basically no other ward is quite sure what to do with her. It's really quite sad."* (Liam, line 62)

> *"I feel that patients are brought to us because there is no other service out there. Patients are being brought to us based on their behaviour rather than their need."* (Marie, line 190)

Marie's comment about behaviour exemplifies a common theme in participants' views about the reasons for SUs' hospitalisation. All participants discussed individuals whose admissions were precipitated by episodes of risky or challenging behaviour. Several nurses considered the pervasive nature of ASD to be incompatible with the intended purpose of an acute inpatient service, which is to support recovery from mental health crises. The experience of working with autistic SUs seemed to evoke a sense of helplessness, as nurses felt uncertain about their role:

> *"It's very difficult for us to **treat** somebody for ASD which…is kind of a lifelong condition more so than an acute illness."* (Natalie, line 22)

*"To **do** any sort of **intervention**…when they're not in an acute phase of their illness…it's quite tough really."* (Charlotte, line 74)

*"His Asperger's, it's him isn't it? You can probably help him in certain ways but you can't really **change** an awful lot about him 'cause that's just how he is."* (Liam, line 134)

The use of dynamic verbs in these quotations (i.e. 'treat', 'change', 'intervene') illustrates the active role nurses usually take in reducing their patients' symptoms. In contrast, the difficulties of SUs with ASD stem from stable traits rather than acute episodes of illness, which reduces nurses' ability to impact on their progress. Being unable to fulfil their usual role was experienced as *"disempowering"* (Natalie, line 42). It is therefore of note that these participants' narratives leaned towards SUs who they did not consider to be mentally unwell. They seemed more able to rationalise their experience of individuals who had comorbid depression or psychosis and kept these accounts relatively succinct. This is perhaps because they saw a clear role for themselves in terms of treating acute symptoms:

"His mental illness…needs to be controlled first." (Liam, line 133)

In contrast, participants' descriptions of SUs with a sole diagnosis of ASD were lengthier and characterised by confusion and/or frustration. Their focus on mental health highlights their attempts to make these SUs fit with their experience and expertise; those who did not fit the mould challenged their competence and therefore became a source of frustration.

'Incompatibility' also captures participants' experiences of struggling to create a suitable therapeutic environment for people with ASD. Those with prior experience recognised SUs' difficulties with unpredictability and sensory overstimulation:

> *"You get patients who find chaos to be the most difficult thing in their life being placed in a situation that is very chaotic."* (Gareth, line 44)

> *"She found the ward very loud. Too noisy, too bright, too much going on...she was saying to me...'I just feel like I'm gonna have a meltdown.'"* (Sally, line 139)

Nurses cited SUs' rigidity as the main barrier to working effectively with them. However, the rigidity of the service was also implicit in their accounts. Paul spoke at length about a patient who lived by a very fixed routine, which was incompatible with that of the ward:

> *"We do things at certain times whereas...she'd want her own routine that she'd always had."* (Paul, line 109)

Three participants stressed that maintaining safety is of paramount importance on an inpatient ward. Liam described his 'battle' with a SU who refused to clean her room:

> *"Obviously that is her way of living, but she's in a hospital and the hospital has to be clean because it's a hospital."* (Liam, line 114)

These examples illustrate the challenge of meeting these SUs' needs in an acute setting. There was a sense of nurses being stuck in the middle as they tried to support inflexible people within the restrictions of an equally inflexible system.

2.4.2. Superordinate theme 2: Remembering the person

> *"It's not just a label, there's a real human being under that."*
>
> (Charlotte, line 246)

All participants emphasised the importance of providing person-centred care. Focusing on their core nursing values of empathy and compassion seemed to provide a way of coping with the confusion and frustration surrounding an unfamiliar presentation. Likewise, they could counteract feelings of helplessness by taking on a role of protecting and advocating for vulnerable SUs.

2.4.2.1. Subordinate theme 2.1: Empathy in understanding

Nurses explained that understanding each SU as an individual person was crucial to their work. A theme of 'learning from the patient' was present throughout Gareth's narrative particularly. He noted that taking extra time and effort is essential for building relationships with people with ASD, as they may not express their distress in the way professionals expect. Reflecting on a SU whose anxiety was hidden by his outwardly calm presentation, Gareth said:

"I was learning from the patient, 'well you know this is what I do when I'm upset, this is what I do when I'm terrified'…there are still some strong emotions, he's just displaying them differently."

(Gareth, line 163)

Despite most participants' lack of knowledge about ASD, all of them believed a formal diagnosis helped the staff team take a different perspective on SUs' unusual or puzzling presentations. Nurses were able to alter their attributions about behaviours they perceived to be antisocial or challenging:

"Knowing his diagnosis, we…can understand that it's not him being inappropriate, it's just the way he communicates."
(Charlotte, line 188)

"People thought when he first come in that he had kind of psychopathic tendencies 'cause he's got absolutely no remorse for what he did…when we realised it's…not just that he's dangerous and doesn't care about other people, but he doesn't understand or relate to other people…it was easier to nurse him. Because he wasn't just a bad person." (Natalie, line 156)

Natalie's statement highlights the challenge of empathising with a person who lacks empathy. Having an explanation for the patient's indifference seemed to resolve a moral conflict that helped her overcome this challenge. Indeed, several participants commented that SUs *"couldn't really help it"* (Paul, line 397) or *"it's not their fault"* (Charlotte, line 189), which lessened their frustration.

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This implies that a diagnosis of ASD helps nurses make fewer attributions of control, thus increasing their empathy for the person.

Participants considered how standard nursing practices might be distressing for someone with ASD:

"You put somebody on close observations, it's quite intimidating…I wouldn't like it, personally…with an undiagnosed autism, to have that would be horrendous." (Sally, line 171)

"It's like Jenga isn't it, pull a bit out and they just collapse. I realised that by cleaning her bedroom, that was part of her daily thing and I ruined it. I was like 'oops, sorry!' I know now to tread carefully when I do that." (Liam, line 255)

Liam's reflection illustrates his process of learning about ASD through his work with a SU. Their conflict helped him recognise the importance of rituals and routines, and to appreciate that disruption to these can be experienced as catastrophic. This is reflected in his use of 'Jenga' as a simile. His description of learning to 'tread carefully' indicates that understanding the SU's rigidity helped him make allowances for her. A number of participants gave examples of how they increased flexibility in their own routines to compensate for their patients' difficulties:

"I've noticed that some people…will only speak to certain staff members…it's trying to get the balance of who's best to approach that person." (Charlotte, line 30)

"We try to be flexible [with the time of ward review] *to make sure that their relatives can attend."* (Paul, line 336)

These adaptations highlight nurses' commitment to creating a therapeutic environment for each SU despite the aforementioned issues around incompatibility. The increase in flexibility extended to the multi-disciplinary team's (MDT) decisions about individual care pathways. Sally explained the reasoning behind a decision to grant home leave to a patient with extreme sensory sensitivities, which she viewed as an act of positive risk-taking:

"She couldn't cope in a dormitory with five other women…I think it was really proactive of us saying, 'yes we understand this and you're saying this to us to prevent it [a meltdown]*, so you need to be at home.'"* (Sally, line 274)

This theme encapsulates nurses' experiences of providing compassionate care based on their conceptualisations of SUs' behaviour. Although a diagnosis supported this process, participants noted the broad range of presentations within the autism spectrum. Their accounts suggested that an empathic attitude is founded on a person-centred approach to nursing:

"I'm still trying to understand that everybody's different. There's maybe some characteristics or signs or symptoms but it's what they mean to that person as an individual." (Charlotte, line 125)

2.4.2.2. Subordinate theme 2.2: Protecting the vulnerable

A dominant theme across all nurses' accounts was a view that SUs with ASD are vulnerable people in need of professional support. All participants discussed SUs who had little or no support in the community before their hospital admission. Implicit in their accounts was a sense of injustice about these patients having been let down by services:

"We were all quite shocked that somebody with this condition that did affect his life, day in and day out, had never been picked up." (Gareth, line 202)

Five participants expressed frustration about being unable to discharge SUs who were no longer in need of their service because other agencies would not take responsibility for them:

"The learning disability team didn't touch him because they said he was too independent and too well functioning…He didn't have a mental illness in terms of he didn't have depression, psychosis, low mood even…We knew he couldn't manage out on his own because he needed support but nobody would touch him."
(Natalie, line 57)

"She's kind of in limbo mode…it's down to their [the funding panel's] *decision and it just goes round in circles."* (Liam, line 266)

Nurses discussed their experiences of caring for individuals who had *"nowhere else to go"* (Charlotte, line 73; Sally, line 104). They seemed to be emotionally impacted by their patients' circumstances and felt a strong sense of duty to provide a safe haven:

"It's not his fault support's not available for him. And by keeping him on the ward, we was attempting to make sure that he was at least supported, you know, as a person more than anything else." (Natalie, line 197)

Three participants described taking on the role of advocating for SUs. Gareth talked about a patient who was diagnosed with ASD during his inpatient admission. He expressed a view that being overlooked and unsupported had led this person to behave very dangerously. Gareth explained that the diagnosis had come as a *"relief"* (line 381) to the nursing team, who were very concerned for this SU's welfare. Persuading authorities to accept this view proved challenging:

"I think we spent six months trying to persuade the Police and housing authorities…that this person actually wasn't a risk to anybody else." (Gareth, line 72)

Nurses seemed to feel compelled to go beyond their usual role to protect SUs they believed were being failed. Participants gave examples of 'bending the rules' to keep patients on the ward despite the high demand for inpatient beds:

"He was well after a week, realistically. But…we were supporting him and trying to make sure that everything was put in place for him." (Gareth, line 171)

"We have to quickly transfer someone to another ward…just to accommodate her." (Liam, line 285)

Gareth's account indicated that the wider MDT took a similar view to the nursing team and supported their efforts to keep SUs with ASD safe:

"We were very lucky that [a senior colleague] *said, 'We're not discharging him until he's got somewhere to live.'"* (Gareth, line 185)

Participants were forthright with their views about gaps in service provision. This is in contrast to their general narratives about ASD, which were characterised by doubt and anxiety. Protecting vulnerable people seemed to help them cope with uncertainty about these SUs by giving them a clear role in their care.

2.5. Discussion

This study aimed to explore mental health nurses' experiences of working with adults with ASD in acute inpatient services, including their perceptions of the

challenges involved in nursing this client group. Two superordinate themes emerged, which will be discussed in relation to previous literature and the research questions. Clinical implications, limitations of the study and areas of future research will be considered.

2.5.1. Exploration of themes

2.5.1.1. Superordinate theme 1: 'Out of our depth'

This theme captures participants' experiences of struggling to make sense of and care for autistic SUs. Nurses described their confusion surrounding presentations they were unfamiliar with. Participants who had little previous contact with people with ASD were notably more frustrated than those who could draw on personal experience. They lacked confidence to work effectively with SUs and were anxious about how their communications would be received. This illustrates a critical issue highlighted in the national autism strategy: *"If staff do not know about autism and how it affects behaviour and responses, then they can have no idea of how to adjust the way they deliver services, their approach to communication, or their expectations"* (DoH, 2010, p. 25-26). Indeed, all participants discussed either their own lack of knowledge about ASD, or that of their colleagues.

Nurses highlighted the impact of confusion on their assessment process. The challenge of disentangling signs of ASD and mental illness has been discussed elsewhere (e.g. Dossetor, 2007; Raja & Azzoni, 2010). Interestingly, participants

seemed to find it easier to work with SUs who exhibited symptoms of psychosis, perhaps because they could see a clear role for themselves in treating illness. In contrast, patients with ambiguous presentations or those with a sole diagnosis of ASD were a source of frustration. Nurses were inclined to make judgements about the appropriateness of SUs' hospital admissions. Several believed the main precipitating factor was risky or antisocial behaviour, rather than mental health crises. This is line with other studies citing physical aggression as the most common reason for inpatient admission in people with ASD (Palucka & Lunsky, 2007; Kokoski, White, Palucka & Lunsky, 2009). However, increases in maladaptive behaviour may be triggered by depression in this population, as people with ASD lack the emotional literacy to make their feelings known (Ghaziuddin *et al*., 2002; Kannabiran & McCarthy, 2009). Behavioural problems may also disguise suicidal intentions (McCoy, 2012). Staff's lack of knowledge about how depression might manifest in ASD is therefore a huge barrier to conducting a comprehensive risk assessment.

Nurses' accounts of SUs having 'nowhere else to go' echoed a widely held view that adults with ASD fall through the gaps between services (Barnard *et al.,* 2001; Griffith *et al.,* 2011). Their opinions about the inappropriateness of placements stemmed from a belief that the core features of ASD are incompatible with the purpose, environment and management of an acute psychiatric ward. Participants' accounts were in agreement with those of some autistic SUs who assert that inpatient services are not equipped to meet their

specialist needs (Christmas, 2011; Shepherd, 2011). A tension was observed between the rigidity of patients and the rigidity of the system. Nurses needed to maintain established routines to manage the ward safely and efficiently, while patients needed to maintain their own rituals to manage their anxiety. Clashes in routines added to staff's frustration with patients. Overall, participants' inability to effect change in very rigid patients evoked feelings of helplessness and disempowerment, as they felt unclear about their role.

2.5.1.2. Superordinate theme 2: Remembering the person

This theme explores nurses' experiences of trying to overcome these challenges. All participants stressed the importance of getting to know each SU as an individual. Understanding patients' perceptions and concerns is essential for therapeutic relationships, which have been described as 'the foundation of mental health nursing' (Shatell, McAllister, Hogan & Thomas, 2006, p. 234). However, practical barriers to therapeutic engagement are frequently reported in the literature (e.g. Shatell, Andes & Thomas, 2008; McAndrew, Chambers, Nolan, Thomas & Watts, 2014). Participants acknowledged that building relationships with SUs with ASD requires a great deal of time and consistency, opportunities for which are sparse in an inpatient setting. Despite these obstacles, they described concerted efforts to understand individual patients, which in turn increased their empathy.

Although participants had limited knowledge of ASD, they commented that a formal diagnosis aided their understanding. A shift in nurses' attributions about SUs' behaviour following diagnosis was apparent in several narratives. Weiner (1985) proposed that the perceived causes of others' behaviour influences emotional experiences and subsequently behavioural intentions. People are more likely to feel hostile if they perceive an event to be under the control of another. This appeared to be the case for nurses who were frustrated by their patients' apparent stubbornness. In contrast, uncontrollable causes are associated with pity (Weiner, 1985). When nurses could explain SUs' behaviour in terms of a diagnosis of ASD, they depicted the SU as vulnerable and blameless.

A wealth of literature in the field of nursing demonstrates that the experience of being understood is highly valued by SUs (e.g. Olson & Hanchett, 1997; Shatell *et al.*, 2006). McAndrew *et al.* (2014) added that mental health nurses share this value; they prize their ability to relate to patients through talking, listening and expressing empathy. In the current study, focusing on these values seemed to help participants cope with the difficult task of nursing adults with ASD. On an emotional level, the experience of understanding and empathising counteracted their confusion and frustration. On a practical level, the task was made easier by adjusting their usual ways of working (National Institute for Health and Clinical Excellence (NICE), 2012; Leather & Leardi, 2012).

Nurses seemed more willing to relax their routines when they appreciated their patients' minimal capacity for flexibility.

Participants overcame feelings of helplessness and disempowerment by finding ways to be of benefit to SUs with ASD. In the absence of a treatable mental illness, assuming responsibility for protecting vulnerable individuals gave them a clearly defined role. Teams' collective moral values led them to prioritise their duty of care and safeguarding issues (e.g. prolonging admissions in order to provide safe lodgings). Nurses were able to make an impact on SUs' futures by acting as informal advocates. This role also gave them an outlet for expressing their frustration with the services they perceived to have neglected these individuals. A review of the literature on advocacy in mental health nursing suggests that nursing advocacy has been necessary in the UK because the errors and poor judgement of professionals has decreased SUs' confidence in the healthcare system (Jugessur & Iles, 2009). The role of advocate is traditionally founded in humanistic approaches to empowerment, which is consistent with the fundamental philosophy of nursing (Nursing and Midwifery Council, 2015). However, practising advocacy is not without risks, as nurses may be brought into conflict with carers, colleagues, employers or professional bodies (Jugessur & Iles, 2009). In the current study, nurses described forming a 'united front' with other professionals and advocating for patients as a whole MDT. However, without adequate knowledge of the needs and wishes of their patients,

individual mental health nurses may be open to negative consequences when advocating for SUs with ASD.

2.5.2. Limitations

The current study was conducted with a small, purposive sample, as per IPA guidelines. However, some sampling limitations were noted. Participants were recruited from two staff teams and were therefore colleagues. A number of them described the same SUs and situations. As a result of their relationships and mutual experiences, participants' accounts may reflect the shared understanding of their teams, and the findings cannot be presumed to reflect the experiences of RMNs working in other inpatient services. There was also some variation in participants' level of awareness of autism, which impacted on the findings. Furthermore, six of the seven participants were of White British ethnicity; the experiences of Black and Minority Ethnic nurses are therefore underrepresented.

The principal researcher had no personal or professional affiliations with the staff teams. However, one of the research supervisors was the ward psychologist, who supported the researcher in recruiting nurses for the study. Although participants were assured that their anonymity would be preserved, awareness of their colleague's involvement in the research may have influenced their accounts.

Finally, the analysis of the data was not discussed with participants before the report was prepared, due to time-constraints. Participant validation is sometimes used by qualitative researchers to increase studies' sensitivity to context (Yardley, 2000). However, this is not required as standard in IPA research (Smith *et al.*, 2009).

2.5.3. Clinical implications

The findings suggest that, five years on from the Autism Act 2009, crucial aspects of the autism strategy are yet to be implemented. The most salient issue for nurses in the current study was their lack of knowledge about ASD. Clinical guidance states, *"staff delivering interventions for coexisting mental disorders to adults with autism should have an understanding of the core symptoms of autism and their possible impact on treatment"* (NICE, 2012, p. 30). It is recommended that autism awareness training should be available and accessible to all health and social care staff (DoH, 2010; NICE, 2012). However, none of the participating RMNs had ever come across these opportunities, either pre- or post-qualifying.

All participants expressed a desire to further their knowledge. Their suggestions were in line with recommendations from the national autism strategy (DoH, 2010). Rather than theory-based courses, nurses were keen for training that provided insight into how ASD can affect people on a day-to-day basis. This may be achieved by involving SUs in designing and delivering

training. SU involvement is highly valued in the education of mental health nurses (O'Donnell & Gormley, 2013). The emotive impact of hearing people's lived experiences has been shown to prompt a high level of self-reflection, which facilitates a process of 'transformative learning' (Rush, 2008). SU involvement in training may help promote positive attitudes towards clients with ASD, as well as giving a voice to a group of people who are currently marginalised by health services.

The DoH (2010) calls for autism awareness to become part of the core curricula for all clinicians. However, nurses in the current study valued direct clinical experience over academic teaching. One participant suggested RMN training courses could create such opportunities by incorporating a brief placement in a learning disability service or, where available, a specialist autism service. Likewise, qualified RMNs wishing to develop their skills may benefit from taking up secondments in services with expertise in ASD.

The findings highlight the importance of providing on-going support to staff working with adults with ASD in psychiatric wards. Participants reported benefitting from regular supervision with a clinical psychologist, which enhanced their knowledge of autism, and offered a reflective space to develop their understanding of individual SUs and consider adaptations to their practice. The NICE guidelines state that staff should have access to professionals with expertise in ASD who can provide consultation on cases (NICE, 2012). Clinical

psychologists are ideal candidates for this role, due to their breadth of training and skills in formulating complex presentations. In recent years, their role has developed to place a greater emphasis on indirect clinical work that effects change at a service level. Providing training, supervision and consultation to nursing staff and other colleagues is an effective way of promoting psychological thinking within services, as highlighted in the *'New Ways of Working'* document (British Psychological Society (BPS), 2007).   These competencies should therefore be considered when recruiting clinicians to multidisciplinary teams in acute psychiatric services.

Participants also stressed the value of working together to support SUs with ASD. Nurses enhanced their practice by learning from the expertise of senior colleagues and staff with personal experience. It is therefore important for ward managers to account for the skill mix of the nursing team when assigning care-coordinators and planning duties. Employing peer support workers with lived experience of ASD may also support staff's engagement with autistic SUs.

Finally, the current study provides further insight into a long-standing issue: which services should take responsibility for supporting adults with ASD? Participants' accounts highlighted the vulnerability of people who were unable to access services in the community and had deteriorated to the point of hospitalisation. The DoH (2010) has outlined plans for the creation of specialist ASD services, which are being developed around the UK. Local autism strategy

groups are also working to develop integrated care pathways for people with ASD (NICE, 2012). However, there is currently a postcode lottery with regard to specialist provision for ASD (National Audit Office, 2009), which needs to be addressed by local commissioning groups.

2.5.4. Future research

To the researcher's knowledge, the current study was the first to explore staff's experiences of ASD in mental health services. Further qualitative research could seek to address the limitations noted above, through recruiting RMNs from a range of services. Exploring staff perspectives in the wider system (e.g. other clinicians in acute service MDTs or community mental health teams) may highlight important considerations for developing integrated care pathways for people with ASD. Building on the current study's conclusions regarding staff training on ASD, future research may include local audits of training need. Furthermore, the effectiveness of local training interventions should be evaluated to inform the development of training packages in other services.

2.5.6. Conclusion

The results of this study highlight, not only mental health nurses' lack of knowledge of ASD, but also a lack of opportunities for developing said knowledge. It is essential that NHS bodies fulfil their duty to act under the guidance of the national autism strategy (as per the Autism Act 2009), in order to meet the complex needs of this neglected client group.

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Chapter 3: Reflective Paper

Personal reflections on research with staff: stigma and stereotyping

in mental health services

In preparation for submission to *Reflective Practice* (see Appendix N for author

instructions)

Overall chapter word count (excluding tables, figures and references): 3,750

3.1. Introduction

This thesis has explored health professionals' experiences and attitudes regarding diagnoses that challenge mental health services, namely personality disorder (PD) and autism spectrum disorder (ASD). Neither of these diagnoses falls under the traditional umbrella of mental illness. However, the 2007 amendments to the Mental Health Act 1983 redefined categories of mental disorder and notions of treatability, opening up services for people diagnosed with PD (Sen & Irons, 2010). Similarly, many people with ASD access mental health services in times of distress, partly because specialist services for neurodevelopmental disorders are scarce (Barnard, Harvey, Potter & Prior, 2001). This thesis highlights the challenges staff face when working with SUs with these diagnoses. This final paper contains my reflections on the research process, with a particular focus on stereotyping and stigma in mental health services.

Suffice to say when I was developing ideas for my thesis I did not set out to investigate either psychiatric diagnoses or the experiences of staff. My interest was in ASD, in particular the paucity of support services for adults. The choice to explore this from the perspective of staff was initially a practical one. My clinical supervisor worked closely with a team of mental health nurses and this seemed to be the best way to produce a meaningful piece of research in the time I had available. However, the process of gathering and analysing data led me away from my focus on service users (SUs). Interpretative

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Phenomenological Analysis (IPA) requires the researcher to immerse themselves in participants' stories, to ensure the analysis remains grounded in their lived experiences (Smith, Flowers & Larkin, 2009). In doing so, I gained a rich new perspective on the issue and an interest in how staff manage their experiences of working with marginalised groups. This inspired the topic for my literature review, which focused on training interventions targeting staff attitudes towards people diagnosed with PD, another cohort of SUs who are frequently marginalised in mental health services (National Institute for Mental Health in England (NIMHE), 2003a; Kealy & Ogrodniczuk, 2010).

The research process has facilitated valuable insights into the dynamics between staff and SUs, including some of the barriers to forming collaborative therapeutic relationships. In this paper, I will discuss my reflections on stigmatising attitudes amongst mental health professionals, including the evolution of my own perspective as a staff member. I will also consider how I plan to take these insights forward to improve my future practice, including thoughts on the potential role of clinical psychologists in supporting staff.

3.2. Preconceptions

3.2.1. *'Rain Man'*: stereotypes of autism

My interest in adults with ASD was initially sparked by my personal experience of having a relative with Asperger's syndrome (DSM-IV-TR; American Psychiatric Association, 2000) who was not diagnosed until his late 40s. I recall that

nobody in my family was surprised when the diagnosis was eventually made; our relative does in fact fit the classic stereotype of Asperger's syndrome that pervades public perceptions – obsessive coin-collector, train-enthusiast, socially inept, but blessed with mathematical genius and a savant-like memory for detail. The diagnosis of ASD made sense and seemed to bring relief, for him, and for family members who had so often worried about his wellbeing.

Years later, I worked as an assistant psychologist in a forensic inpatient service, mainly based on a ward for adults with high-functioning ASD. Despite my previous experience and interest in ASD, it was here that I began to challenge the stereotypical perception that I held. In my daily interactions with eighteen patients, each with distinct strengths, vulnerabilities, personalities and idiosyncrasies, it occurred to me that no two people with autism are the same, just as no two 'neuro-typical' people are the same. This didn't feel like a particularly sophisticated revelation even at the time, but it went against everything I had learned. At university, I had been taught about theories and common traits that unified people with ASD. I volunteered at a special school, where I noticed similarities in the mannerisms and behaviours of autistic children. And of course, I was subject to the media's standard portrayal of people with autism as asocial and odd, a view that was confirmed by having a relative who could indeed be likened to *'Rain Man'* (Levinson, 1988) or the protagonist in *'The Curious Incident of the Dog in the Night-time'* (Haddon, 2003).

A qualitative study investigating depictions of autism in British newspapers highlights the media's tendency to present ASD in "a homogenised way that fails to recognise human diversity" (Huws & Jones, 2010, p. 102). Reading the article now, on completion of this thesis, it is the word 'human' that stands out. When talking to nurses about their experiences of caring for adults with ASD, I got a strong sense of them having to work hard to see these SUs as human beings. Their patients' world views were so separate from their own that they seemed almost alien. This is reminiscent of Oliver Sack's account of meeting Dr Temple Grandin, a renowned professor and author with a diagnosis of autism, who famously described herself as "an anthropologist on Mars" (Sacks, 1995, p. 259). Sacks describes how Grandin firmly distinguishes herself from "normal" people, curiously observing them from a disconnected outsider's perspective (p. 275). The extraordinary workings of Grandin's mind are noted; extremely keen visual skills, memory and attention for detail, but also a distinct lack of emotional responses and a reduced capacity for empathy (Sacks, 1995). In my study, participants' inability to understand the inner world of autistic SUs was a huge source of frustration. Some of their accounts implied that they felt irritated or manipulated by patients, which reminded me of the ways in which I have heard colleagues discuss SUs diagnosed with PD.

3.2.2. "Oh God, not her again": perceptions of personality disorder

As noted earlier, the choice to review literature regarding staff attitudes towards PD was inspired by participants' accounts of their struggle to connect with SUs. When I started to read relevant articles, I was far from surprised by the negative perceptions of PD that are widespread in mental health services. This is highlighted by the following extract from the reflective journal that I kept throughout the research process:

> *"I feel like I should be shocked or outraged by some of the things*
>
> *I'm reading but it's all so familiar. I've heard plenty of colleagues*
>
> *I liked and respected talk about patients in this way...maybe I was*
>
> *too accepting of it at the time."*

My first job in mental health services was as a support worker in a community-based team that was frequently accessed by people diagnosed with PD. I quickly became aware of an undercurrent of hostility towards these SUs, who were deemed 'manipulative' and 'attention-seeking'. Some senior colleagues seemed to express the opinion that people with PD should not be entitled to a crisis intervention service because PD "is not mental illness." As noted, this view is no longer endorsed by mental health policies. The publications of *'No Longer a Diagnosis of Exclusion'* (NIMHE, 2003a) and *'Breaking the Cycle of Rejection'* (NIMHE, 2003b) were intended to ensure fair access to services for people diagnosed with PD. However, the literature I reviewed indicates that some professionals still hold these beliefs. Pejorative attitudes such as these

are summed up by Lewis and Appleby (1988), who state, *"Those labelled as personality disordered appear to be denied the benefits of being regarded as ill, but also denied the privilege of being regarded as 'normal'"* (p. 48).

I recall feeling uncomfortable with how certain clients were demonised; however, as a young and inexperienced staff member, I was not inclined to challenge my superiors' firm beliefs. I also suspect my reflections on this experience are distorted by a self-presentation bias, as I regret to acknowledge having shared this prejudice at times. I have certainly been guilty of immediately thinking, "Oh God, not her again" on receiving a referral about a SU in crisis. The obvious explanation for such a reaction is that my prior experience of the client had been challenging. The sheer intensity of her emotional expressions had evoked strong feelings in me and I felt intruded upon. Working in a service with no psychological input, I was ill-equipped to understand and manage this experience of countertransference, so I attributed my feelings to the client's diagnosis, with little consideration of her as a person. It wasn't until I moved to the forensic service and became privy to a more psychological notion of PD that I was able to recognise my error. I had been swept up in the culture of a team whose construction of PD was one of moral and value judgements rather than clinical ones (Aviram, Brodsky & Stanley, 2006).

Wright, Haigh and McKeown (2007) describe this as 'otherness', whereby people with PD are cast as different, unworthy, even inhuman. This undoubtedly reflects the attitude of my former team, which was comprised of individuals whom I considered to be generally caring and professional. Likewise, I could not question the compassion or good intentions of my research participants, who expressed elements of 'otherness' in their descriptions of patients with ASD. It occurred to me that staff's difficulties in connecting with certain groups of SUs are perhaps rooted in their emphasis of difference, which leads to a denial of common humanity (Wright *et al.*, 2007).

3.3. Iatrogenic stigma in mental health services

The issue of 'otherness', raised by both my literature review and empirical research, led me to reflect more broadly on the stigmatisation of SUs by mental health professionals, a phenomenon that has been termed 'iatrogenic stigma' (Sartorius, 2002). This was first prompted by my interview with Sally, an experienced senior nurse who also had a family connection to someone with ASD. Sally described a SU whose long-standing diagnosis of PD had recently been replaced with one of autism:

> *"People present as quite demanding and all that when they've*
>
> *got personality disorders, people will talk about, you know, you're*
>
> *doing it for attention and all the rest of it. And I think that maybe*
>
> *a few people felt that this autism thing was just attention*
>
> *seeking. You know, now she'd got this label and all of a sudden*

we was putting weighted blankets on her and doing this and doing that and she was just getting the attention that she wanted anyway." (Sally, line 254)

Sally expressed her view that sometimes professionals dismiss a diagnosis of autism as a reason for poor behaviour. This is akin to a widely held belief that the behaviours of people with PD are under their voluntary control and therefore manipulative (Lewis & Appleby, 1988). Indeed, attributions of control and responsibility are often associated with staff's social rejection of psychiatric SUs (e.g. Feldman & Crandell, 2007). After the interview with Sally, I wrote the following in my reflective journal:

"I think of ASD and PD as fundamentally different, but I can see how staff might experience them similarly if they perceive that the client is just being difficult. Regardless of which diagnosis was correct, it sounds like Sally's colleagues were responding to what they knew about the labels rather than the actual person."

3.3.1. The power of diagnostic labels

Sartorius (2002) suggests that a major source of iatrogenic stigma is the "careless use of diagnostic labels" (p. 1470). Indeed, it could be argued that assigning someone to a particular category of mental disorder is the first step towards 'otherness'. Sally's account, in addition to the literature on staff attitudes, highlights negative connotations of PD. As discussed, these are

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consistent with my own experiences of working in mental health services.

Having been through a process of recognising and challenging my own negative

assumptions about clients diagnosed with PD, I was extremely conscious of

wanting to be sensitive and respectful when it came to writing up my literature

review. I read with increasing discomfort as the papers I was reviewing

frequently referred to 'PD patients' or, even more bluntly, 'borderline patients',

and I vowed not to do the same. However, I found it extremely challenging to

completely avoid using pejorative labels whilst trying to write clearly and

succinctly. As much as I wanted to emphasise the human beings beneath the

label, repeated use of 'individuals diagnosed with personality disorder' was not

conducive to my word limit.

Interestingly, I did not experience the same internal battle when writing my

empirical paper. I felt entirely comfortable using the words 'autism' and

'autistic', as well as the acronym 'ASD'. I came to the research process fully

aware that I was in favour of labelling people with ASD; my interest in detecting

and supporting adults on the spectrum was, after all, the basis of my project.

This undoubtedly influenced my subjective position as a researcher, and the

extent of this potential bias was brought to my attention during a bracketing

interview that I arranged before I began interviewing participants. As a result, I

made efforts to reflect on my preconceptions about the benefits of diagnosis, in

order to remain open to alternative views. Natalie, for example, expressed her

opinion that a diagnosis of ASD *"closed a lot of doors"* (line 185) for a particular

SU. Following this line of enquiry provided rich data regarding the current state of local services for people with ASD, which may not have been gathered had I paid less attention to her view.

The inconsistency in my feelings about different diagnostic labels was an interesting subject for reflection. My previous experiences had made me acutely aware of the stigma that a label of PD carries, whereas I saw a label of ASD as an opportunity for understanding. However, I was shocked by how little my participants knew about autism, which limited their understanding and left them feeling anxious about SUs who were, to them, 'unknown quantities'. Likewise, my literature review highlighted that stigmatising attitudes towards PD are inevitable when staff are unaware of its basis in childhood adversity and trauma. Through the research process, I came to appreciate that any label can be harmful if the people it affects – SUs, carers and staff alike – don't have adequate knowledge of its meaning. With this in mind, I almost certainly underestimated the potential for stigma regarding ASD. Indeed, SUs who do not identify with society's stereotypes of autism may experience these as stigmatising (Huws & Jones, 2008; MacLeod, Lewis & Robertson, 2013), as the discrepancy between one's personal and social identities can evoke a negative experience of 'spoiled identity' (Goffman, 1963).

3.3.2. 'Difficult patients'

Another aspect of stigma that was apparent in both papers was the notion of 'difficult patients'. On considering what ASD and PD might have in common, I reflected that neither group of SUs conform to the typical expectations of staff and services. Several of the nurses who participated in my empirical study referred to autistic SUs' 'refusal' to engage, either with the staff team or with their prescribed treatment programme. Likewise, a dominant theme in the literature on staff attitudes towards PD was the notion that patients are 'difficult' and 'controlling', that they 'push boundaries' in order to engage 'on their own terms'. In each case, responsibility for the perceived 'difficulty' was attributed to the SU and their behaviour. However, Hinshelwood (1999) points out that the term 'difficult' is not a valid clinical category, but a value judgement that professionals use to describe their own emotional state during an interaction with a client. He suggests that so-called 'difficult patients' are those that do not complement the professional's helping role, either because they do not inhabit the same world of meaning, or because the patient does not acknowledge them as a helper. Indeed, in my empirical study, nurses commented that SUs with ASD lived "in their own world", to which they could not relate. In the case of people diagnosed with PD, the helping role is perhaps obstructed by SUs' inherent suspicion of those who try to help (Hinshelwood, 1999). Hinshelwood (1999) suggests that when staff members' professional identities are threatened, they "retreat into a scientific attitude" (p. 188). Maintaining an objective stance may protect staff from experiencing those

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unwanted, subjective feelings of 'difficulty' that patients evoke. However, I would argue that this emotional withdrawal surely removes the possibility of building a genuine therapeutic relationship with these clients.

Reflecting once more on my experience in forensic services, I thought about how SUs' progress and ultimately their liberty were dependent on a prescribed level of engagement. The responsibility for engaging was placed firmly on the patient and seen as an indication of their commitment to change. However, I often wondered whether the positive engagement we observed was merely compliance. Essential conditions for a good therapeutic relationship are considered to be empathy, genuineness and unconditional positive regard (Rogers, 1951). Given the prevalence of iatrogenic stigma in mental health services, I wonder how often this is experienced by SUs whose difficulties are primarily interpersonal (e.g. those diagnosed with PD or ASD). It seems that many professionals have expectations of how SUs should engage with them, rather than of how they might work towards engaging the SU. This was apparent in the analysis of my empirical study; 'incompatibility' emerged as a theme, referring to participants' views about a mismatch between ASD and acute inpatient services. However, their narratives indicated that the problem of incompatibility lay in SUs' inability to adapt to the ward environment, rather than the ward's inability to meet SUs' needs.

3.3.3. The cultural context of health services

The issues raised above have important implications for health services in general. In recent years, examples of failings in the healthcare system have thrown light on the potentially devastating consequences of putting services' needs ahead of clients' needs. The enquiry into unacceptable standards of care in Mid Staffordshire NHS Foundation Trust cites one of the causes as, *"a culture of doing the system's business – not that of the patients"* (Francis, 2013, p. 4). Meeting financial and waiting list targets was prioritised over clinical duties, leading staff to treat patients with "callous indifference" (p. 13). In the current NHS climate, with services under pressure to demonstrate their efficiency, it may be difficult for staff and teams to invest in a person-centred, compassionate approach to working with difference. Reducing stigma in mental health services therefore requires a whole-organisation culture of putting clients' needs first, supported by NHS managers.

3.4. Changing perspectives

As discussed, the research process has facilitated important developments in my perspective on stigma and stereotyping in mental health services. Coincidentally, around the time I was having these insights, two of my close friends took to social media to share their stories of mental distress during their adolescence, inspired by the 'Time to Change' anti-stigma campaign. Reading that people I cared about had felt isolated in their distress had an emotional impact, and reinforced my thoughts about the importance of establishing

genuine, empathic connections with SUs. Engaging with an individual's personal meaning of their story, rather than an assumed meaning based on their diagnosis, is surely the most powerful and immediate way of reducing their experiences of stigma. This is summarised by Eleanor Longden, a research psychologist and former psychiatric SU, who talks about her recovery after years of ineffective treatments for psychosis: *"An important question in psychiatry shouldn't be what's wrong with you but rather what's happened to you"* (Longden, 2013, 10:40).

This person-centred approach to clinical practice was highlighted in the analysis of my empirical study. Nurses coped with their negative experiences of working with people with ASD by working hard to understand each SU as an individual. Throughout my training, I have strived to maintain the same attitude, which has allowed me to build positive therapeutic relationships with clients. However, I am aware of my privileged position as a Trainee Clinical Psychologist. In the past three years, I have had ample time, space and encouragement to constantly reflect on my thoughts and feelings towards clients. I have been able to take any particularly negative reactions to supervision, where I have been supported to consider their meaning in relation to both the client's experience and my own. I am in a small minority of staff who are able to access such intensive support.

I return to my description of the community team full of caring, well-intentioned professionals who were unable to overcome their negative countertransference regarding SUs diagnosed with PD. With the insights I have gained through the research process, I firmly believe their stigmatising attitudes resulted from having no adequate support systems in place to help them recognise, understand and cope with their strong emotions towards these SUs.

3.4.1. A role for clinical psychologists

The issues discussed in this paper highlight some important roles for clinical psychologists. The *'New Ways of Working'* document outlines ways of promoting psychological thinking within services, to enhance team-working and individual service planning (British Psychological Society (BPS), 2007). With regard to SUs who are vulnerable to stigma and stereotyping, psychologists are well placed to facilitate peer-consultation and reflective practice, supporting colleagues to challenge their negative attitudes and consider the client as an individual. Likewise, psychologists can support workforce development by offering training about conditions like ASD that are poorly understood within mental health services. Furthermore, psychologists can use their skills to support SUs in finding a voice and becoming involved in service planning and provision (BPS, 2007).

3.5. Conclusion

Although I did not set out to study the dynamics between mental health staff and SUs, the most important thing I have learned in this process is how closely intertwined their experiences are. I was already aware of how the quality of the therapeutic relationship can impact on clients; however, I have come to appreciate that the same is true for staff. I have also gained a greater respect for the very difficult jobs of our colleagues – particularly nursing staff – who work tirelessly to do their best for SUs with very little supervision or support. I intend to take this forward into my clinical practice and seek out opportunities to work collaboratively with colleagues. The research process has therefore helped confirm some of my thoughts about the way I would like to work when qualified, as supporting staff through challenging encounters with clients have been some of the most enjoyable and rewarding experiences of my clinical training. Finally, the research process has heightened my awareness of stigma and stereotyping within mental health services. I will endeavour to maintain this and to challenge instances of iatrogenic stigma in the services I work in.

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Appendix A

Author instructions for *Clinical Psychology Review*

PREPARATION
Use of word processing software
It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.
To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure
Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.
Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.
It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (http://www.prisma-statement.org/statement.htm) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Appendices
If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. *Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.*

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

Corresponding author. Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication.

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address"' (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in
the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References
Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from http://books.apa.org/ books.cfm?id=4200067 or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference style
References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. *References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).*
Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.
Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).
Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

Appendix B

Quality assessment checklist and guidance

Quality assessment criteria; *guidance in italics* (questions specific to type of methodology are shaded)	Score: Yes/Partial/No
1. Does the title reflect the content? *The title should be informative and indicate the focus of the study. It should allow the reader to easily interpret the content of the study. An inaccurate or misleading title can confuse the reader.*	
2. Are the authors credible? *Researchers should hold appropriate academic qualifications and be linked to a professional field relevant to the research.*	
3. Does the abstract summarise the key components? *The abstract should provide a short summary of the study. It should include the aim of the study, outline of the methodology and the main findings. The purpose of the abstract is to allow the reader to decide if e study is of interest to them.*	
4. Is the rationale for undertaking the research clearly outlined? *The author should present a clear rationale for the research, setting it in context of any current issues and knowledge of the topic to date.*	
5. Is the literature review comprehensive and up to date? *The literature review should reflect the current state of knowledge relevant to the study and identify any gaps or conflicts. It should include key or classic studies on the topic as well as up to date literature. There should be a balance of primary and secondary sources.*	
6. Is the aim of the research clearly stated? *The aim of the study should be clearly stated and should convey what the researcher is setting out to achieve.*	
7. Are all ethical issues identified and addressed? *Ethical issues pertinent to the study should be discussed. The researcher should identify how the rights of informants have been protected and informed consent obtained. If the research is conducted within the NHS then there should be indication of Local Research Ethics committee approval.*	

8. Is the methodology identified and justified? *The researcher should make clear which research strategy they are adopting, i.e. qualitative or quantitative. A clear rationale for the choice should also be provided, so that the reader can judge whether the chosen strategy is appropriate for the study.*	
Quantitative method	
9a. Is the study design clearly identified, and is the rationale for choice of design evident? *The design of the study, e.g. survey, experiment, should be identified and justified. As with the choice of strategy, the reader needs to determine whether the design is appropriate for the research undertaken.*	
10a. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined? *In experimental research, the researcher should provide a hypothesis. This should clearly identify the independent and dependent variables, and state their relationship and the intent of the study. In survey research the researcher may choose to provide a hypothesis, but it is not essential, and alternatively a research question or aim may be provided.*	
11a. Is the population identified? *The population is the total number of units from which the researcher can gather data. It may be individuals, organisations or documentation. Whatever the unit, it must be clearly identified.*	
12a. Is the sample adequately described and reflective of the population? *Both the method of sampling and the size of the sample should be stated so that the reader can judge whether the sample is representative of the population and sufficiently large to eliminate bias.*	
13a. Is the method of data collection valid and reliable? *The process of data collection should be described. The tools or instruments must be appropriate to the aims of the study and the researcher should identify how reliability and validity were assured.*	
14a. Is the method of data analysis valid and reliable? *The method of data analysis must be described and justified. Any statistical test used should be appropriate for the data involved.*	
Qualitative method	
9b. Are the philosophical background and study design identified and the rationale for choice of design evident? *The design of the study, e.g. phenomenology, ethnography, should be identified and the philosophical background and rationale discussed. The reader needs to consider if it is appropriate to meet the aims of the study.*	

10b. Are the major concepts identified? *The researcher should make clear what the major concepts are, but they might not define them. The purpose of the study is to explore the concepts from the perspective of the participants.*	
11b. Is the context of the study outlined? *The researcher should provide a description of the context of the study, how the study sites were determined and how the participants were selected.*	
12b. Is the selection of participants described and the sampling method identified? *Informants are selected for their relevant knowledge or experience. Representativeness is not a criteria and purposive sampling is often used. Sample size may be determined through saturation.*	
13b. Is the method of data collection auditable? *Data collection methods should be described, and be appropriate to the aims of the study. The researcher should describe how they have assured that the method is auditable.*	
14b. Is the method of data analysis credible and confirmable? *The data analysis strategy should be identified, what processes were used to identify patterns and themes. The researcher should identify how credibility and confirmability have been addressed.*	
15. Are the results presented in a way that is appropriate and clear? *Presentation of data should be clear, easily interpreted and consistent.*	
16. Is the discussion comprehensive? *In quantitative studies the results and discussion are presented separately. In qualitative studies these maybe integrated. Whatever the mode of presentation the researcher should compare and contrast the findings with that of previous research on the topic. The discussion should be balanced and avoid subjectivity.*	
17. Are the results generalizable/transferable?	
18. Is the conclusion comprehensive? *Conclusions must be supported by the findings. The researcher should identify any limitations to the study. There may also be recommendations for further research, or if appropriate, implications for practice in the relevant field.*	
Score out of 36 (single method) or 48 (mixed method)(%)	

Appendix C

Summary of quality assessment checklist results

Qualitative studies	Schafer *et al.* (2013)
1. Does the title reflect the content?	Yes
2. Are the authors credible?	Yes
3. Does the abstract summarise the key components?	Yes
4. Is the rationale for undertaking the research clearly outlined?	Yes
5. Is the literature review comprehensive and up to date?	Yes
6. Is the aim of the research clearly stated?	Yes
7. Are all ethical issues identified and addressed?	Yes
8. Is the methodology identified and justified?	Yes
9. Are the philosophical background and study design identified and the rationale for choice of design evident?	Yes
10. Are the major concepts identified?	No
11. Is the context of the study outlined?	Yes
12. Is the selection of participants described and the sampling method identified?	Partial
13. Is the method of data collection auditable?	Yes
14. Is the method of data analysis credible and confirmable?	Yes
15. Are the results presented in a way that is appropriate and clear?	Yes
16. Is the discussion comprehensive?	Yes
17. Are the results transferable?	Partial
18. Is the conclusion comprehensive?	Yes
Score out of 36 (%)	**32 (89%)**

Quantitative studies	Commons-Treloar & Lewis (2008)	Commons-Treloar (2009)	Krawitz (2004)	Lamph *et al.* (2014)	Miller & Davenport (1996)	Rogers & Acton (2011)	Shanks *et al.* (2011)
1. Does the title reflect the content?	Partial	Partial	Yes	Yes	Yes	Yes	Yes
2. Are the authors credible?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Does the abstract summarise the key components?	Yes	Yes	Yes	Yes	Yes	No	Yes
4. Is the rationale for undertaking the research clearly outlined?	Yes	Yes	Yes	Yes	Yes	Partial	Yes
5. Is the literature review comprehensive and up to date?	Yes	Partial	Yes	Yes	Yes	Yes	Yes
6. Is the aim of the research clearly stated?	Yes	Yes	Yes	Yes	Yes	No	Yes
7. Are all ethical issues identified and addressed?	Yes	Yes	No	No	No	No	Partial
8. Is the methodology identified and justified?	Partial	Partial	No	Partial	Partial	No	No
9. Is the study design clearly identified, and is the rationale for choice of design evident?	No	No	No	Partial	Yes	No	No
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	No	No	Yes	No	Partial	No	Partial
11. Is the population identified?	Yes	Yes	Yes	Yes	Yes	Partial	Partial
12. Is the sample adequately described and reflective of the population?	Yes	Yes	Yes	Yes	Yes	No	Yes
13. Is the method of data collection valid and reliable?	Partial	Partial	No	Yes	Yes	Partial	Partial
14. Is the method of data analysis valid and reliable?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15. Are the results presented in a way that is appropriate and clear?	Yes	Partial	Yes	Partial	Yes	Yes	Yes
16. Is the discussion comprehensive?	Yes	Partial	Yes	Partial	No	Partial	Yes
17. Are the results generalizable?	Yes	Partial	Yes	Partial	Yes	Partial	Partial
18. Is the conclusion comprehensive?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Score out of 36 (%)	**29 (81%)**	**25 (69%)**	**28 (78%)**	**26 (72%)**	**32 (89%)**	**15 (42%)**	**27 (75%)**

Mixed method studies (questions specific to type of methodology are shaded)	Clarke *et al.* (2014)	Davies *et al.* (2014)	Hazelton *et al.* (2006)
1. Does the title reflect the content?	Yes	Yes	Yes
2. Are the authors credible?	Yes	Yes	Yes
3. Does the abstract summarise the key components?	Yes	Yes	Yes
4. Is the rationale for undertaking the research clearly outlined?	Yes	Yes	Partial
5. Is the literature review comprehensive and up to date?	Yes	Partial	Partial
6. Is the aim of the research clearly stated?	Yes	Partial	Partial
7. Are all ethical issues identified and addressed?	Partial	No	Partial
8. Is the methodology identified and justified?	Yes	Yes	No
Quantitative method			
9a. Is the study design clearly identified, and is the rationale for choice of design evident?	Yes	Yes	Partial
10a. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	Partial	No	No
11a. Is the population identified?	Yes	Yes	Yes
12a. Is the sample adequately described and reflective of the population?	Yes	Yes	Yes
13a. Is the method of data collection valid and reliable?	Yes	Yes	Partial
14a. Is the method of data analysis valid and reliable?	Yes	Yes	No
Qualitative method			
9b. Are the philosophical background and study design identified and the rationale for choice of design evident?	No	Partial	No
10b. Are the major concepts identified?	No	No	Partial
11b. Is the context of the study outlined?	Yes	Yes	Yes
12b. Is the selection of participants described and the sampling method identified?	Yes	No	No
13b. Is the method of data collection auditable?	Partial	Partial	No
14b. Is the method of data analysis credible and confirmable?	Partial	Yes	No
15. Are the results presented in a way that is appropriate and clear?	Yes	Yes	Partial
16. Is the discussion comprehensive?	Yes	Partial	No
17. Are the results generalizable/transferable?	Yes	Partial	No
18. Is the conclusion comprehensive?	Yes	Yes	Partial
Score out of 48 (%)	**40 (83%)**	**34 (71%)**	**21 (44%)**

Appendix D

Author instructions for *Issues in Mental Health Nursing*

Issues in Mental Health Nursing conforms to the guidelines of the Publication Manual of the American Psychological Association (2010) regarding plagiarism and self-plagiarism. To wit, "Just as researchers do not present the work of others as their own (plagiarism), they do not present their own previously published work as new scholarship (self-plagiarism) (American Psychological Association, 2010, p. 16). The potential for self-plagiarism is greatest when several aspects of a study are reported in different articles. To avoid this ethical violation, make sure that each article makes a unique contribution to the science. Clearly delineate where other articles about the study have been reported. Extensive duplication of one's own words (for example, in a methods section) requires a citation of the previously published work.

IMHN also conforms to the criteria for authorship specified by the American Psychological Association (2010, p. 18): "Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed." Please specify, in your cover letter, the role played by each author on the project (for example, formulated the hypothesis, collected data, participated in data analysis, wrote part of the paper). Individuals who did not play a major role (e.g., recruiting subjects, data entry) should be listed in "Acknowledgments," but not credited with authorship.

All papers should be submitted via the journal's online Manuscript Central site http://mc.manuscriptcentral.com/umhn. Microsoft Word files are best for the text of the document. Tables and figures should be submitted as separate individual files. Manuscript and other requirements conform to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" established by the International Committee of Medical Journal Editors (N Engl J Med 1991;324:424-8).

Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher. All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text.

Declaration of interest. It is the policy of all Informa Healthcare, to adhere in principle to the Conflict of Interest policy recommended by the International Committee of Medical Journal Editors (ICMJE). (http://www.icmje.org/index.html#conflict)

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. It is the sole

responsibility of authors to disclose any affiliation with any organization with a financial interest, direct or indirect, in the subject matter or materials discussed in the manuscript (such as consultancies, employment, paid expert testimony, honoraria, speakers bureaus, retainers, stock options or ownership, patents or patent applications or travel grants) that may affect the conduct or reporting of the work submitted. All sources of funding for research are to be explicitly stated. If uncertain as to what might be considered a potential conflict of interest, authors should err on the side of full disclosure.

All submissions to the journal must include full disclosure of all relationships that could be viewed as presenting a potential conflict of interest. If there are no conflicts of interest, authors should state that there are none. This must be stated at the point of submission (within the manuscript after the main text under a subheading "Declaration of interest" and where available within the appropriate field on the journal's Manuscript Central site). This may be made available to reviewers and will appear in the published article at the discretion of the Editors or Publisher.

If no conflict is declared, the following statement will be attached to all articles:

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

The intent of this policy is not to prevent authors with these relationships from publishing work, but rather to adopt transparency such that readers can make objective judgments on conclusions drawn.

References. Cite in the text by author and date (Smith, 1983). Prepare reference list in accordance with the APA Publication Manual, 6th ed. Examples:

Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. Archives of Sexual Behaviour, 7(6), 417–427.

Book: Millman, M. (1980). Such a pretty face. New York: W. W. Norton.

Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), Ageing in the 1980s (pp. 239–252). Washington, DC: American Psychological Association.

Illustrations. Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.)should be digital files for highest quality reproduction and should follow these guidelines: 300 dpi or higher

Sized to fit on journal page

Submitted as separate files, not embedded in text files

EPS, TIFF, or PSD format only

Tables and Figures. Tables and figures (illustrations) should not be embedded in the text, but should be included as separate files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double spaced, in a separate file.

Proofs. Page proofs are sent electronically to the designated author. They must be carefully checked and returned within 48 hours of receipt.

Appendix E

Confirmation of Coventry University ethical approval

Mental health nurses' experiences of working with adults with Autism Spectrum Disorders   P20209

REGISTRY RESEARCH UNIT
ETHICS REVIEW FEEDBACK FORM
(Review feedback should be completed within 10 working days)

Name of applicant: Rachel Squires...................................

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: Mental health nurses' experiences of working with adults with Autism Spectrum Disorders

Comments by the reviewer

1. Evaluation of the ethics of the proposal:
A clear rationale is provided for the study, which overall is ethically appropriate.

2. Evaluation of the participant information sheet and consent form:
In the participant information sheet, under the heading "Are there any potential risks of participating in the study?", it is stated that if the participant becomes distressed during the interview, "...You will be given immediate support". It is not the role of a researcher or any member of the research team to provide immediate support to a distressed participant. Instead, any distressed participant should be signposted to an appropriate source of support, such as their GP. This should be made clear on the participant information sheet, to ensure that participants clearly understand the role of the researcher and to avoid any perception that the researcher may be able to provide support. In addition, there does not appear to be a need to provide other "...information about further support you may wish to access.." other than signposting to GP, unless there is a dedicated staff support service available, in which case the information about this service should appear in the participant information sheet.

The consent form is ethically appropriate, though it is recommended a specific date in February 2015 is given, to indicate the final date by which participants can withdraw from the study (this should be amended on both the consent form and the partici |

3. Recommendation:
(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

X	Approved - no conditions attached
	Approved with minor conditions (no need to re-submit)
	Conditional upon the following – please use additional sheets if necessary (please re-submit application)
	Rejected for the following reason(s) – please use other side if necessary
	Not required

Name of reviewer: Anonymous..

Date: 03/04/2014..

Rachel Squires   Page 1 of 1   03 May 2015

Appendix F

Confirmation of Worcestershire Health and Care NHS Trust R&D approval

Worcestershire Health and Care **NHS**
NHS Trust

Research & Development
Worcestershire Health and Care NHS Trust
Isaac Maddox House
Shrub Hill Road
Worcester
WR4 9RW

Tel: 01905 681514

Samantha.Whitby@hacw.nhs.uk
www.hacw.nhs.uk

16 October 2014

Rachel Squires

Dear Rachel,

Project Title: Mental health nurses' experiences of working with adults with Autism Spectrum Disorder
Our R&D Ref: 14_134_NP
REC Ref: N/A

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Worcestershire Health and Care NHS Trust, and details of your study have been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Participant Information Sheet	2	19/09/2014
Consent form	2	19/09/2014
Demographic questionnaire	-	19/09/2014
Revised research protocol	-	19/09/2014
Interview schedule	-	19/09/2014
Debriefing information sheet	-	19/09/2014

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events and to ensure that they are reported according to the Trust Adverse Incident policy, where

Page **1** of **2**

required. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely,

Sam Whitby
Audit, Research & Clinical Effectiveness Manager

Appendix G

Participant information sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

Mental health nurses' experiences of working with adults with Autism Spectrum Disorders

Participant Information Sheet

This research study is part of a Doctorate in Clinical Psychology. Please take time to read the following. If you are interested in participating, please contact the main researcher directly (details at the end of this sheet) or notify Tim Lacey who will ask them to contact you. Participation in this study is entirely voluntary and will have no impact upon your work.

What is the purpose of the study?
This study aims to investigate the experiences of frontline staff of working with adults with autism spectrum disorders (ASD) in mental health hospitals. Its particular focus will be on how staff members understand and respond to service users whose difficulties have not previously been recognised as owing to ASD, and how this new diagnosis impacts on staff members' work with these service users.

Why have I been asked to take part?
All Registered Mental Health Nurses (RMNs) working in acute inpatient wards within Worcestershire Health and Care NHS Trust who have experience of working with adults with ASD have been contacted to request their participation in the study.

What would I have to do?
If you choose to participate, the researcher will meet with you at your place of work, at a time that is convenient for you. You will be asked to sign a consent form to confirm your agreement to participate in the study, and you will be given a copy to keep.

The researcher will then conduct an interview with you, which will be digitally recorded and will last approximately one hour. You will be asked about your experiences of and views on working with adults with ASD. You will also be asked to complete a demographic information sheet, which will ask for the following information: age, gender, ethnicity, job title, professional qualification, length of time qualified, and length of time in current role.

Are there any potential risks of participating in the study?
As with most research, it is possible that participation will raise issues that you may find difficult or emotive. The interview schedule focuses on professional experiences, which will hopefully minimise

the risk. However, should this occur, the interview can be terminated. You will have the opportunity to reflect on the experience and raise any queries or concerns after the interview.

What will happen to the information I provide?
All data will be kept confidential and used for the sole purpose of the study. Data will be made anonymous promptly after collection and identified by a participant code. All data will be stored in locked cabinets at secure Coventry University or NHS sites. Any electronic data will be kept on encrypted memory devices or password protected computers.

Your interview recording will be transcribed and then promptly destroyed. You will be given a copy of your transcript to read and confirm that the information in it accurately represents your experience. The transcription will be analysed along with those of other participants. The main researcher may share your anonymised data with the other members of the research team and a peer supervision group to ensure reliability of analysis. However, only the main researcher will know you name and contact details. Some interview quotes may be used in the final report but the researcher will ensure that you are not personally identifiable from any quotes used.

What will happen to the results of this study?
It is hoped that findings of the study will be published in a peer reviewed journal. A final report will be submitted to Coventry University as part of the researcher's doctorate course and you will be offered a summary of the findings upon completion in June 2015.

What if I change my mind and no longer want to participate?
Participation in this study is entirely voluntary. You can withdraw your consent by contacting the main researcher, and any information you have provided will be destroyed. You will not have to provide a reason and your work will not be affected. You may withdraw from the study at any time up until completion of the analysis by the end of February 2015.

Who is the organising and funding the research?
This study is being jointly organised by Rachel Squires (Trainee Clinical Psychologist, Universities of Coventry and Warwick) and Tim Lacey (Clinical Psychologist, Worcestershire Health and Care NHS Trust). No payment is being received by any of the organisers for conducting this study.

Version 1

<u>Who has reviewed this study?</u>
All research is reviewed by a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed by the Coventry University Research Ethics Committee and the Worcestershire Health and Care NHS Trust R&D department.

<u>Who can I contact for further information?</u>
Thank you for taking the time to read this information sheet. I hope it has been helpful for you in deciding whether you wish to participate. If you have any queries or would like to discuss the study further, please contact the main researcher, Rachel Squires, or another member of the research team.

Chief Investigator: Rachel Squires, Trainee Clinical Psychologist.
Clinical Psychology Doctorate, James Starley Building, Coventry University, Coventry, CV1 5FB
Email: squires3@uni.coventry.ac.uk

Clinical Supervisor: Tim Lacey, Clinical Psychologist.
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Email: Tim.Lacey@hacw.nhs.uk

Academic Supervisor: Jo Kucharska, Clinical Director
Clinical Psychology Doctorate, James Starley Building, Coventry University, Coventry, CV1 5FB
Email: aa3539@coventry.ac.uk

You may also visit the National Institute for Health Research website for further information about clinical research: www.nihr.ac.uk

Version 1

Appendix H

Consent form

THE UNIVERSITY OF WARWICK   Coventry University

Mental health nurses' experiences of working with adults with Autism Spectrum Disorders

Participant Consent Form

Please read the points below and initial each box to indicate that you understand and agree to each point before signing and dating at the bottom of the page.

☐ I confirm that I have read and understood the Participant Information Sheet for the above study and have been given the opportunity to ask any questions or raise any issues with the researcher.

☐ I agree to participate in the above study.

☐ I give permission for my interview to be digitally recorded, transcribed and used anonymously for the purposes of the research.

☐ I give permission for the main researcher to share my anonymous data with the wider research team as identified on the Participant Information Sheet and a peer supervision group for analysis purposes.

I understand the following:

☐ That all information will be treated as anonymous. I will not be identifiable from any findings published or to anyone other than the main researcher.

☐ That my participation is voluntary and I can withdraw my consent at any time up until completion of the data analysis (28th February 2015).

_____   _____   _____

Name of participant   Date   Signature

_____   _____   _____

Name of researcher   Date   Signature

Appendix I

Demographic information form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK   Coventry University

Mental health nurses' experiences of working with adults with Autism Spectrum Disorders

Demographic questionnaire

Age:

Sex: _____

Ethnicity: _____

Job title: _____

Qualification: _____

Length of time qualified (years and months): _____

Length of time in current role (years and months): _____

To be completed by researcher:

Participant number: _____

Version 1

Semi-structured interview schedule

Thank you for taking part in this study. As you know, this study is concerned with adults with autism spectrum disorders (ASD).

1. Can you tell me a bit about what you understand about ASD.

Possible prompts:

- What is ASD?
- What type of features would you expect someone with ASD to display?
- How might someone with ASD be vulnerable to mental health problems?
- What training have you had on ASD?

2. Can you tell me about your experiences of working with people with ASD in an inpatient setting. It may be helpful to think of a specific service user, but please be mindful of confidentiality when talking about their case.

Possible prompts:

- How did they come into hospital?
- What challenges did they present for:
    - You as a staff member
    - Your colleagues
    - The multidisciplinary team
    - Other patients on the ward
- What sense did you make of their behaviour? If necessary and appropriate, the researcher may prompt the participant to discuss the following topics:
    - Communication and/or interpersonal difficulties
    - Emotional understanding
    - Sensory sensitivities
    - Symptoms of mental health problems
    - Service user's insight into their own problems

3. Adults with ASD are often unrecognised before they come into contact with mental health services. What experience have you had of working with service users receiving a diagnosis of ASD for the first time?

Possible prompts:

- How did the diagnosis come about?
    - What was your involvement?
    - What roles did various members of the MDT have in making the diagnosis?
- What did you notice about your work with the service user following the diagnosis?
    - How, if at all, did it help and/or hinder your work?
    - How, if at all, did your perception of the patient change?
- What did you notice about the work of the MDT following the diagnosis? In terms of:
    - the decisions made about the service user's care
    - the MDT's conceptualisation of their presentation
- What did you notice about the diagnosis of ASD for service user themselves?
    - How did they respond to their diagnosis?
    - How, if at all, did it help and/or hinder their progress?
    - What did you notice about their understanding of themselves?

4. In light of these experiences, what, if anything, has changed about your knowledge and understanding of ASD?

Possible prompts:

- How has your confidence to work with service users with ASD changed, if at all?
- How might you work differently with them now?

5. What thoughts do you have about what might help staff support patients with ASD in this setting?

6. Do you have any other thoughts about this topic that I have not already asked you about?

Appendix K

Debriefing information sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK

Coventry University

Mental health nurses' experiences of working with adults with Autism Spectrum Disorders

Debriefing Information Sheet

Thank you for participating in this study, which looked at your experiences of working with adults with autism spectrum disorders (ASD) in an acute psychiatric service. Research shows that ASD is poorly understood in adult mental health services, which can prolong service users' distress and increase their risk of being misdiagnosed. We wanted to look at how staff members make sense of these service users' presentations, and whether this was affected by a new diagnosis of ASD.

If you have any further questions about the study, please feel free to contact the main researcher, Rachel Squires, or another member of the research team (contact details below).

In the event that you feel distressed by participating in this study, we encourage you to speak to your line manager, or to contact the Occupational Health department for advice on support for staff members.

Thank you again for your participation.

Research team's contact details:

Chief Investigator: Rachel Squires, Trainee Clinical Psychologist.
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www.coventry.ac.uk

Version 1

Appendix L

Example of coding a transcript using IPA

154   I) Ok, so it's been quite difficult to-
[margin: cuts me off - urgency, importance]
[margin: implication throughout that SU has control and refuses to how the line.]

155   *[margin: global/internal]*

156   P) She is difficult, yeah.
[margin: sense of prep describing SU w/ASD in the way many staff describe SUs w/PD. Does he see her as manipulative?]

157   *[margin: difficult patient]*

158   I) Can you tell me a bit about what's been difficult?

159

160   P) Um... communication. Asking her to do things. I asked her to tidy her room, I gave her a
[margin: Difficult patient]
[margin: communicating instructions]

161   24 hour deadline 'cause I thought she likes to work to times so if she's got a pre-plan of
[margin: Communication barriers]
[margin: attempts to work with her ASD more.]

162   what I'm gonna do, if you don't do it, I'm gonna do it for you. Um, I gave to a certain time,
[margin: Working with/being adapting]
[margin: (in a directive way - is no real empathy/understanding)]

163   date, 'cause I know she works on that level, but she still wouldn't do it so [laughs] I tidied

164   it. Um, she came back and caused.... She refused to speak to me, wouldn't speak to
[margin: Lack of understanding]
[margin: CONTROL/CHOICE refusal to engage.]

165   anybody, probably for about a week. She's talking to me again now, we've made up.

166   *[margin: caused what? [A scene?]]*

167   I) But it sounds like it's quite tricky to maintain a relationship with this patient?
[margin: Barriers to therapeutic relationship]
[margin: hard to maintain r/ship.]

168

169   P) It is. So our peer support worker, he gets on really well with her because he has
[margin: Relying on colleagues]
[margin: using expertise of colleague - personal understanding]

170   Asperger's and she knows that, so they've got that kind of link and understanding of each

171   other, which helps. So we can relay messages through him, which works quite well but he's

172   only just started working here, he's been here about a month. But before that, we were

173   just trying our best [laughs]
[margin: Trying our best]
[margin: trying our best.]

174   *[margin: not enough]*

175   I) What did trying your best look like, how did you negotiate some of these problems?

P) Just helped her bit by bit really. The cleaning the bedroom, I think she moved about 3
carrier bags? Which took her all afternoon to do. Just putting it here and moving it back
again, putting it there and getting bits of paper out, putting it in another bag, and... she
didn't really tidy anything, it was just moving one thing to another place and putting it back
again, but I don't really know how her thought process works.

repeated movement – lack of confidence.   FRUSTRATION

I) You said she seems to have OCD like traits?

P) Yeah, yeah. She'll do things like, you know, she won't touch things. Doors she won't
touch, she has to wear gloves, she won't hold a cup unless it's got a paper towel round it,
won't food down unless there's a paper towel under it. But the ironic thing is, she doesn't
shower. So she won't touch things 'cause they're dirty but she also won't clean herself. So
she kind of lives in her own mess but won't touch other people's mess. And trying to *b (cleaning)*
encourage her to have a shower and change her clothes is, yeah... it's challenging. *Contrast with 'change' earlier.*

I) So what sense have you made of that, kind of, paradox almost... yeah, it's quite
contradictory.

P) Yeah... I don't know, I don't know if I've made any sense of it at all! [laughs] I mean I
don't understand how she won't pick up a cup unless it's clean and got a clean paper towel
round it, yet she won't shower or bath herself to keep herself clean. Normally people with

Line numbers: 176 177 178 179 180 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 196 197

Left margin annotations:
Slow.
Lack of understanding / confidence.
Contradiction
Difficult patient?
Doesn't make sense!
Not like mental illness.

Right margin annotations:
slow process
description of rituals / SU's
can't fathom her processing style. / Is so different to his own.
Obsessive behaviours.
irony/contradiction.
sense of being diagnosed? or simply frustrated?
doesn't make sense to him
implication there's a 'correct' way to have OCD / to behave unusually.

198   OCD, with cleanliness, they'll you know clean their house 10 times a day and themselves,

199   shower multiple times a day but she's, yeah, contradicting herself. But that could be the

200   Asperger's and that's how she's wired. Could be. I don't know, I don't know the clinical way

201   of describing that. One for you to look into! [laughs]

202

203   I) [laughs] Yeah it is interesting. Um... you said this lady, her diagnosis was established and

204   she understands it quite well. How has that been helpful to her?

205

206   P) I don't know really. It's quite hard because communication with her isn't that great

207   anyway. Um, she doesn't express any needs, I mean, occasionally she'll ask for Fortisip

208   drink to boost her calories. She won't eat meals, she doesn't do an awful lot of what we'd

209   like her to do, she does things on her own accord. She'll bring in food and leave it down in

210   her room until it rots and she'll eat it. I just don't really have any understanding of her and

211   her situation altogether really.

212

213   I) And you said that she would tell you about her diagnosis?

214

215   P) Yeah. It's... she's got a bit of behaviour problems as well. Not in like an aggressive way,

216   but if she doesn't want to do something she'll say, this is how I am, I'm not gonna do it.

217   Instead of understanding that she is in a hospital, and she has to work with us, she thinks

218   it's her room, she can do what she likes. Yeah trying to explain that to her is a no go.

219

Left margin handwritten labels:
Confusion.
Hard to emphasise?
'Difficult'
Non-conforming
LACK OF UNDERSTANDING
Won't work with us.

Right margin handwritten notes:
not like OCD so he recognises it
Contradiction.
the way she's wired.
— recognition of difference
doesn't answer question
hasn't fully thought about what it means to her — too difficult to take her perspective
doesn't express needs.
does things of own accord ↳ doesn't conform to expectations ("difficult")
no understanding of SU or her situation
defiant.
rigidity of mind
hard to explain rules.
implicit on that it isn't her space.

220   I) It sounds quite frustrating.

221

222   P) Yeah. In the end we kind of just keep a close eye on her and let her do her own pattern,

223   just to save arguments. She is vulnerable, we don't want her disappearing, You know, she'll

224   go on overnight leave and we won't see her for three days. Um, then we'll suddenly get a

225   phone call from the police saying she's run out of money and we're giving her a lift home.

226   Then they'll come and drop her back off here [laughs]

227   *being done to – SU has no control*

228   I) So it is almost like this is home for her

229

230   P) Yeah, well it is at the moment. She hasn't got anywhere else.

                        NFA.

231

232   I) What would you like for her?

233

234   P) Um, an Asperger's placement. Somewhere people who's trained in Asperger's can talk

235   to her in a way she can understand. If she doesn't like touching things they can

236   accommodate that. You know, that kind of environment and, I don't know what you can

        active – doing

237   do to change people's thought processes in Asperger's. But she needs a suitable

238   environment for her, not an acute mental health ward. Um, the people she's round are

239   probably not suitable for her. We've got people who are aggressive, verbally aggressive,

240   physically aggressive. She's vulnerable, timid, she won't even come through a corridor

241   unless the coast is clear and she's got an exit, so, yeah it's difficult.

Handwritten margin annotations (left side):

Vulnerability
Protecting her

Home, but not.

Nowhere else to go.

Inappropriate placed

Vulnerability

Handwritten annotations (right side):

leave her to it, keep the peace.

VULNERABILITY
protecting her, prioritising
safe haven

ward = home

– he recognises this
but expresses little
empathy for her situation
and how vulnerable she is
– it's her home, but
she shouldn't

nowhere else to go

– because who are
inappropriate?

needs an appropriate
placement
↳ specialist environment
+
staff.
we're not able
to help.

other patients not suitable
is aggression.

vulnerable, timid.

extreme
social anxiety.

242

243   I) So the other patients have an impact on her

244

245   P) Yeah some of them, it's quite pleasant at the moment, but we have had not so nice

246   people here.

247

248   I) And does she have an impact on the other patients at all?

249

250   P) She fixates on a couple of people. So she'll... she really likes one of the OTs and will kind

251   of latch on to her, but others she'll blank completely. She's obsessed with a celebrity

252   actually. I think she got a restraining order, she used to find out where he was and hunt

253   him down. She's really clever, it's amazing how her mind functions compared to mine. Her

254   way of organising, I mean I'm messy but she's messy but it's perfectly organised for her I

255   think. It's organised chaos, literally. You know, (to me) her room's an absolute state but to

256   her, she's put it in that set pattern of where things should be. If it's moved that will, you

257   know, take her ages to get over. It's like Jenga isn't it, pull a bit out and they just collapse.

258   I've realised that by cleaning her bedroom, that was part of her daily thing and I ruined it. I

259   was like oops sorry. I know now to tread carefully when I do that.

Handwritten margin annotations:

- Vulnerability
- How SU's mind works.
- Totally different perspectives.
- Flexibility = catastrophe.
- Impacting - veg on SU.
- Increasing empathy.
- 'not nice' patients have impact on her.
- fixation on staff. obsessions w/people.
- again intelligence - related to determinant of control? seems fascinated by her
- organised chaos
- 'ages to get over' - rigidity flexibility = chaos/ catastrophe state
- recognising his impact on his mental state.
- becoming more empathic, recognising her difficulties - remorse.
- learning to 'tread carefully' (like eggshells or consolidated) seems to be gaining understanding of the limitations

Master table for one superordinate theme

Superordinate theme 1: 'Out of our depth'			
Subordinate themes	**Key cross-references**	**Indicative quotes**	**Notes**
Utter confusion	Marie: 7, 78, 110, 231 Liam: 121,193 Natalie: 42, 78 Sally: 167, 363, 370 Charlotte: 96, 142, 224 Gareth: 249, 468 Paul: 85, 299	"He talked about suicide as if it was someone going to the shop and buying a box of chocolates. There was no emotion...he was as calm as anything." (Marie L110) "I don't know if I've made sense of it at all...she's contradicting herself. But that could be...how she's wired...I don't know." (Liam L193) "We end up going on the Internet and looking at NHS websites...It just doesn't seem very professional." (Natalie L78)	Participants described feeling baffled by their clients' presentations. Less experienced participants seemed more frustrated. There is an implication that patients with ASD are 'difficult' (Liam) and more attributions of control (e.g. Charlotte's use of 'won't'). Participants made attempts to learn more using public resources. All commented that they would appreciate guidance in some form.
Incompatibility	Paul: 109, 141, 252 Liam: 62, 114, 133 Natalie: 22 Sally: 139 Marie: 190, 321 Charlotte: 74, 84 Gareth: 44, 60	"You get patients who find chaos to be the most difficult thing in their life being placed in a situation that is very chaotic." (Gareth, line 44) "We do things at certain times whereas...she'd want her own routine that she'd always had." (Paul L109) "To do any sort of intervention...when they're not in an acute phase of their illness...it's quite tough really." (Charlotte, line 74)	Participants seemed to think patients with ASD were inappropriately placed on acute wards. Accounts eluded to a tension between rigidity of patients and rigidity of the system. Participants' inability to 'treat' patients led to feeling helpless and disempowered in role, and frustrated with services.

Appendix N

Author instructions for *Reflective Practice*
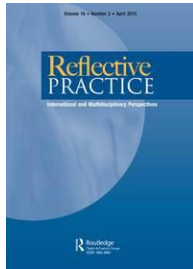
Reflective Practice
International and Multidisciplinary Perspectives

Instructions for authors

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- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript has been submitted only to *Reflective Practice*; it is not under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

Manuscript preparation

1. General guidelines
- Manuscripts are accepted in English. British English spelling and punctuation are preferred. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented with quotation marks.
- A typical manuscript will not exceed 6000 words including tables, references, captions, footnotes and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page

(including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

- Abstracts of words are required for all manuscripts submitted.
- Each manuscript should have 3 to 6 keywords.
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here.
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Please supply a short biographical note for each author.
- Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:
  - *For single agency grants:* "This work was supported by the [Funding Agency] under Grant [number xxxx]."
  - *For multiple agency grants:* "This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx]."
- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to SI units. Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript

2. Style guidelines

- Description of the Journal's article style.
- Description of the Journal's reference style.
  - An EndNote output style is available for this journal.
- LaTeX template.
- Word templates are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.

3. Figures

- Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.
- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

4. Ethics

- Authors must ensure that research reported in submitted manuscripts has been conducted in an ethical and responsible manner, in full compliance with all relevant codes of experimentation and legislation. All manuscripts which report in vivo experiments or clinical trials on humans or animals must include a written Statement in the Methods section that such work was conducted with the formal approval of the local human subject or animal care committees, and that clinical trials have been registered as legislation requires.
- Authors must confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment or clinical trial who is described in the manuscript has given written consent to the inclusion of material pertaining to themselves, and that they acknowledge that they cannot be identified via the manuscript; and that authors have anonymised them and do not identify them in any way. Where such a person is deceased, authors must warrant they have obtained the written consent of the deceased person's family or estate.
- Authors must confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in the manuscript; and that the manuscript contains all appropriate warnings concerning any specific and particular hazards that may be involved in carrying out experiments or procedures described in the manuscript or involved in instructions, materials, or formulae in the manuscript; and include explicitly relevant safety precautions; and cite, and if an accepted standard or code of practice is relevant, a reference to the relevant standard or code. Authors working in animal science may find it useful to consult the Guidelines for the Treatment of Animals in Behavioural Research and Teaching.

Manuscript submission

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