

SOCIAL ANXIETY: PERSONAL NARRATIVES ON JOURNEYS TO RECOVERY

Catherine McCarthy

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ABSTRACT

Introduction: Social anxiety is a common experience. For some it is a debilitating, chronic difficulty, which becomes problematic during childhood and can have devastating effects. Talking therapies are useful for many, particularly in reducing anxiety. However, many people never access treatment and for those that do, therapies do not tend to improve their quality of life, particularly their social worlds. Do we need to look beyond clinical recovery measures when assessing therapeutic outcomes? There has been no research that has explored personal recovery in social anxiety. This thesis seeks to understand whether people with problematic social anxiety experience personal recovery and if so, how.

Methods: A participatory action research (PAR) approach was used to develop the project. People with problematic social anxiety advised on study design, data collection, analysis and dissemination of the findings. 8 narratives of living with problematic social anxiety were collected to explore how people negotiate social anxiety and what this can tell us about personal recovery. A narrative analysis was then carried out, drawing upon Frank's (1995, 2012) dialogical narratives analysis of illness stories and Adame and Hornstein's (2006) typology of emotional distress narratives.

Findings: The participants' stories of living with problematic social anxiety highlighted the variety of ways that people make sense of this difficulty. The types of stories told were reminiscent of Frank's (1995, 2010) illness narratives, as people told stories of restitution, chaos and quest. People drew upon traditional, counter and alternative mental health narratives to negotiate social anxiety, reminding us of the multiple ways people can find to overcome emotional distress.

Discussion: The PAR study showed how people struggling with a mental health difficulty can be at the centre of research which strives to better understand their struggles and improve talking therapies. The study reminds us that the "social" aspects of social anxiety need to be better acknowledged within therapies so that we do not only focus on reducing anxiety but help people improve their relationships and quality of life.

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STUDY INTRODUCTION

Note for the reader: throughout the thesis the term ‘problematic social anxiety’ will be used as a generic term to refer to social anxiety disorder and social phobia. There are many commonalities between social anxiety and shyness but these will be referred to separately, reflecting the longstanding debate around what, if any, real differences there are between these experiences.

My earliest memories are of hiding behind my dad’s legs to shield me from the children he wanted me to play with. This experience was fairly symbolic of a childhood, adolescence and early adulthood paralysed by social anxiety. Fast forward more than 30 years and I found myself on a counselling psychology doctorate, a long held dream that seemed impossible a few years ago. I received professional help for social anxiety over five years ago when it had become so crippling that I had frequent panic attacks and struggled to get to work each day or spend time with family and friends. It has not been an easy process. It was only when life was becoming unbearable that I stumbled across a diagnostic description of social anxiety and found the first explanation that made sense.

As highlighted in the NICE (2013) guidelines for social anxiety disorder, there is low public and professional recognition of this difficulty. This was my experience in which to access services I had to self-diagnose and find appropriate psychological services in Australia and the UK. In both countries there seemed to be low awareness: a number of times I was asked: “Social anxiety. What is that?” In some ways the panic attacks were a blessing in disguise as this type of anxiety is better understood and got my foot in the door to specialist anxiety centres in both countries. As things started to change and I became better able to manage relationships, I began to see a way through the anxiety and I started to think about what it might be like for the 1 in 10 people that are understood to be affected by this problem.

All of us experience some social anxiety during our lives. There are not many of us who do not get at least a little nervous when giving a speech, meeting new people or going to a party (Sanders, Wills, & Hallam, 2003). That social anxiety is such a common experience can undermine our acknowledgement of how debilitating it can be for some. It is reminiscent of how problems like depression were viewed only a generation ago. The research literature is abundant with quantitative studies on the features and aetiology of social anxiety as well as treatment outcome research. Current treatments for social anxiety include pharmaceuticals (such as anti-depressants) and talking therapies, with the greatest evidence base for cognitive behavioural therapy (CBT) (Butler, Chapman, Forman, & Beck, 2006; Clark & Beck, 2009; Lampe, 2009). It generally takes people many years to access any type of treatment (Wang et al., 2005). Most people will never receive any professional help for their social anxiety (NICE, 2013).

Counselling psychology is a discipline of psychology which claims to value the subjective worlds of clients, rather than taking a mechanistic view of mental health difficulties. The study's approach has been informed by the recovery movement in mental health, which emerged in opposition to clinical recovery's focus on symptom alleviation (Slade, 2009). Personal recovery research describes how people live with mental ill health without being overwhelmed or dominated by these problems (Ajayi et al., 2009). It is about viewing mental health difficulties as part of the person rather than the whole person (Slade, 2009). People experience recovery in many ways. It is understood to be a deeply personal process, which involves finding a way to frame distress, whether through diagnosis or formulation or as a cultural, spiritual or existential crisis (Brown & Kandirikirira, 2007; Lieberman et al., 2008; Slade, 2009). So whilst the recovery literature tends to present personal recovery and clinical recovery as dichotomous constructs, there is some acknowledgement that this does not always have to be the case. This movement has to allow for a plethora of recovery experiences or it runs the risk of becoming prescriptive and mirroring the systems it opposes. As highlighted by recovery researchers such as Slade (2009), we need to acknowledge that for some, but not all, clinical recovery will lead to symptom reduction and much more. We also need to make room for different therapeutic responses when recommended treatments do not work. Finally, it is

important that we also recognise that recovery is rarely a solo endeavour (Harper & Speed, 2012).

Recovery researchers view personal recovery as not necessarily being about returning back to normal or being fixed; it is about living a satisfactory life (Ajayi et al., 2009; Barnett & Lapsley, 2006; Brown & Kandirikirira, 2007; Lapsley, Nikora, & Black, 2002). So whilst recovery can take many forms, part of this process tends to involve a search for meaning of one's psychological distress. This is understood to be positive when people construct meaning, resolution or purpose from these experiences (Basset & Stickley, 2010; Pals, 2006; Salem, 2011). This indicates that this process of meaning making may be a key feature of recovery.

My own experience of recovery mirror these findings. Recovery has involved exploring (both in and outside therapy) how my social anxiety developed, its meaning and how to live with it rather than be defined by it. This has seen a shift from viewing the world as a hostile place towards a less defensive position which has helped me to foster satisfying relationships. Increasingly I have come to understand that this process has not just been about overcoming personal deficits or obstacles. I have been shaped by the world that I live in, my personal and professional relationships and have been able to access resources to negotiate this difficulty. We can not assume that our clients have equal access to these opportunities.

This thesis tells others' stories of how they negotiate problematic social anxiety. The study has explored what getting better means to people with problematic social anxiety. I was interested in hearing how people understand their social anxiety and what they feel helps and hinders personal recovery. Is recovery something they experience? And if so, how? The study hopes that the findings will offer additional ways for psychologists to better facilitate personal recovery.

The current study invited people who had experienced problematic social anxiety for at least 10 years to share their stories of living with and recovery from social anxiety. My own experiences of problematic social anxiety shaped my initial research ideas. I felt it was important to offer others with problematic social anxiety the opportunity to be involved in this process, through using a participatory action research (PAR) approach. Too often those affected by a topic area are excluded from decision making on what and how a topic is researched. However, in recent years people with mental health problems have become involved in research as more than participants (Cohen, 2008; Kidd & Kral, 2005). Both PAR and the mental health recovery movement share the view that people affected by a problem should play a central role in determining what help they need and subsequently receive.

People with problematic social anxiety have advised on the study design, including the research topics and study methods, as well as commented on analysis and the dissemination of the research findings. Participatory research is political and critical of the status quo. However, having these ideals does not negate the power imbalances inherent within research nor the threat of tokenism. As a trainee counselling psychologist with limited resources and expertise, my hope is that all those involved feel that they have been listened to and that the findings are useful for them. This needs to be reflected in the study's design, conduct, findings and how this information is shared and potentially used in the future.

LITERATURE REVIEW

Social anxiety is a common experience that most of us experience to varying degrees (Crozier & Alden, 2005). For some, social anxiety is a crippling and chronic lifelong problem (Beidel & Turner, 2007; Clark & Beck, 2009; Hofmann, Heinrichs, & Moscovitch, 2004). Problematic social anxiety typically develops in late childhood or adolescence (Brook & Schmidt, 2008). The factors which contribute to social anxiety becoming disabling are not well understood.

Social anxiety can have a number of detrimental effects on people's lives. People with problematic social anxiety avoid many activities, contributing to lower attainment rates at school and work (Brook & Schmidt, 2008); impairments in social functioning; increased suicide risk; high comorbidity with other mental health conditions (Kessler, Chiu, Demler, Merikangas, & Walters, 2005); high rates of alcohol and drug misuse (Morris, Stewart, & Ham, 2005) and poor reported quality of life (Brook & Schmidt, 2008; Clark & Beck, 2009). Clinical recovery rates are significantly lower than for other anxiety difficulties (NICE, 2013). Given the number of adverse outcomes, why does this difficulty continue to sit below the radar of the public and many healthcare professionals? (NICE, 2013) It is time for this silent population to start to have a voice in mental health narratives.

The first part of the literature review looks at the main therapeutic approaches for social anxiety. The next section looks at outcome research, with a particular focus on what is missing from therapeutic approaches. The final section looks at the lack of narrative studies on problematic social anxiety; why this study needed to be undertaken; and, how it can add to our understanding of problematic social anxiety and potentially inform our therapeutic work. The literature review covers all of this ground as social anxiety continues to be paradoxically both a contested construct (e.g. pathologising shyness) and predominantly understood and treated within biomedical and/or cognitive behavioural frameworks. From the vantage point of a service user and trainee psychologist, there is more work to be done to understand how people with problematic levels of social anxiety live a meaningful life and move talking therapies closer to facilitating this process.

1 How Social Anxiety is Understood and Treated

This section of the literature review discusses the main conceptualisations and therapies currently available for problematic social anxiety. The reader will note that the section on interpersonal approaches is more detailed as this is an emerging research area and one which potentially can build upon existing therapies. The section argues that we need to remember the social in social anxiety. Looking at how to incorporate relational factors into talking therapies is an exciting way to possibly improve current therapies, such as CBT.

1.1 Medical Model

Within the medical model, problematic social anxiety is classified as an anxiety disorder, referred to as social anxiety disorder (SAD) or social phobia. The recently published fifth edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (2013) classifies social anxiety disorder as a persistent fear and avoidance of social and performance situations, which provokes excessive anxiety. This anxiety interferes significantly in people's lives and causes considerable distress (American Psychiatric Association, 2013).

Social anxiety disorder is one of the most common anxiety disorders (NICE, 2013). Lifetime prevalence rates in Western countries are understood to be between 7% and 13% (Brook & Schmidt, 2008; Furmark, 2002). Rates of social anxiety are slightly higher amongst women than men, with a ratio of 3:2 reported in many studies (Brook & Schmidt, 2008). There is considerable variance in prevalence rates across different cultures, yet it appears to be found in most cultures and countries (Heinrichs et al., 2006; Hofmann, Asnaani, & Hinton, 2010).

Problematic social anxiety can impact on particular activities and/or permeate many areas of someone's life. It tends to take a chronic but fluctuating course. Long term clinical recovery rates are low (NICE, 2013) which, with our understanding that social anxiety is a common experience, indicate that trying to get rid of problematic social

anxiety may not be a realistic treatment aim. Treatments may need to instead focus on helping people to have greater insight into their social anxiety, become less distressed by it and, reduce the negative impact of social anxiety on people's lives.

For some or many clients a diagnosis provides an exploratory model and reduces one's sense of isolation (Slade, 2009). It is also commonly the way one accesses help, such as medication and/or therapy. As psychologists, it is important to spend time exploring the meanings and utility that diagnosis has for clients. We also need to remember that symptoms rarely provide us with the full picture of clients' difficulties. Whilst there are many different ways of doing assessment and formulation, a holistic, integrative approach to understanding psychological distress incorporates the symptoms of social anxiety but moves beyond this to gain a fuller picture of how social anxiety is understood by the client and how this impacts on their life. The counselling psychologist then needs to convey their understanding of what the client has told them to then jointly agree what type of help may be most useful to the client (O'Brien & Houston, 2007).

1.2 Cognitive Behavioural Model

Therapeutically, the dominant model of how social anxiety is understood and treated is the cognitive or cognitive behavioural (CBT) model. CBT is the most researched and well supported psychological therapy for problematic social anxiety (Clark & Beck, 2009; Hofmann, 2008; Lampe, 2009; Rodebaugh, Holaway, & Heimberg, 2004). In this model, social anxiety is understood to reflect a cognitive bias which leads to social situations being interpreted as threatening. This exaggerated fear is understood to be sustained by behavioural avoidance. Clark and Beck's (2009) three-phase cognitive model of social anxiety is informed by their extensive work in this area. The first phase is an anticipatory phase, marked by beliefs around social inadequacy, a desire for avoidance and anticipatory anxiety. The second phase, the social situation, triggers the activation of maladaptive social self-schemas, processing feedback from others as negative and a heightened focus on performance, which triggers anxiety and a range of safety behaviours or involuntary inhibitory behaviours. The third phase, post-event processing, involves biased recall

and interpretation of social performance, leading to feelings of shame and embarrassment (Clark & Beck, 2009).

The CBT model succinctly captures the pattern of behaviours, thoughts and feelings that many with problematic social anxiety experience on a daily basis. Therapy targets what is understood to be a cognitive deficit in the way the individual interprets both one's own behaviours and how others will respond. CBT typically involves changing these processes through techniques such as psycho-education; behavioural experiments which target self-focused attention, safety behaviours and distorted self-imagery; cognitive restructuring; modifying core beliefs; modifying pre and post event processing; and, relapse prevention (Clark & Beck, 2009; NICE, 2013).

CBT is very good at reducing anxiety experienced in social situations. It is less clear whether these cognitive and behavioural changes lead to other changes in people's lives, particularly in how they relate to themselves and others. There are some studies, albeit limited given the scale of treatment outcome research, that have looked at the impact of CBT on quality of life (Watanabe et al. 2010) and other factors, such as shame and guilt (Fergus, Valentiner, McGrath, & Jencius, 2010). It is too early to make any sweeping claims but the evidence suggests that CBT's impact on other areas of people's lives are limited and that more work may be needed to adapt therapies to target these areas.

1.3 Psychodynamic Perspectives

Whilst CBT focuses primarily on the here and now, psychodynamic perspectives explore how social anxiety has developed. Psychodynamic theories and practices constitute a vast array of often competing views on how to understand and relieve psychological distress. Whilst not widely recognised in the psychodynamic literature, some psychodynamic writers have written specifically about social anxiety. Leichsenring, Beutel and Leibing (2007) summarise how social anxiety is conceptualised within a number of psychodynamic schools of thought, including self-psychology; object relations; attachment; ego-psychology; and, instinctual models.

The commonality in these differing theories is that the socially anxious internalise negative early relational experiences into largely negative representations of self and others which lead to ways of relating which perpetuate and sustain these representations.

Leichsenring and colleagues (2007) psychodynamic therapy manual for social anxiety is broadly based on Luborsky's (1984) supportive-expressive therapy with additional specific treatment components for social anxiety, including psycho-education, exposure, exploring unrealistic demands and shame. Supportive expressive therapy identifies and works with clients' Core Conflictual Relationship theme (CCRT), which is made up of three components: a wish (W); a response from the other (RO); and, a response from the self (RS). This can be conceptualised as: "I wish that... but others will... so I will..." Whilst there is not one CCRT specific to problematic social anxiety, the authors provide an example of how this could look in social anxiety: I wish to be affirmed by others (W) but will be humiliated by others (RO), so I avoid being with others (RS). CCRT's are repeated maladaptive relational patterns found in past and current relationships, including the transference relationship. As people with problematic social anxiety are not a homogenous group, therapy can be more supportive or expressive/interpretive depending on the clients' needs. Therapy focuses on changing the unhelpful CCRT which perpetuates social anxiety. This is done through bringing these patterns into consciousness as well as graded self-exposure to change these patterns (Leichsenring, Beutel, & Leibing, 2007). Therefore, whilst this approach is psychodynamic it also incorporates features from CBT, particularly around changing behavioural patterns. This potentially offers an exciting way forward in incorporating successful elements of CBT into a more psychodynamic approach.

1.4 Developmental Perspectives

Research indicates that problematic social anxiety typically develops in late childhood or adolescence (Brook & Schmidt, 2008; Clark & Beck, 2009). When

recognised in childhood, the recommended therapy is group CBT (7-15 year olds) or CBT for parents with younger children (NICE, 2013). NICE guidelines recommend involving systems (e.g. family; school) in therapies for children and young people but do not recommend this for adults (NICE, 2013). Current treatments for adults do not tend to account for the development features of problematic social anxiety.

One review found problematic social anxiety was already a difficulty for some children, suggesting it may be better understood as a developmental issue (Bögels et al., 2010). The interaction of genetics, temperament (behavioural inhibition) and parent-child interactions (attachment and parenting styles) play a role in the development and maintenance of problematic social anxiety. Other factors such as traumatic experiences, quality of peer relationships, social skills and social withdrawal also appear to play a role (Elizabeth et al., 2006; Festa & Ginsburg, 2011; Knappe, Beesdo-Baum, & Wittchen, 2010).

Research with socially anxious adults found that they recalled growing up with parent(s) who were overprotective and overanxious, but also uninvolved and disconnected from them. These families were socially isolated and mindful of others opinions of them. These children came from rigid, rule bound families, which hampered autonomy and encouraged or at least did not discourage avoidance of social situations (Clark & Beck, 2009; Stravynski, 2007).

Research has indicated that people with early onset shyness and social anxiety grew up with shy parents; whilst later onset shyness and social anxiety is associated with childhood emotional, physical and sexual abuse (Alden & Taylor, 2004). Having a behaviourally inhibited child seems to affect parenting styles too, perpetuating social reticence. This behavioural inhibition can however be mediated by a secure attachment relationship (Alden & Taylor, 2004). Social anxiety is associated with peer bullying and rejection throughout childhood and adolescence. It is not clear if this is a cause or consequence of social anxiety (Alden & Taylor, 2004). What does emerge from the literature is that social anxiety seems to be grounded in our relationships from early on in life.

1.5 Interpersonal Perspectives

Alden and Taylor (2004) reviewed the interpersonal processes in social anxiety, in recognition that this problem is not just about anxiety. Social anxiety disrupts social relationships throughout the life course, with the socially anxious found to be more socially withdrawn, with fewer friendships and romantic relationships. This is not only in comparison with non-clinical populations but also compared to those with other anxiety difficulties. In relationships, the socially anxious have higher rates of dissatisfaction, over-reliance, non-assertiveness and less intimacy and closeness (Alden & Taylor, 2004).

Angelico and colleagues (2010) reviewed research on social skills impairments in those with problematic social anxiety. The review found that the socially anxious do not function as well in social situations, but that these are differences in degrees rather than in kinds of skills. It seems that situations in which the socially anxious feel threatened trigger self-protective behaviours to guard against criticism (Angélico, Crippa, & Loureiro, 2010). Negative social experiences appear to be more likely amongst the shy or socially anxious, partly due to their interpersonal style eliciting less positive responses from others (Alden & Taylor, 2004). This appears to be less about displaying anxiety or skills impairments and more about a lack of pro-social behaviours, (such as displaying interest in others and reciprocal self-disclosure), which inadvertently communicates disinterest in others (Alden, Taylor, Mellings, & Laposa, 2008; Davila & Beck, 2002).

Research has explored the role of approach and avoidance motivational systems on social behaviours (Gable, Reis, & Elliot, 2003; Waugh & Fredrickson, 2006). People with social anxiety seem to evoke more negative responses from others, making it harder to form relationships (Alden & Taylor, 2011). The social approach system is understood to facilitate friendliness and openness with others, which might prompt the question: do people with problematic social anxiety have a dysregulation of the social approach system (Alden & Taylor, 2011)? If so, how does that impact on the often complementary interpersonal transactional cycles that occur between people, in which one's behaviour tends to elicit a corresponding response (e.g. friendliness

evokes friendliness etc.)? Talking therapies tend to focus on avoidance systems and behaviours which are useful but may not go far enough to change relational patterns.

In a related study, Kashdan and colleagues (2011) explored how self-regulatory strategies employed by the socially anxious to manage their anxiety deplete their capacity to experience positive experiences. This means that positive emotions are not fed back into the motivational approach system, which is responsible for guiding us towards rewarding, positive experiences (e.g. relationships) (Kashdan, Weeks, & Savostyanova, 2011). This self-regulatory model of social anxiety highlights the perpetuating, cyclical nature of this problem and provides some insight into how the socially anxious struggle to enjoy positive experiences. People with problematic social anxiety, particularly earlier in life when they are finding their place in the world, report lower rates of curiosity and positive affect. They can find it difficult to describe feelings and find it difficult to express their feelings openly. They also try to suppress their feelings, associating emotional expression with weakness (Kashdan et al., 2011). This has knock on effects on the capacity to relate to others. The authors recommended that treatments move beyond symptom reduction and directly target positive emotions and experiences, building clients' strengths and improving fulfilment across various domains of clients' lives (Kashdan et al., 2011).

Sung and colleagues (2012) looked at emotional regulation in people with social anxiety. The study found that people with social anxiety feel less able to draw on others' support to manage emotional difficulties. The study highlighted the importance of being able to express one's feelings to access emotional support. The study authors recommended that the best way for CBT therapies to address this, is by targeting perceived deficits or negative self-perceptions in emotional regulation (Sung et al., 2012). It is not clear how this would look in practice but does seem to suggest that changing one's way of thinking about relationships rather than their actual relationships is the key to improving quality of life. What would it look like to target both?

Some research has found that even within close relationships, people with problematic social anxiety tend to avoid emotional expression (Davila & Beck, 2002; Nielsen & Cairns, 2009). Further, it seems that people with problematic social

anxiety have little insight into how this reticence impacts on their relationships, instead attributing their relational problems to personal inadequacy (Alden & Taylor, 2011). A qualitative study by Nielsen and Cairns (2009) explored what it is like for people with social anxiety to be in a close relationship. 8 participants' responses to a written questionnaire were analysed using hermeneutic phenomenology. Participants chose a range of different relationships, including romantic partners, friends or family, with two participants unable to identify a close relationship. Participants talked about difficulties forming close relationships and opening up to others. They were generally self-critical of their relationship skills. People talked about learning through family and peer experiences to not express their feelings and not trust others. Not surprisingly, participants found it difficult to seek help or reassurance from their close relationships as they feared being a burden or resented being expected to disclose their difficulties to others (Nielsen & Cairns, 2009).

Participants who described closeness and intimacy in their relationships said they were also over-dependent, reliant on these relationships to manage their anxiety and, found it difficult to assert their needs. The participants' had formed insecure attachment relationships, so whilst they generally were able to form and maintain close relationships, their social anxiety impacted on their relationships which in turn reinforced their anxieties. The authors argued for more focus on interpersonal factors in talking therapies, so that therapy helps to strengthen both the clients' sense of self and their relationships. This requires a greater focus on the therapeutic relationship and integrating CBT with interpersonal therapy (Nielsen & Cairns, 2009).

In interpersonal psychotherapy, social anxiety is understood to be created and perpetuated by social role insecurity, in which people feel unsure about how to socialize with others; have difficulties being assertive; and, difficulties experiencing positive social encounters (Borge et al., 2008; Lipsitz, Markowitz and Cherry, 1997). A range of self-protective strategies are used to manage these difficulties. These strategies can include not expressing one's wishes and feelings, hiding anxiety, and, withdrawing from others. These strategies can unfortunately make the socially anxious seem aloof and uninterested, so that others then withdraw from them. Therefore, these self-protective behaviours have the opposite of the desired effect, maintaining and consolidating social role insecurity, social anxiety, and a view of the

self as somehow defective. In interpersonal psychotherapy, the focus of therapy is on targeting social role insecurity through identifying and changing transactional relational cycles (Borge et al., 2008; Lipsitz et al., 1997). The research evidence for interpersonal approaches are not as robust as for CBT (NICE, 2013) but this may be partly because the outcome measures do not map as well onto these talking therapies (Cooper, 2008).

1.6 Summary

The section discussed some of the main conceptualisations and talking therapies for social anxiety. Research, theory and practice within each of these conceptualisations tend to operate independently rather than in a complimentary way. In particular, interpersonal and psychodynamic theories could be incorporated with the robust cognitive and behavioural understandings of how social anxiety is manifested and maintained.

The section highlighted the importance of looking beyond the individual when trying to make sense of this problem. Social anxiety occurs in particular interpersonal contexts. Whilst we are still seeking clarity in understanding how social anxiety becomes crippling, what is apparent is that our relationships from when our lives begin and how the environments around us supports or exacerbates this anxiety seems to play a crucial role in social anxiety becoming problematic. Further, as Johnstone (2000) argues, what tends to be lost within the medicalization of distress and its focus on aetiology, categorisation and associated treatments are the meanings of emotional distress (Adame & Knudson, 2007).

2 Talking Therapies: Moving Beyond Symptoms

There are many treatment outcome studies looking at the efficacy of medication and talking therapies for social anxiety disorder. The majority of studies are RCTs, which as discussed in the NICE treatment guidelines, support the use of CBT for alleviating social anxiety symptoms (NICE, 2013). This section of the review does not go into

detail about this body of research. Instead I wish to cast a critical eye on the accompanying assumption that the only challenge going forward is rolling out manualised CBT. This section highlights that we still have work to do to get people into therapy; that when we do manage to get clients into therapy, that one size does not fit all; and, that symptom alleviation may not go far enough to move clients towards living a good life.

2.1 Treatment Seeking

Limited professional and public recognition of problematic social anxiety are concerning and likely to play an important role in the limited uptake of talking therapies. There is low awareness of this problem amongst professionals and the public (Clark & Beck, 2009; Schneier, 2006; Wagner, Silove, Marnane, & Rouen, 2006). Health professionals do not tend to detect this problem in their patients (Wagner et al., 2006). There are low levels of treatment seeking and uptake (Clark & Beck, 2009), with a median delay of 16 years in seeking professional help (Wang et al., 2005). It is estimated that around 50% of those who experience problematic social anxiety will never seek professional help (NICE, 2013).

2.2 Client-Therapist Factors

There is little research on the client-therapist variables which predict therapeutic outcome for people with problematic social anxiety. Research on how interpersonal factors impact on therapy have found that negative interpersonal patterns, such as detachment and easily displaying anger are correlated with higher drop-out rates in CBT. Establishing a therapeutic alliance can be difficult, particularly with clients who experienced parental abuse or whose social anxiety permeates many areas of their lives. There is a need to identify negative interpersonal patterns early in therapy so that its impact both in and outside the therapy room can be explored and worked through (Alden & Taylor, 2004). This requires therapies to be tailored to the individual, which creates a tension for counselling psychologists working with the manualised protocols which are increasingly used for social anxiety. It is arguable

how much scope there is in existing manuals to tailor therapies to clients, despite the considerable heterogeneity seen in problematic social anxiety.

2.3 Outcome Measures: How Do We Assess Whether Therapy Works?

Widely used outcome measures for social anxiety therapies, such as the Liebowitz Social Anxiety Scale (LSAS-SR), the Social Phobia Scale (SPS) and the Social Interaction Anxiety Scale (SIAS), map onto the CBT conceptualisation of social anxiety (NICE, 2013). These measures are sensitive to picking up behavioural and cognitive changes during therapy. This is not inappropriate as these are important areas to target for many clients experiencing problematic social anxiety. However, there is a debate about how well these measures can assess alternative therapeutic approaches (Cooper, 2008).

There have been calls to develop outcome measures which look beyond clinical symptoms and instead use a multi-axial system to measure recovery, which would include measures of disability and quality of life (Bobes, 1998). This recognises that problematic social anxiety has a chronic course and therefore it is important to look at how well therapies target other factors associated with wellbeing, such as one's relationships. It is not clear how current protocols which focus on the reduction of anxiety symptoms enable people with social anxiety to develop more and closer relationships. There is some way to go as the NICE (2013) guidelines highlights how many trials do not look beyond clinical symptom measurement.

2.4 Quality of Life and Talking Therapies

In the recent NICE (2013) review a handful of studies looked at quality of life (QOL) improvements following therapies. Of the RCT studies which included a measure of this construct, there was limited or no impact on quality of life following CBT either directly following the therapy or at follow up (Eng, Coles, Heimberg, & Safren, 2005; Ledley et al., 2009). Whilst the majority of outcome research focuses on symptom

alleviation, QOL measures look at the individual's perception of their own wellbeing across a variety of domains.

Some research has indicated little relationship between symptom severity and QOL (Barrera & Norton, 2009). Whilst other studies have found that QOL is considerably worse for those whose social anxiety is generalised to many areas of their lives, compared to those who are mostly troubled by performance related social anxiety (Pallanti et al., 2008). Could this mean that offering everyone the same therapy and focusing on symptoms alone is insufficient for long term, meaningful change in people's relational worlds? Aderka and colleagues (2012) identified distinct clusters of patients seeking help for social anxiety. The differences between clusters related to the level of impairment in people's lives. The authors argued that clinicians consider impairment and the impact of social anxiety on people's lives so as to offer tailored interventions (Aderka et al., 2012).

Watanabe et al (2010) looked at long term QOL outcomes for people who had group CBT for social anxiety. QOL studies tend to aggregate this construct into one or two areas (e.g. physical health and mental health) but the authors argued that QOL should assess at least four domains, including physical functioning, disease, psychological functioning, and social functioning. Using an extended measure, the study found that symptomatology and some aspects of QOL improved and this improvement was maintained for up to 12 months. However, in terms of social functioning, there were no significant changes, outside of a small effect at post treatment. So whilst symptomatology was significantly reduced using CBT, this did not appear to improve people's feelings about how they relate to others or the quality of their relationships (Watanabe et al., 2010).

An encouraging pilot study offers a possible way forward on how therapies can maintain therapeutic strategies which have been shown to reduce anxiety, whilst also focusing on improving relationships. Alden and Taylor (2011) integrated standardised group CBT with techniques which explored how participants' relational patterns had developed; psycho-education on interpersonal transactional cycles; and, behavioural experiments which promoted social approach behaviours. The study found similar outcomes to standard CBT in reducing anxiety and avoidance

behaviours but also significant gains in social approach behaviours and satisfaction in participants' social relationships. Encouragingly, these social gains were maintained at six months follow up. Perceived social support, which looked at close friendships, did not significantly change which the authors recognised may have been too ambitious to achieve in a three month treatment period, particularly with participants with significant interpersonal difficulties (e.g. never married or dated; high levels of social isolation). The authors recommend longer therapy times and using strategies that focus specifically on developing close relationships (Alden & Taylor, 2011).

2.5 Summary

Current therapies are very good at alleviating anxiety in the socially anxious (NICE, 2013). This is a considerable achievement and provides strong support for the CBT model of social anxiety. However, the focus on anxiety symptoms does not seem to go far enough. As discussed, there are some encouraging adapted talking therapies that wish to incorporate and target interpersonal difficulties commonly found in problematic social anxiety. These adapted talking therapies move beyond symptoms to improve clients' relationships and QOL. What is still missing though are the voices of the socially anxious in this debate and the next section will move onto a discussion of what we know so far and how we can look at ways to incorporate people's views into therapies.

3 Where are the Stories of People with Problematic Social Anxiety?

The research literature abounds with the voice of experts: the psychologist; the academic; the doctor. This literature provides clinicians and fellow researchers with important information relating to social anxiety, whether on aetiology or treatment outcomes. Psychological research continues to largely sit within positivist or post-positivist paradigms. These paradigms take a scientific approach to understanding

people, reflecting psychology's adoption of the medical (psychiatric) model (Ponterotto, 2005). There have been growing critical movements challenging this as the only credible source of knowledge. Some psychologists have joined these critical voices to ask us to make room for different types of research and understandings of emotional distress, as most research in this area has inadvertently neglected peoples' embodied experiences of emotional distress (Basset & Stickley, 2010; Riessman, 2002).

3.1 Qualitative Research on Social Anxiety

There are a scant number of qualitative studies exploring problematic social anxiety. It is frustrating trying to get a sense of the difficulties clients bring to therapy (such as problematic social anxiety), and coming face to face with the way that psychology, in research and practice, medicalises the human condition (Keen, 2011). In practice we are trying to strike a balance between the biomedical, positivist paradigm in which psychology largely operates and the humanistic tradition in counselling psychology which values the narratives people bring to therapy. This is by no means an easy balance to strike. As Keen (2011) argued, emotions such as anxiety or depression are expressions of fear and sadness which clients are trying to cope with and make sense of through their stories. And yet, reading through the research literature, one would suspect that the best way to understand and work with client difficulties is by categorisation and measurement.

Once a mental health condition is conceptualised, it is difficult to challenge dominant paradigms, which perhaps discourages psychological researchers from taking a more inductive, qualitative approach. Diagnosis and manualised treatments do not only provide order and a sense of control to our clients. Breaking down mental health difficulties into a clear set of behavioural, cognitive and affective processes reassures both client and psychologist that meaningful change can be achieved. However, in some areas of mental health research, particularly in psychosis (Roe & Lysaker, 2012; Thornhill, Clare, & May, 2004) there has been a growing critical movement challenging the dominant biomedical model. This is where the current study wishes to focus.

What we can gather from treatment outcome research is that we generally do not seem to be moving people towards personal recovery and improving their QOL. However, simply adding QOL measures to existing treatment outcome research is insufficient as this would assume that all current therapies need are more measures; whereas I am arguing that we need to go back to our individual clients to gain a shared understanding of what their problems are and how we can work together to get them closer to the life that they wish to live.

3.2 Mental Health Recovery Research

Mental health recovery research and QOL research share an interest in what helps people live a meaningful, rich life. Whilst the latter generally uses quantitative measures to assess wellbeing, research on personal recovery recognises that people experience recovery in many ways and therefore tends to employ qualitative research methods, such as first person narratives (Ajayi et al., 2009; Brown & Kandirikirira, 2007; Salem, 2011). The process of reconstructing one's story following mental health difficulties provides rich data on what can move people closer to recovery. So, whilst quantitative QOL studies can give us information on general trends for a particular population, they lack the rich narratives on the processes involved in making sense of mental health difficulties. The majority of recovery research take an experience-centred approach to narratives, which views narratives as meaningful, sequential, a way that people make sense of their experiences, representative, reconstructive and potentially transformative (Squire, 2008).

Mental health recovery research has been influenced by critical-ideological paradigm, which seeks to challenge dominant discourses and treatments for common mental health problems. As previously mentioned, the majority of research in this area has been with people who have experienced psychosis, to reduce stigma and oppression, increase support, and move treatments closer to what people say they need to live a meaningful life (Adame & Knudson, 2007).

This shifts away from the dominant medical discourse of physical and mental illness which is depersonalising; making it difficult for the psychologist to see the person;

and loses the opportunity to hear and learn about the unique stories of how each person negotiates emotional distress (Adame & Hornstein, 2006). The willingness to consider alternative discourses recognises that psychological therapies for difficulties such as psychosis are not as well equipped to alleviate symptoms but can reduce distress through helping clients to make sense of their experiences (Chadwick, 1997). As Thornhill, Clare and May (2004) argue, psychosis is marked by a chaotic narrative and so giving meaning to these experiences and understanding what helps or hinders the construction of a narrative of recovery is important to understanding how therapies can better facilitate this process.

Mental health recovery research has been influenced by narrative psychology, particularly the meaning making processes involved in constructing stories and how people construct their stories through their social environments (Adame & Hornstein, 2006; Bruner, 1990; Sarbin, 1986). Writers such as Bruner (1990) and Sarbin (1986) argue that we order our experiences through narratives, with our subjective sense of self rooted in the narratives we construct. These narratives develop through our interactions with others and the world that we live in.

One study by Adame and Hornstein (2006) looked at 10 written first person narratives of emotional distress. They found that in a number of the accounts, the process of telling one's story helped people to shift from feeling lost and stripped of their individuality towards integrating their distressing experiences into their overall life narratives and moving towards recovery. The types of stories people told about emotional distress included stories of continuity, traumatic interruption, purposeful or revelatory suffering, psychiatric oppression, and, psychiatric empowerment. This process often involved sharing their stories with others to reduce stigma, to share views on treatments and explore what mental illness means to them. As the writers recommend, we have much to learn as psychologists from these accounts on how to build relationships with clients in distress and work together to help them to navigate this experience (Adame & Hornstein, 2006).

The way that someone makes sense of their experiences and subsequently constructs their narratives seems to be an important part of the recovery process (Adame & Hornstein, 2006). This fits with narrative therapy in which changes in

meaning making processes help people resolve, move on or reframe emotional distress (White & Epston, 1990). Frank (1995) identified different types of illness narratives which underlie this argument. In chaotic or frozen narratives, illness is spoken about like a series of random, incomprehensible events, in which the narrator is caught up in and therefore unable to make sense of their experiences. In quest narratives, the narrator goes through a process of change as they reconstruct the meaning of their illness or distress. Quest narratives draw upon a wide range of narratives and resources, including counter-narratives, alternative narratives and established narratives of suffering and heroism. Whilst in restitution narratives, the narrator seeks a resolution or repair from their experience by primarily drawing upon established medical narratives and resources (Frank 1995, 2010).

Recovery researchers have explored what helps or hinders the construction of a story which allows people to make sense of and move on from emotional distress (Adame & Hornstein, 2006). This has included considering both personal factors as well as the role of wider social and cultural meta-narratives on this process. This is not necessarily about an individual overcoming or ridding themselves of psychological difficulties. Instead, this can involve reframing these experiences and shifting from viewing this as an individual activity to a politicised position in which they challenge ideas of what it means to recover and live a good life (Adame & Knudson, 2007, 2008).

There have been criticisms of recovery research for continuing to place recovery within the individual. Harper and Speed (2012) call for a balance between the personal and political in recovery discourses. One Australian study (O'Brien & Fullagar, 2008) on women's experiences of recovery from depression highlighted how wider systems and cultural discourses impact on distress and recovery. Many of the women in the study talked about the impact of trying to be superwoman and not attending to their own needs in the quest to meet unrealistic cultural ideals. Whilst many psychologists would argue that this is a perception which we could work with clients to change, there is also an argument that what these women are experiencing reflects wider gender politics. Do we need to look beyond the therapy room in our work? It is important that we maintain our humanistic values, working with the person in front of us but there also needs to be scope for our social justice ideals to not only

be fostered in the therapeutic relationship but also in how we can tackle wider societal inequalities. It is important for us to remember and apply our knowledge about how our clients' distress relates to their place in the world (Milton, 2010).

3.3 Narratives of Problematic Social Anxiety

There have not been any recovery studies which have focused on the stories of people with problematic social anxiety. The research literature on social anxiety highlights the features of this problem and how social anxiety develops but it has not explored how people make sense of this experience or the resilience of people with social anxiety to largely operate in socially adept ways despite often struggling with social encounters (Stravynski, 2007). Collecting personal narratives on living with social anxiety is an opportunity to look at individual and collective experiences of this problem and what helps and hinders personal recovery. To date, there has been limited narrative research on social anxiety and what exists focuses on factors which maintain social anxiety (Anderson, Goldin, Kurita, & Gross, 2008) rather than what promotes recovery.

External factors are largely ignored in social anxiety treatments despite this problem being about difficulties relating to others in a particular socio-cultural context. Understanding mental distress systemically involves exploring interrelated processes between the individual, their relationships and the wider society in which they live (Hedges, 2005). Stravynski's (2007) integrative model views social anxiety as both a strong fear of public humiliation and a defensive interpersonal pattern to protect oneself against being hurt by others. It is an exacerbation of normal social fears evoked by living in groups, which leads to the development of interpersonal defence patterns that hinder rather than improve social functioning. In this model, social anxiety is not a result of personal deficits. It is a purposeful interpersonal pattern of powerlessness which develops from childhood and is culturally and socially constituted (Stravynski, 2007). In the current study, life stories are being collected to move beyond a focus on individual deficits and contextualise people's stories of recovery.

3.4 Summary

Collecting life story narratives of problematic social anxiety has a number of potential gains. Over the last few decades, psychologists have turned more to narratives to explore how people make sense or bring coherence to their experiences. Also, increasingly, as seen in narrative therapy, psychologists have started to explore how the stories we tell influence our psychological wellbeing. McAdams (2008) talked about how our narratives are functional and become the “story that we live by” (McAdams, 2008; McAdams & Adler, 2010). People generally seem to be compelled to maintain their story of themselves and others as it provides a sense of order and identity. As social anxiety tends to develop during one’s formative years, it will be interesting to see not only how people make sense of this experience but also how these explanations and stories act to maintain the problem or move people towards personal recovery. Further, it will be interesting to look at what contextual factors allow or hamper this process.

Research has found that people experiencing emotional distress can find solace and a sense of hope from hearing about how others have negotiated and recovered from their mental health difficulties (Adame & Hornstein, 2006). There are stories of other common mental health problems but little available on the stories of the socially anxious, even though this is a problem that is faced every day as one negotiates living in a social world. Narratives are grounded in the culture in which they are produced within a dynamic process in which each individual’s story both originates from and adds to shared knowledge (Gallo & Mattingly, 2000). The present study hopes to explore how people make sense of a difficulty in which there are limited discourses available and by doing so add to (and potentially change) our evolving understanding and talking therapies. How the study findings are shared beyond the thesis (both with the participants and wider audiences) are important to achieving this goal.

Counselling psychology puts formulation at the heart of what we do so that therapy is tailored to the individual. However, there increasingly seems to be a disconnect between the valuing of an individualised approach and what most of us can offer to clients experiencing problematic social anxiety, particularly as the standard recommended treatments are short term, manualised and focus on symptom alleviation (NICE, 2013). This study hopes to remind us that we do not have the full story on social anxiety and have further to go to ground therapies in what people need. This would mean ensuring therapies are grounded in formulations and take into account the many factors which perpetuate and sustain clients' difficulties. For some, this could mean then receiving standardised CBT; for others, taking a more pluralistic therapeutic approach (Cooper, 2008).

Specifically the research will collect life story narratives from people who have experienced problematic social anxiety for at least 10 years to explore the following questions:

- How do people make sense of problematic social anxiety?
- What can these life stories tell us about personal recovery from problematic social anxiety?

The research wants to both value the subjective experiences of participants whilst challenging the notion that mental health recovery sits solely within individuals. As “recovery” has become propagated by policy makers and increasingly wrestled away from service users, it has lost its focus on challenging structural inequalities which increase the risk of experiencing chronic emotional and psychological distress (Harper and Speed, 2012).

None of us exist in a vacuum. It is likely that changes in how people negotiate problematic social anxiety will involve some personal changes but context always matter. Whilst wider factors are difficult to address within therapeutic settings, it can be argued that as psychologists we have a duty to look beyond the treatment room to see how we can help to address structural inequalities which perpetuate client difficulties, such as problematic social anxiety (Milton, 2010). This occurs within

treatment approaches such as systemic therapy but could also be expanded to mental health promotion and education to communities, schools and workplaces on how to identify and help those struggling with social anxiety.

METHODOLOGY

This chapter discusses how the study has evolved and been conducted. The chapter starts by discussing my initial interest in conducting this research. It then moves onto describing how the study has been co-constructed with others who have struggled with social anxiety throughout their lives. This has been a long, often challenging learning process for us all, in which I have been reminded about the difficulties and rewards of conducting participatory action research (PAR). It has been important to document this process to critique how participatory the study has been and also so that it can inform others interested in conducting this type of research on what needs to be considered and avoided.

4 Reflexive Statement: How the Study Came To Be

My interest in this topic and method is grounded in my own life experiences and practice. This is commonly found amongst PAR researchers, for whom practice sits alongside with or inspires one to seek out particular philosophical and theoretical perspectives (Wicks, Reason, & Bradbury, 2008). It is an approach to research which grounds theory in practice, building upon Freire's (1972) argument that knowing is grounded in reflection of our own actions. During my training I have been in various NHS placements in which I have worked with clients who experience problematic social anxiety. This has included clients who have struggled to manage anxiety throughout their lives. I have also worked with clients who have experienced social anxiety in relation to other mental health difficulties, such as clients who hear voices, clients who stutter and clients with post-traumatic stress. This has highlighted the many different ways that social anxiety can interfere with someone's life.

Some clients' experiences share commonalities with my own struggles. The challenges of living with and negotiating problematic social anxiety informed my initial interest in this topic. Social anxiety has impacted on my life since I was a child. It took me many years to seek professional help. I received CBT for panic attacks in Australia and for social anxiety in the UK. I gained a lot from these talking therapies,

particularly in understanding how I respond to anxiety and how my thoughts and behaviours led to vicious cycles which sustained and fed my anxiety. However, post-treatment I felt that I had not had the opportunity to consider how I came to view the world as a hostile place nor how to negotiate a different way of being with others. I was left with the feeling that CBT was helpful but did not go far enough. Through personal therapy during training I have had an opportunity to gain insight and make changes in these areas. This has been an ongoing process of learning a new way of being with others, which has enriched my relationships and now makes social anxiety something which is there but not as powerful as in the past.

This personal journey led me to start thinking about how others negotiate this difficulty. There are limited public or professional discourses on problematic social anxiety. As someone with high mental health literacy, it took me many years to gain professional help. My difficulties being amongst others, particularly talking to them, were either underplayed or seen as a character trait (or flaw). This got me thinking about how people struggling with social anxiety come up against various systems and structures which do not tend to recognise, and so inadvertently dismiss, our struggles.

Despite being one of the most common mental health difficulties and one which often originates during childhood and takes a chronic course for many, we have little voice in mental health research, treatment or wider societal discourses. I felt this needed to change and wanted to reach out to others to see whether they were feeling the same way. I wanted to make use of being someone inside the system to try to make this happen. I felt this was not only a chance to protest but for those of us who struggle with social anxiety to be at the forefront of how it is understood and treated. The lack of available discourses could be an opportunity for us to be involved in shaping it if we can mobilise and get our voices heard.

My dual role as a mental health professional and ex-service user has not always been easy to navigate. It felt risky to disclose during training but crucial to the study being conducted transparently. By being open about my own mental health history, I am letting participants know that I may share some of their experiences. I am also letting them know that I am wondering whether they are getting the help that they

need, including whether current talking therapies for social anxiety are accessible and good enough. As I started to consult treatment outcome research, this hunch started to take shape. However, if I took that information to then design and conduct a study without involving participants beyond the interview itself, I felt I would be taking up a position of authority and going against the social justice and empowerment agendas which brought me to this profession. I want to be involved in work which breaks down notions of us and them.

5 Research Paradigm and Epistemological Position

Whilst counselling psychology has adopted qualitative methods more so than other branches of psychology (Creswell, Hanson, Clark, & Morales, 2007; Morrow, 2007), psychological research continues to be dominated by positivist and post-positivist paradigms and associated quantitative research methods (Ponterotto, 2005). Much qualitative psychological research also sits within these paradigms (Madill & Gough, 2008; Ponterotto, 2005). Things have been changing over the last 30 years with the emergence of postmodern perspectives and associated qualitative research methods. Paradigms reflect our views of what the social world is and how it can be understood, which guides research practices and methods. Within each paradigm there are different views about the nature of reality (ontology), knowledge construction (epistemology), the values of the research (axiology), the role of the researcher and participants in the research (rhetoric), and scientific rigor (methodology) (Hays & Wood, 2011).

We often move between different paradigms. However, within each research project it is important to communicate the underlying assumptions and beliefs guiding the research as without this, it is difficult to judge its relative merit (Hays & Wood, 2011; Morrow, 2007). In the thesis I do not neatly fit into one paradigm. I am primarily drawing upon a critical-ideological position to challenge dominant discourses and talking therapies for social anxiety through a PAR study. A critical-ideological paradigm assumes multiple realities, whilst stating that there is a reality related to power and oppression. This paradigm has critical-realist ontology whilst valuing

subjectivity and the co-construction of meanings. The researcher's position is value laden (Morrow, 2007; Ponterotto, 2005).

Psychological research largely operates within a positivist paradigm, which values certain types of knowledge (e.g., RCTS; systematic reviews) over others (e.g., personal accounts). Service users have criticised this approach, which traditionally has placed less value on their experiences. Service user researchers argue for a shift to knowledge-based policy and practice, which values both individual and collective experiences (Beresford, 2006). The current study shares this agenda.

I have also drawn upon social constructionism to analyse the recovery narratives. The analysis has taken an experience-centred approach to narratives but also looked at the role of wider social and cultural factors (Squire, 2008). This approach recognises that we frame our experiences and identity through the stories we tell. We construct, deconstruct and reconstruct our identities through narratives of experience (Basset & Stickley, 2010). The personal and social are always interconnected. The mental health service user literature has criticised social constructionism for not adequately accounting for the lived experience of emotional distress (Chadwick, 1997; Crossley, 2000). Like any paradigm, social constructionists do not all hold the same views on subjectivity. Social constructionism can take a top down approach whereby people are shaped by discourses but there are many social constructionists interested in how people interact with discourses. Rather than taking an either/or view of the individual and society, they view the relationship as both/and or as part of a wider systemic model (Burr, 1995, 2003). This is where the current study situates itself.

6 Participatory Action Research (PAR)

PAR aims to emancipate marginalised populations by actively involving them in research to improve their lives (Cohen, 2008; Kidd & Kral, 2005). PAR brings together the traditions of action research and participatory research. The former originated through the work of social psychologists, such as Lewin (1958), who

argued that researchers need to act in or on the social system to generate theory and improve social problems. This saw a shift from positivist, objective view of social behaviour to grounding events and their meaning in individual and social contexts. Action research involves cyclical processes of planning, acting and evaluating to solve problems and create new knowledge (Khanlou & Peter, 2005).

Participatory research originated in work with exploited and oppressed groups in the developing world (Fals Borda, 2001). This humanistic research approach aims to mobilise people's resources to control research and make structural changes which improves their lives (Khanlou & Peter, 2005). This process helps people to recognise their own resources and move them towards self-determination. It recognises that we are all able to reflect upon and act on our environments if provided with the opportunity, skills and support to do so (Rahman, 2008). Bringing these traditions together in PAR provides a framework for involving those who have been marginalised in mental health research (in this case those with problematic social anxiety) to the centre of how a problem is defined, analysed and tackled.

General principles and objectives of PAR include meaningful participation, empowerment and improvement of service users lives. Knowledge generation is in itself an insufficient outcome of PAR. One needs to ensure that the research process and findings work towards improving the lives of those involved in the research. PAR prioritises experiential knowledge, values the subjective and challenges the idea of the neutral, objective researcher (Beresford, 2006). As Lewin (1958) argued, social knowledge is not directly observable; it is co-constructed between all those involved in the research process. PAR is not a method per se. It is better understood as an orientation to research, in which a variety of methods can be used, depending on what is being investigated (Khanlou & Peter, 2005; Wallerstein & Duran, 2006). There does not have to be a marriage between these principles and the method used. However, in this study, it has been important to bring the two together as using a positivist research method would feed into the reductionist, biomedical model of distress that recovery researchers want to move away from.

Traditional (positivist) notions of validity are not particularly relevant to PAR. Whilst it has grown in popularity in recent years, it is still a contested approach, particularly in

academic settings, in which PAR has been seen as something which practitioners do whilst academics get on with “real” research (McTaggart, 1998). However as post-modern perspectives took hold, ideas of what constitutes valid research changed. In PAR this includes how the research process and findings reflects and affects social, cultural and political practices (McTaggart, 1998). Research needs to be credible, coherent and useful for those involved in it. As the process itself plays such a key role, negotiating how the study is conducted and documenting and critiquing this process are important considerations in assessing validity (McTaggart, 1998). Ideas of what is “truth” are consensually negotiated between all those involved in the research (Rahman, 2008). There are still battles to be fought in having PAR recognised as a valid approach to research, which include the need for these studies to be conducted within academic settings to build its credibility (Fals Borda, 2001). This study is my modest attempt to be involved in this movement.

7 Ethics

The study has ethics approval from UEL, which involved establishing clear procedures for informed consent; voluntary participation and right to withdraw; anonymity and confidentiality (including explaining in what circumstances confidentiality would be breached and how this would occur); data protection; protection of participants, including debriefing; and protection of the researcher, including conducting all interviews at UEL or at Social Anxiety Self Help (SASH) (See Appendix 1). The distinct ethical considerations in conducting a PAR study have been considered throughout the research process.

Guidelines for conducting ethical PAR health research have been developed to assist researchers and research ethics panels’ review research quality and conduct (Green et al., 2003). Broadly, these assess the level of involvement of stakeholders in each stage of the research process: how participants collaborated in developing the design; choosing the topic, determining the purpose of the research; carrying out research tasks; determining findings and how they are shared; and, whether the research facilitated changes in stakeholders lives (through education, action or other

changes). In the present study, people have been involved as advisors and/or participants. This has involved discussing and agreeing each stage of the research process, including which tasks require me to take the lead (e.g. narrative analysis).

8 Research Design

Koch et al. (2005) used a PAR approach that moves through a process of “looking, thinking and acting” with participants. This cyclical process was originally proposed by Stringer (1999) and shares much with Freire’s (1972) idea of “conscientization”: which is the raising of critical consciousness to facilitate self-actualization and change (Koch, Mann, Kralik, & van Loon, 2005). My aim has been to jointly move through this cycle during each stage of the research process. The following section documents this journey and how this will continue to be undertaken when the research ends and it is agreed how to share and use the findings outside of the doctoral thesis.

8.1 Selecting a Topic and Study Design

As a first step I wanted to talk to people with problematic social anxiety about my research ideas and invite them to become involved in shaping what the research would explore. I commenced the research in May 2012. I developed a relationship with the organisation Social Anxiety Self Help (SASH) in London and joined the online forum Social Anxiety UK (SAUK) at <http://www.social-anxiety-community.org/db/>.

I posted an overview of the study, including information on my position, history and research aims and suggested four broad research topics for feedback. These topics were:

- your experiences of social anxiety, including how it all started
- how you understand your mental distress/mental health problems
- recovery and getting better
- what has helped you to get better?

Around 20 people offered feedback. The feedback supported these broad topic areas as all being important topics to explore, rather than choosing to focus on one over the others.

“I think the areas you are researching at present are precisely where you need to be”
(Female, SASH group)

“I think it is a good research topic to choose because although it is one of the most common mental health conditions because of the nature of it, it also one of the least known about.” (Male, SASH group)

“I’m so pleased to have found your study. I love what you are doing and of course, it would be great to help by being interviewed and in many other ways” (Female, SAUK forum user)

I also asked people whether there were other topics and/or sub-topics that they wanted the study to explore. The following ideas were provided via users of SAUK and SASH self-help group:

- The long term impact of therapy, including CBT
- The role of shame and lack of self-acceptance in social anxiety
- Societal and medical models of social anxiety and how these models impact on recovery
- Are there different types of social anxiety and if so, do they require different types of treatments?
- The role of early significant relationships, including overprotective parenting on social anxiety
- Cultural factors in social anxiety
- Providing safe environments for people with social anxiety to learn new ways of being with others
- The role of anticipatory anxiety

People also talked about how they had felt left out of the research agenda and therefore liked being consulted and involved throughout the research process. People also talked about how they felt little research was being conducted into this problem; how they struggled to find information on getting help; and, often felt dismissed by health professionals, including mental health professionals. I was overwhelmed by the thoughtful responses from the public and, with my supervisors, looked at how to incorporate these suggestions.

Each topic could have worked as a stand-alone topic but this would have involved choosing one over another, which I did not want to do, as I wanted to try to incorporate each person's feedback. The suggestions could be broadly grouped as relating to causes and maintenance factors in social anxiety (which fits with topics 1 and 2 from my original list) and as relating to recovery and getting better (fits with topics 3 and 4). These topics seemed to be about trying to make sense of this experience (e.g. what caused it? Why is social anxiety a problem for me?) and finding ways to move on or overcome this difficulty (to recover). It was agreed with potential participants that by taking a life story, narrative approach, participants' would be able to tell their story and focus on what was important to them. I sent individual emails to all who had provided feedback as well as posted this idea onto Social Anxiety UK and SASH's websites. Feedback on this idea was also positive, with people agreeing that this was a good way to incorporate their suggestions. I also posted the draft topic guide for feedback. The topic guide covered three key areas (with prompts):

- Experiences of problematic social anxiety
- What people think about recovery/getting better
- What has helped or hindered recovery/getting better

People agreed these were good key questions. They were also enthusiastic about the idea of offering a variety of ways to participate given how difficult it is for some people with problematic social anxiety to be in an interview. This was borne out during the data collection stage as discussed later in the chapter.

8.2 Participants

Recruitment then began through the same channels (SASH and SAUK) inviting people with at least ten years of problematic social anxiety to participate (see Appendix 2). For most people, social anxiety becomes problematic during late childhood or adolescence. By talking to people who had struggled with social anxiety for a number of years I hoped to gather rich, multi-layered narratives that captured the various ways that people negotiate the problem itself and move towards personal recovery. I also asked for participants who were not currently receiving NHS talking treatments as the purpose of the study was not to critique a particular treatment. Also as many people who struggle with social anxiety never access health services, I did not wish to exclude people who had not come into contact with the NHS about their social anxiety. A summary of participants are included in table below:

Pseudonym	Age	Gender	Ethnicity	Relationship status	Diagnosis (SAD)?	Participation Method
Mia	24	Female	White-British	In relationship	No	Face to face
Samuel-James	34	Male	White-British	Married dad	No	Phone
Mohammed	26	Male	British-Asian	Single	Yes	In writing
Alice	41	Female	White-British	Divorced	Yes	Video Skype
Janet	45	Female	Black-British	Single mum	No	Video Skype
Rose	28	Female	White-Irish	Single	Yes	Phone
Sally	42	Female	White-British	In relationship	No	In writing
Massimo	40	Male	White-European	In relationship	Yes	Face to face

8.3 Data Collection

30 people expressed interest in participating in the research. I offered a variety of ways of sharing one's story. Nine narratives were collected, using a variety of mediums. Face to face interviews were conducted at UEL and SASH. It has been a slow but fruitful process. A few interviews were cancelled at the last minute due to anxiety, yet people kept in touch and we negotiated the best way for them to participate, which meant that most cancellations translated into interviews at a later date. Participants said it helped knowing that I have had problematic social anxiety in

the past. They also talked about how despite their anxiety, they felt that participating in the study would be useful and worthwhile for them. Many said that it was the first time they had spoken to anyone about their struggles with social anxiety.

One of the phone interviews has not been included in the analysis as the participant found it difficult to engage in the interview process and talk about the research topics. She would share a part of her story then ask for reassurance and diagnosis, which I declined to do. In retrospect, I think it would have been good to stop the interview and talk about what was going on. Whilst I am not using this story in the analysis, I did maintain a dialogue with the participant, offering information on sources of further support.

The initial interviews used three key questions (experiences of social anxiety; helping and hindering factors; personal recovery) with a number of prompts. To alleviate anxiety, I provided participants with the interview topic guide (Appendix 3) before the interviews. As data collection progressed, I found that participants talked about these topics without being directly asked. As a result, I stopped sending the topic guide and instead, asked people to start wherever they wished to begin and used a prompt like “and then what happened?” to gather rich stories. Everyone started their story from childhood, either with their first experience or awareness of being socially anxious or what they were like before social anxiety became problematic.

I was influenced by narrative therapy questions, which are used to help people to tell rich narratives but also encourage deconstruction of the master narratives that sustain problems. This was to encourage participants to move beyond problem saturated stories by identifying and building upon unique outcomes in their accounts (Morgan, 2000; White & Epston, 1990). The interviews were not narrative therapy sessions but when I was present during the story telling, I would encourage people to talk more about unique outcomes (e.g. when someone spoke primarily about their struggles being with others but then spoke about people they felt comfortable with, I would ask them to talk about what is different about these relationships/people).

8.4 Narrative Data Analysis

Narrative analysis is an umbrella term for a range of different methods and theoretical orientations, which have been used in different disciplines to study people's stories. As a novice narrative researcher it has taken me time to start to understand the different approaches to narrative analysis. As previously mentioned, the majority of recovery research takes an experience-centred approach to narratives (Squire, 2008). Recovery, like narratives, has a temporal order, following a chronology of experiences and events. Brown and Kandirikirira (2007) talk about this narrative process in narrative therapeutic terms, highlighting how the act of re-narrating or re-storying one's life can be positive and empowering. This recognises that the act of reflecting on an experience may change it (Polkinghorne, 2005).

This type of narrative inquiry is broadly social constructionist (Burr, 1995, 2003). Writers such as Bruner (1990) and Sarbin (1986) argue that we order our experiences through narratives, with our subjective sense of self rooted in the narratives we construct. These narratives develop through our interactions with others and the world that we live in. This is one of the dichotomies found in narrative research: valuing the subjective whilst exploring the role of wider discourses. Increasingly, there are narrative researchers finding ways to work with this dichotomy rather than claiming that it can or should be resolved (Squire, Andrews, & Tamboukou, 2008).

People's lives are multistoried. We tell different stories at different times to different people. When conducting this type of research, one needs to constantly think and interpret how meaning is being conferred, how narrators arrive at their stories, and how researchers arrive at conclusions about these stories (Bamberg, 2010). The challenge is in judging when to stop this cyclical analytic process (Squire, 2008). To complicate matters further, unlike other qualitative approaches, there are rarely clear guidelines on how to do narrative analysis (Riessman, 2002; Squire et al., 2008). Reflexivity and checking in with supervisors and participants has helped to manage this process, as has constantly returning to the research questions to ensure the analysis is grounded in trying to answer them.

Validity or trustworthiness of the data is seen in the persuasiveness of accounts, cross-checking with participants, coherence of findings and their pragmatic use (Brown & Kandirikirira, 2007; Hoshmand, 2005). These principles for assessing rigor are found in the narrative analysis literature (Hoshmand, 2005; Riessman, 2008). The current study has taken a similar approach, asking participants to identify key themes and then sharing my initial analysis for further feedback.

I found it useful to interrogate each narrative using a recovery narrative typology developed by Adame and Hornstein (2006) (see Appendix 4). This typology analyses narrative characteristics, including the structure, purpose, voice and meanings of subjective, first person accounts of emotional distress. Using this typology was helpful to ask initial questions of the stories and think about what was being conveyed in the participants' stories. The typology poses a set of questions for each narrative characteristic. To analyse each of these characteristics, I went through the stories line by line and pulled out examples from people's stories which I felt answered each question. This process involved constant shifting between a micro and macro analysis of the stories so that particular segments or quotes were contextualized in relation to the whole story (e.g. whether as points of difference or similarity).

For example, to analyse Mohamed's subjective experience of emotional distress, two typology questions asked were "*Does the narrator identify a specific cause for his or her emotional distress?*" and "*Does the narrator explain the cause of his or her distress?*" Mohamed wrote about this in detail, identifying social anxiety as a developmental problem, situated both within the family and influenced by wider cultural factors. For example, he spoke about living with an authoritarian dad (128-171) and his feelings of inferiority and difference as a Bengali growing up in a White British community (174-187) to explain how social anxiety became problematic for him.

In the analysis of narrative structure, one question asked: "*Is there a turning point in the narrative that distinguishes the pre-distressed narrator from the post-distressed narrator?*" How this looked in each of the participants' stories varied. For example, in Janet's story there was a clear distinction made between herself as the bubbly child

(62-68) before the impact of childhood abuse manifested itself in adolescence into enduring social anxiety and depression (74-86). When analyzing narrative structure, I also considered what was missing from the typology and looked at other narrative analytic approaches to deepen the analysis. I found it useful to incorporate Frank's work on illness stories (1995, 2012) to explore the dominant story genres being presented. This involved considering the story structure as a whole as well as by drawing out particular examples of how the story told was predominantly a story of chaos, restitution, or quest.

To analyse narrative voice, I considered typology questions such as "*Does the experience of emotional distress (social anxiety) lead to a reconstruction of the narrator's concept of self?*" This question was particularly pertinent as each participant talked about how they had struggled with this problem for a number of years and so had spent considerable time trying to understand and negotiate this problem. In each story, people were at different stages of this reconstruction. For example, in Samuel James' story he talked about how his efforts to make sense of his experiences or "to get to the bottom of it" (63) allowed him to not only view himself and his history differently but to then use this information to move into a helping role which better fitted this new story of himself (475-479).

The typology questions on narrative purpose were the most difficult to apply to the participants stories as many of the questions are more pertinent to stories from the psychiatric survivor movement (e.g. questions on exposing systemic abuses; whistleblowing). However, there were still some useful questions to consider, such as, "*Is the narrative proposing an alternative viewpoint about mental illness?*" As seen in Massimo's story of the helpfulness of using a range of physical and psychological therapies to change his way of being with others (238-51; 286-309).

For a detailed example of how I applied this typology to people's stories of problematic social anxiety, please see the analysis notes from Alice's story which is included in Appendix 5. The typology provided a good starting point but as this was developed for a particular type of emotional distress narrative, specifically from stories from the psychiatric survivor movement, I felt I needed to look at other narrative approaches to think about how to contextualize participants' accounts.

In later studies (Adame & Knudson, 2007, 2008), the authors moved beyond subjective accounts to explore how people's recovery stories draw upon or reject dominant cultural narratives of emotional distress. I found it useful to apply their question on positioning within stories, specifically, what is the positioning of the narrator's story in relation to the master mental health narrative? Does the story support, challenge this master narrative or offer an alternative perspective on emotional distress? These studies are interested in how people deploy wider cultural narratives in their personal narratives, recognising that the cultural and personal are interconnected. These studies provided good starting points on how to move beyond a subjective analysis in the thesis and situate people's stories within wider cultural, societal and political narratives (Riessman, 2002, 2008). To identify these wider cultural narratives, I found it useful to also incorporate Frank's (2005, 2012) dialogical narrative analysis approach to consider how people's accounts drew upon or rejected narratives. Frank (2005, 2012) recommends identifying the following in people's stories, such as the multiple voices in a story; the resources or wider narratives available to the narrator in their story; why the narrator is telling this story at this time; and, how the narrator's story acts to "hold their own", as in how does the story sustain the narrator's sense of self and identity, including their membership in particular groups or shared identities (Frank, 2012). For example, in Rose's story she was able to draw upon psychiatric, psychological and self-help narratives to not only negotiate social anxiety but to also claim membership of these groups (523-24). Please see Appendix 5 for a detailed example of how these questions informed and deepened the analysis of people's accounts of social anxiety.

Drawing upon these studies, including using typologies to ask particular questions of people's stories, helped to consider how people's adoption or rejection of dominant mental health and other cultural narratives and counter-narratives facilitated sense-making of problematic social anxiety. And, what, if any role, this ongoing process has in facilitating personal recovery.

8.5 Participatory Data Analysis

There is a power and status associated with doing analysis that many researchers find difficult to relinquish (Nind, 2011). Involving participants in the analysis is arguably the most challenging part of participatory practice. I was concerned that sharing my analysis with vulnerable participants could be potentially upsetting and, therefore, unethical. People with social anxiety are generally worried about how they come across to others and, hence, I needed to ensure the analysis did not feed into this. I noticed that the participants seemed eager to please and were unlikely to disagree with me as the supposedly knowledgeable expert. An initial answer to this dilemma was to look at how I might provide training on analysis. This would have been time consuming and it is questionable I have the skills to provide adequate training.

Holland and colleagues (2008) used an informal approach, exploring and encouraging feedback on thematic ideas with participants. This type of approach tries to remove the tendency to view the researcher as expert (Holland, Renold, Ross, & Hillman, 2008). Someone's narrative is their story, not mine; therefore, I needed to find ways to check in with them the key messages in their story that they wanted me (and others) to hear. Asking participants to highlight key messages rather than imposing them onto participants has helped facilitate this process.

Four of the participants provided feedback on their stories (see Appendix 6). Each person was asked to read through their story and identify three main themes. Participants also provided an update on how things had been for them since the interview, particularly what, if any, changes they had experienced. They also talked about the impact of sharing and reflecting on their story. Many talked about how this process had given them a different perspective on their social anxiety. Many came to realise how they were already on a journey towards recovery, of which involvement in the research seemed to play a part. Many also started to articulate and bring to life their own notions and experiences of personal recovery, which often looked very different from clinical recovery.

Some of the challenges doing the analysis have included being too prescriptive and biased by looking for “good” narratives which fit within my ideas of recovery. I am coming from a particular position, but I have needed to make room for stories which contradict this position. Involving participants in the analysis has hopefully allayed some of these biases. For example, for some participants existing therapies and wider discourses on understanding social anxiety have been useful and sufficient to move them towards recovery. For others, the idea of recovery is something that felt unattainable. In PAR studies, McTaggart (1998) talks about the importance of making room for a juxtaposition of points of view rather than trying to fit everything within one interpretive frame.

ANALYSIS

Each narrative has been analysed and presented individually. The types of narratives and sense-making processes, including how local and wider contexts impacted on the types of stories told varied from story to story. The analysis considered what these stories of problematic social anxiety can tell us about personal recovery. This way of analysing the stories recognised the important contribution each person's story has made to the study. It also acknowledged the sharing of each person's story, often for the first time, about their struggles with social anxiety. Taking this approach also facilitated participant involvement in the analysis.

All of the stories were rich accounts of living with problematic social anxiety. Drawing upon narrative research on illness and recovery (Adame & Hornstein, 2006; Adame & Knudson, 2007, 2008; Frank, 1995, 2010) I was interested in how people made sense of their social anxiety and the types of stories they told. What narrative resources were available to people to construct their stories? Have people drawn upon or rejected dominant narratives of mental health to navigate recovery? What other cultural narratives and social structures have played a role in shaping the stories told? See Appendix 5 for an example of the analysis.

9 Traditional Stories: When the Mental Health Narrative Makes Sense

Three of the participants (Rose, Alice and Mohamed) received a diagnosis of social anxiety disorder and completed a course of individual CBT for social anxiety. Whilst all three displayed symptom reduction according to clinical measures, their stories of social anxiety and recovery highlighted different ways of negotiating the CBT story of social anxiety. I found it useful to think about group narrative templates when analysing these stories. Specifically, about how groups impose particular narratives onto their members which are then expressed through members' stories. Research

has looked at narrative conformity within particular groups, such as AA (Frank, 2010; Holstein & Gubrium, 2004). These narrative processes are also likely to be at work in other groups, such as between clients and mental health professionals.

Rose's and Alice's stories fit within Frank's (1995, 2010) definition of a restitution illness narrative. In their stories, they largely drew upon an explanatory framework which came from professionals to explain and respond to problematic social anxiety. As will be discussed, adopting this narrative resource seemed to have done more than explain their social anxiety. It also appeared to shape how they talked and made sense of their lives in general, leading up to diagnosis and through treatment and beyond. Whilst for Mohamed he wrote about his experiences of social anxiety and CBT to then reject this master narrative of social anxiety.

Alice's Story: CBT as the Path to Recovery

In the interview, Alice's story of social anxiety was primarily a restitution illness narrative. A restitution narrative plot involves health professionals providing stories about others like the patient who have become ill; received successful treatment; leading to restoration of a life as it was before illness (Frank, 1995, 2010). In emotional distress stories like Alice's, the restoration does not seem to be so much about returning to a pre-illness state but to a new post-illness way of life. In this type of story this occurs if one follows or enacts the story of distress offered by mental health professionals.

Alice's story highlighted how integral our relationships are to our stories and sense of selves. She explicitly talked about this in relation to old and new relationships in her life. She talked about how new friends in her life *"know nothing about my past so are not reminding me about how I used to be"* (432-3) therefore helping co-construct a re-authoring of her life. The importance of these relational changes in recovery also seemed to influence her perspective and engagement in older relationships. For

example, when she talked about how her mum would say that her and Alice were the same (e.g. *"my mum always said, oh you've got my genes or you're just like me, you're a chip off the old block"* (181-2); *"my mum says I have McLaren bad luck"* (569-70), she appeared to be talking about how these family scripts (Burnham, 1988) had shaped her views on her distress as inherited, genetic, or familial bad luck. These are perspectives she has now disavowed.

What voices are in the story? (Frank, 2012) She seemed to move between two distinct voices, using both past and present tenses to distinguish between how she saw things then and how she sees them now; possibly to reinforce her position now? There was a voice which I identified as the confused child and adult, trying to deal with dad's illness (48-9; 185-7); mum's anxiety and over-protectiveness (46-7; 175-8); attracting relationships in which she felt protected (at school; with mum; her marriage) (100-1; 115); overworking to avoid the mistakes which would lead to humiliation (84-5); and, people-pleasing to avoid conflict and being disliked (29-32). She talked about how she did not really understand at the time what was going on and put it down to being dysfunctional (96) weak and weird (98-9): *"all I thought was that I was slightly dysfunctional and was born with it"* (20).

The other voice in her voice seemed to have been enlightened through a restitution narrative in which CBT had provided her with *"the facts"* (102). She talked about looking back on how things were in the past with amazement (94); using the language of CBT (e.g. *rumination*) (82); *avoidance behaviour* (299) to explain how she views that time in her life now or as she put it *"so it wasn't until I had CBT that it really got to the nub"* (284).

Extract 1: *I didn't know that was going on not until I broke it down into thoughts, feelings, um you know thinking, anticipating what was going to happen and then um you know looking at hindsight, you know the more cognitive behavioural thing, I really didn't know or understand how much I was in my head and how I was not paying attention to what was around me* (370-4)

Extract 2: *“I can’t remember now whether I was starting to think am I socially anxious after something I found on a Google search or whether I did it after speaking to the clinical psychologist I can’t quite remember what came first but I know once I knew it I got lots of information and started thinking yes gosh that’s me oh my god! I just thought oh great! (laughs) this isn’t normal I can feel different, I thought this was me!” (696-700).*

In these Extracts we see Alice talking about how she has negotiated the mental health (particularly CBT) narrative of social anxiety to understand and move on from her problems. So through finding the diagnostic label, receiving a diagnosis and CBT, she seemed to have achieved much more than changes in her anxious thoughts, feelings and behaviours. She shifted from seeing herself as deficient in some way to being able to use this narrative to develop a non-shameful conceptualisation of her difficulties. In her story this process promoted self-compassion and acceptance and triggered many changes in her life, including new insights into her past; her sense of self (228-30); relational changes; and a career shift (735). Or as she put it: *I just feel more authentically myself* (345-6).

Whilst, in her story, she now recognised that she had struggled with social anxiety for much of her life, her diagnosis and treatment had occurred within a year of the interview (194-5). How did being a relatively recent recruit to this psychological understanding impact on her allegiance to this master narrative? Her story evoked the fervour of a new recruit when they find a way of seeing things which are novel and make sense. She talked about what it was like to get the description of social anxiety disorder (one of her *Eureka* moments) (379); how her CBT therapist normalised and explained her experiences (467-72); and, about how receiving CBT process (370-4) was like a process of enlightenment which then permeated other areas of her life.

Is this the new script for Alice’s life? Her story fitted neatly together, had been thought about and told to others before (i.e. *“it was in my blog”* (34)). At the time of the interview, she was moving into a mental health role, to provide opportunities for

people with social anxiety to practice CBT skills outside of therapy. It seemed important that she presents herself as recovered: *I still have some difficulties but um I would say I'm recovered to a normal level I would say* (337-8) and committed to the CBT model of social anxiety, which had not only facilitated her recovery but which she now positioned herself to represent, almost like a disciple to this cause.

So in Alice's story there were aspects of a chaos narrative (to describe her pre-treatment perspective of what was going on) and a quest narrative (to describe how she has drawn on the CBT narrative template to make sense of her life and change it) (Frank, 2012). There is a tendency to view these genres as opposing types of stories; perhaps undermining how the narrative processes involved in taking on and rejecting master narratives are the same. There can be a tendency to remove agency or negotiation within a restitution narrative; or to view this master narrative as so powerful that its emplotment demands all or nothing from narrators. This is not how this narrative genre was presented in Alice's story, which was reminiscent of a "psychiatric empowerment" narrative (Adame & Hornstein, 2006), in which Alice has come to advocate for the mental health system which has offered her a new way of life.

Rose's Story: Social Anxiety as Psychiatric Disorder

Similar to Alice's story, the life story that Rose told me was primarily a restitution illness narrative (Frank 1995, 2010) which drew upon the psychiatric narrative template of social anxiety disorder. Clinical psychology (which she hoped to train in in the future) and talking therapies, such as CBT, seemed an extension or part of this mental health narrative template for Rose. She generally spoke positively about this narrative, as seen in a psychiatric empowerment narrative (Adame & Hornstein, 2006).

The meanings and stories we have about an illness can act to take care of us (Frank, 2007). This seemed particularly pertinent for Rose given the considerable grief she has had to manage since losing her mum to motor neurone disease when she was 12 years old. This narrative may have played some role in helping her to make sense of and negotiate this pain and its effects.

Extract

I know it wasn't a straightforward diagnosis but what do you think of the idea of being given a diagnosis of social anxiety disorder? How did you feel about that?

"to be honest I was really happy cause it felt like validation um and I felt like for a moment I could maybe not feel guilty about how I am or who I am, that maybe part of what I'm experiencing or part of the reason I do things is this disorder that you know that they are telling me about and it felt like relief I suppose in a way and also my identity in that I could identify with other people who had the same diagnosis, that I wasn't alone, that it wasn't a personality flaw and also something that was potentially treatable you know and I think unless you have this diagnosis then it's difficult to look for the most appropriate treatment and I know people complain about labelling and you know pathologising shyness and stuff but I can't stand those arguments because for me it was a relief to have a diagnosis to have a label, in a way I like that label, it gives me an identity and um sometimes I might use it like if I have negative thoughts sometimes I'm able to step back and say that social anxiety disorder's speaking not an objective, rational appraisal of reality this is social anxiety disorder so I get a lot of value from it to be honest" (515-33)

The diagnostic label of social anxiety disorder seemed to serve a number of possible functions for Rose. In the extract she mentioned how having a label gave her an *identity* and *validation*. This label possibly helped her to identify with other members of her family, whom she talked about in relation to their own mental illness diagnoses and problems "*within my family there's been um a history of mental illness*" (241-253); perhaps reducing the sense of difference she had felt growing up (54-63).

There was a social function to her diagnosis. In the Extract she talked about being able to *identify with other people who had the same diagnosis*. It appeared that being given this diagnosis by a psychologist had allowed Rose to unequivocally claim membership of a group, rather than constantly doubting her right to be part of it, which she alluded that she had and continues to struggle with in other social groupings (546-7;628-9; 641). This group membership seemed to have also given her permission to join support groups for those with social anxiety (776-88), which had allowed her to start to build personal relationships in which social anxiety is acknowledged and discussed.

It appeared that her anger at others who dismiss the diagnosis as *pathologising shyness*, related to how, for Rose, if it is shyness, then this means it is a *personality flaw*, which sits solely within her, whereas if it's a diagnostic label, it is a disease which is external and can be treated. Her concerns about her difficulties not being taken seriously were later talked about in relation to seeing a psychiatrist: *"I felt like they just didn't really have the time for me to listen to my you know young woman neurosis"* (495-6). This appeared to be Rose talking about how hard it had been for her to have had only negative cultural narratives to draw upon to explain her personal experiences.

Whilst there is often a moral dimension to illness this seemed to work differently in Rose's account. When someone receives a diagnosis, particularly of a stigmatised condition, part of making sense of this commonly involves asking "why me?" and in turn wondering whether one has acted in some way to cause the illness. This can include feeling partly to blame and that illness is in some way deserved. In Rose's account, this process seemed to work the other way around: she had had to take responsibility for her difficulties with social anxiety which now could be taken on and explained by the diagnosis.

In Rose's talk, embracing this psychiatric or medical narrative of her emotional distress seemed to partly function like we see in many affected by a physical illness,

as something which attacks the body and can be treated or expelled. But it was more than that, as for Rose, living with social anxiety is an ongoing, day to day experience in which social anxiety had become inseparable from her life history. Often the Western biomedical narrative and illness meanings are viewed in opposition to each other, like the former is unable to adequately account for the latter (Kleinman, 1988). This did not seem to be the case in Rose's story. When she talked about *I could maybe not feel guilty*, she seemed to be saying that this narrative provided an explanation for not only the *how* (social anxiety's impact on her body) but also the *who* (social anxiety's impact on her sense of self).

This label also seemed to (perhaps surprisingly) have helped Rose to externalise her social anxiety. Externalisation is used in narrative therapies to separate the person from the problem. The narrative therapy mantra is "the person is not the problem; the problem is the problem". This approach was (at least partly) developed in opposition to the psychiatric/biomedical narrative of emotional distress and its focus on pathologising distress, which is often assumed to reinforce the idea that "the person is the problem" but this did not seem to be the case with Rose (White & Epston, 1990).

This label also reassured her that help was available, rather than thinking there was something unfixable in her, that what she had been experiencing was *potentially treatable*. As one would who takes on this psychiatric narrative, she seemed to have embraced evidence based treatment approach of then finding the *most appropriate treatment*. So the diagnosis also seemed to provide Rose with hope for a better future.

Was there anything problematic for Rose in embracing this label and taking on this narrative template? Whilst she found counselling and CBT helpful (203; 440-8; 563-604), it was interesting to consider how embracing the medical/psychiatric narrative impacted on how she makes sense of what is happening when social anxiety comes up now (408-13).

Specifically, when she talked about *“I did my CBT, I have all the tools... but then these symptoms haven’t gone you know?”* (420-2); *“they all helped in some way but um I think when I continue to feel the symptoms that I’d gone for treatment for initially after I’d had the treatment I was kind of at a bit of a loss about what to do because it felt like I was trying all of these things on top of medication and if they were still there you know?”* (448-52).

At these times in the interview, Rose seemed to be saying that treatment should lead to cure, specifically having no symptoms of social anxiety. She seemed to be talking about clinical recovery as the alleviation of symptoms. This captured an problematic aspect of adopting the medical model to account for emotional distress. Viewing distress as disease involves the clinician identifying a group of symptoms which are understood to be caused by the said disease; treatments are provided which target symptoms with the aim to cure the person. In this model, clinicians (and their patients) are encouraged to operate primarily or even solely within this explanatory framework which does not account for the meanings of ill health. Traditionally, meanings of illness were dismissed as superfluous to treating disease (Kleinman, 1988). This Western medical model was established for acute illness, where we are more likely to see the process of diagnosis, treatment and cure, working most effectively. Rose’s talk and her confusion about continuing to live with symptoms highlighted how the medical model seems ill equipped to explain and manage difficulties which are enduring or chronic. Or, as Rose put it, it leaves her *“at a bit of a loss”* (450).

Mohamed’s Counter-Narrative: Looking Beyond Clinical Measures

Mohamed’s story differed from Rose’s and Alice’s (who had also received CBT for social anxiety) as whilst he appeared to have responded well to therapy, he was covertly constructing an opposing perspective, what Adame and Knudson (2007) called a “counter-narrative”. In essence, he argued that standard CBT is not enough for people who have struggled with social anxiety all of their lives.

Mohamed's written story moved between a first person and third person account of living with problematic social anxiety. The analysis explored the possible functions of telling his story in this way. Mohamed's story of childhood highlighted how social anxiety can develop within particular cultural contexts. His account of his childhood was dramatized, vivid and written in the first person. Mohamed traced the origins of his social anxiety to his experiences growing up in a foreign culture within controlling, unsupportive environments at home: *"my father maintained strict control over what I could do"* (36-7); at school: with *"its clear hierarchies developed of social status (192-3). I was very aware of my low status"* (195); and, in the wider community: *"I had little interaction with British people (175). I developed a perception of the English lifestyle as being "normal" and "civilised", whilst my Bangladeshi lifestyle, shaped by my father's obsessive and erratic behaviour, was abnormal and weird"* (177-9).

He wrote about a childhood of fear and repression with considerable effort made by himself and other family members to avoid upsetting dad, which seemed to be primarily achieved by withdrawing into himself. When he wrote about his sense of difference, the *"cultural divide"* (173), he seemed to be writing about the family's experience of racism, growing up in a White, English community at a time when his family were part of a new wave of Bengali migration. When he wrote about the English as *normal* and his Bengali lifestyle as *abnormal* and of being aware of *"his low social status"* at school, these appeared to be examples of Mohamed internalising racism and stigma experienced by him and his family.

He also wrote vividly about when social anxiety manifests itself into his day to day life now:

Extract 1: *"If I am sat in a train opposite a stranger, I may try to read a book. However, chances are, my mind cannot focus on the words. My primary thoughts will be: "my face is tense – should I relax it?" "Do I look angry?" "Should I glance at the other person, just to be natural?" "But, having not looked at him at all, will a sudden glance seem weird?" "Is he even looking at me?" "Wait, I haven't turned the page for*

so long – it probably looks like I’m not reading... (78-83) Feeling trapped and under pressure, I will be frozen in the reading posture but not actually reading” (85-6)

This rich, emotive insight into the inner workings of Mohamed’s mind vividly captured his embodied experiences of struggling in encounters with others. In Extract 1, he illustrated how even when he is not conversing with others, he is still consumed with worries about how he comes across to them. This built a picture of someone who has a clear and coherent understanding of his struggles with social anxiety but is let down by his physical and social self – indeed ultimately by his mind, when social anxiety takes hold, leaving him feeling trapped, exhausted and powerless.

In Mohamed’s story, he partly used Extract 1 to illustrate his arguments about what is happening to him (and possibly others?) when he is socially anxious, which he defined a number of times in his account as “*depersonalisation*” or “*cognitive dysfunction*”. The example of his lived experience from Extract 1 and the use of these terms have perhaps been used to capture for the reader how he can look on what is happening and understand it whilst feeling it is out of his control and therefore unable to stop it. So that sense of powerlessness and inferiority (156-201) that he experienced growing up continued to be played out in many of his interactions with others now (185-7; 311-30).

The other voice in the story seemed detached and intellectual, used when Mohamed wrote in the third person, for example, when he referred to “*the patient*” in his critique of CBT; also, when outlining his views on how social anxiety developed; and, when defining what is going on when social anxiety strikes (92-104).

Extract 2: *“I believe that it is too simplistic to think of social anxiety as simply originating from “negative thoughts... I think that negative thoughts do bombard the patient - however, the origin lies deeper, in the subconscious, in self-esteem and*

vulnerability. To me, the patient must find social and self-acceptance through altering their isolated lifestyle before CBT can have any chance of having an effect” (265-70)

Mohamed had a diagnosis of moderate social anxiety and depression and received 8 sessions of individual CBT. He told me that he disagreed with the clinical judgement based on self-report measures that he had made improvements in therapy (241-2). Mohamed articulated in Extract 2 how and why the standard talking treatment approach, for him, came up short. When he wrote about “*origins*” he seemed to be saying that therapy needed to spend time exploring the meanings behind his negative thoughts and social anxiety experiences. This seemed to be opposed to what happened in his therapy which focused on identifying and challenging his negative thoughts as the root of the problem. When he wrote about “*altering isolated lifestyle*” this seemed to be about therapists helping clients to make practical changes but could also mean building upon what is being done in CBT to ensure that learning does transfer from within to outside sessions. I did not necessarily read this as meaning that CBT and altering lifestyles need to be done separately: more that Mohamed was saying they need to be married together more.

He offered an interesting take on his clinical improvements: “*I found the questions too vague to score with any certainty or felt obliged to imply improvement in order to satisfy my therapist.*” (244-5). He wrote about how therapists need to take into account the socially anxious’ “*desire for approval*” (249) and how this may impact on how people respond to outcome measures and in-session exposure exercises. This raised some interesting points about the validity of these measures; also about what needs to occur in the therapeutic relationship for people to feel able to answer truthfully, rather than being: “*inclined to answer the therapist in order to satisfy them, rather than to always express their true feelings*” (250-1) and raised questions about what the therapist working within this model and using a manual would be able to do with this information if it had been shared. Mohamed responded by doing what he was told, feigning improvement, believing that this is what the therapist wanted to see. It was not clear how much his history had been taken into account and whether

there was room in the therapy to do so, particularly how having no room for dissent growing up may have left him unable to raise these issues in the therapy.

Mohamed's inability to provide this feedback to this therapist was reminiscent of "the drama of emotion work" (pg.384), which is how social roles require us to act in particular ways for the benefit of self and the other (Frank, 2007). For example, Murphy (1987) talked about the expectations placed on patients to act in particular ways and how this restrains and restricts impression. These implicit performative expectations may restrain opportunities for dissent. In healthcare settings, clients who dissent run the risk of being dubbed a "difficult patient", a risk that a client like Mohamed would appear to find too difficult to take on.

Mohamed wrote about looking beyond clinical measures and seen behaviours to what is going on underneath: the "*unconscious*" as he put it. Through this experience and evaluation of why CBT appeared to work but had not, Mohamed seemed to have developed a clearer sense of how social anxiety became problematic and what he needed to move on from social anxiety as seen in Extract 2. He seemed stuck with this new understanding as his insights had not led to changes in his life. Later in his story, he wrote about replacing the term recovery with "*empowerment*" (382) which was perhaps a cry out to me or others who provide care to people struggling with social anxiety to provide opportunities to put this understanding into practice.

At follow up, when he identified the three main themes in his story (which were: *temporary cognitive dysfunction; vulnerability; lack of socialising in childhood development* (517-22)), he continued to write in a detached, expert way, again possibly to convince the reader that his experiences and understanding could be useful for not only him, but also for others who struggle with social anxiety and who feel that current talking therapies do not go far enough. Mohamed agreed (see Appendix 6) with this interpretation.

When reading Mohamed's account of CBT, it was useful to consider what we do to articulate and convince others of a counter-narrative. As Mohamed is challenging accepted knowledge, did he need to move into this style of writing to validate his right to critique the dominant way social anxiety is understood and treated? In doing this he seemed to draw upon and use the language of CBT (e.g. the detached objective observer of behaviours) to present his argument against CBT. By using medical terminology such as "*the patient*" and writing his critique in this way, he perhaps was seeking to position himself as an expert and therefore with permission to talk for others.

Summary

As seen in the three stories, when one enters into the mental health system and receives a diagnosis and treatment, they are being provided with a narrative template for understanding and responding to their emotional distress. These narrative templates represent a particular truth that the group (in this case the mental health system) ascribes to, which offer its members finite, preferred narratives to draw upon. This process of co-construction, which occurs constantly throughout our lives has been termed *emplotment* (Mattingly, 1998).

Emplotment is the process of being offered a plot which transforms incoherent events into meaningful experiences. *Emplotment* shapes and constrains how people reflect on their past, their present but also imagine potential futures (Frank, 2010; Garro & Mattingly, 2000; Mattingly, 1998). In these stories, we see how the participants talked about how they experienced social anxiety as confusing growing up, with limited, if any, narrative templates to draw upon to make sense of their experiences. Their stories showed how each person responded to the *emplotment* of the mental health narrative or template. Specifically how being offered the CBT narrative for social anxiety to explain their experiences seemed to have played crucial but differing roles in how they have constructed their past, present and futures. This is not to claim this was the only *emplotment* in their stories or indeed

their lives but that I was particularly interested in exploring this in the context of telling a story about negotiating social anxiety.

10 Traditional Stories: Social Anxiety as a Response to Childhood Abuse

In all of the stories, people's social anxiety became problematic during their childhood or they traced the roots of this difficulty to experiences during this period of their lives. Everyone had sought to identify a cause to explain problematic social anxiety. This was partly in response to the questions I asked them, which included their views on how social anxiety became problematic. Yet, given how readily people seemed to respond to this question, it did not appear that being asked was the only reason people spoke about this. Seeking to understand and make sense of our experiences through the stories we tell ourselves and others seems to be a universal human endeavour as it shapes our identity and place in the world (Bruner, 2004).

Whilst everyone talked about difficulties in relationships in childhood and/or traumatic experiences during this time, there were two accounts (Sally's and Janet's) which framed their social anxiety as a response to abuse suffered in childhood. As will be discussed, in both of their stories, they clearly linked the two in a causal way. Williams' (1984) identified the genesis illness story in which people show a strong attachment to their beliefs about how their illness began. These stories tend to express conflicts, such as resentments and doubts about one's world and how one has lived their life. These conflicts often generate a task for the narrator (Frank, 2007; Williams, 1984). In Janet and Sally's stories, their task was to find a way to use their understanding of how social anxiety became problematic to move on.

As will be discussed, whilst their accounts of the relationship between social anxiety and trauma were coherent, they were both still very much caught up in this, unable to find a way to use these explanations to recover. Their social anxiety continued to

be marked by chaos, as an overwhelming experience. Their stories were reminiscent of Frank's (1995, 2010) chaos illness narratives.

Sally: Moving Out of a Chaos Story?

Sally provided a written account of her life: of a relentless struggle to find a safe place in the world with others. A year later, Sally's story had shifted from a tale of tragedy to one of trying to negotiate ways to triumph over adversity. Sally's story showed how the characters we represent ourselves as (i.e. one's narrative voice) play a role in how we respond to adversity; the types of relationships we foster; and our sense of self. In Sally's account, she seemed to represent herself as a victim of abuse and suffering. A year later, this representation had shifted to someone who survives and has found ways to fight back.

Extract 1: *"I spent years playing a victim wanting someone to care and help, I have attracted very negative people in my life because I had to have that feeling of being scared and needed negative people to clarify my own feelings of worthlessness and that everything was my fault (80-3)... I am petrified of people but I know this stems from my childhood, I don't go out because my home is my safe place, no one can hurt me in anyway here" (95-7)*

In her account, Sally wrote about how her history of interpersonal traumas has had a profound impact on every area of her life, her relationships and sense of self. Re-enacting abusive relational patterns seems to have led to Sally's pervasive feeling of being unsafe, terrified of being hurt again. In Extract 1 she talked about how she managed these experiences. When she wrote about "*playing a victim*" she appeared to be saying that she needed to act in a way that she had not wanted to, to access "*care and help*"; that adopting this role had not worked, that it had been counter-productive, leading to more relationship difficulties; and, that she seemed to be, at least partly, blaming herself for choosing the wrong strategy as "*playing a victim*" did

not only involve finding a hero to save her but also required an aggressor to harm or injure her. In her story she seemed unable to differentiate between hero and villain and that although damaging, abusive relationships were familiar as it was the way her life was and fitted with her life script.

A year later, Sally identified the three main themes from her story in **Extract 2**:

“1 Abuse - This was one of the biggest causes of my social anxiety and what made me petrified of people

2 Traumatic childhood experiences - which also lead me to not trust anyone through my fear of getting hurt if I got things wrong

3 Depression - This can cause a person to see everything in a very negative way and in my case it caused me to see people in such a negative way” (225-30; Appendix 6)

In Extract 2, whilst Sally’s core narrative of social anxiety was the same, she seemed to be writing about it in a different, possibly non-blaming way. There was an acknowledgement that how she responded to the abuse was adaptive and understandable, in that she linked these experiences to her difficulties (e.g. trauma and abuse linked to depression and difficulties relating to others). This shift in perspective encouraged me to revisit her story to see whether the way she wrote about recovery had shifted. In the original story, she wrote about recovery as such:

Extract 3: *“Recovery to me means getting better from an illness, It means improving my life from what it is today, getting better, having a life, doing things that I cannot do now. The only time I would use the word Recovery is with a therapist for fear if I said to someone I was recovering from mental health I would open myself up to ridicule and bullying from people who don't understand. It sounds awful I know but to say you are in recovery of say, cancer would get a better reaction than mental health. I'm not sure what I would say but recovery does not seem the right thing to say” (135-141)*

In Extract 3, Sally seemed to grapple with both the medical and the recovery movement's definitions of recovery. This perhaps reflected the inherent tension of adopting this term. The "recovery" movement wants to move away from thinking about emotional distress in terms of pathology, illness and symptoms but how effectively can this occur when the word used to promote this critical shift is part of the Western medical narrative? The desire for recovery to be redefined and co-opted by an opposing narrative does not necessarily make it so, particularly when the prevailing cultural understanding of this term sits within medicine and psychiatry (Pilgrim, 2008).

In Extract 3, Sally also seemed to be writing about her attempts to negotiate the relationship between the medical model, stigma and mental health. Governments and mental health charities have focused on changing societal attitudes by increasing mental health literacy, specifically encouraging people to view a mental health problem in the same way they would view a physical health complaint. For example, The Time to Change campaign defines mental health as such: "We all have mental health, like we all have physical health. Both change throughout our lives. And, like our bodies, our minds can become unwell. The effects are as real as a broken arm, even though there isn't a sling or plaster cast to show for it." <http://www.time-to-change.org.uk/what-are-mental-health-problems>.

Promoting biomedical explanations of emotional distress may have the opposite than desired effect; with increased mental health literacy amongst the public linked to higher rates of stigma (Angermeyer, Holzinger and Matschinger, 2009). There is no easy solution as encapsulated in how Sally attempted to negotiate this dilemma. And so, she seemed to reject this master narrative as too problematic to use and articulated another way to conceptualise recovery:

Extract 4: *“My recovery when it happens would be being able to go out even just for a walk, going to the shop without worrying what others think, going for a meal with my boyfriend without worrying if people are looking or talking, moving out of the area (145-7).. having a job, going on holidays I have a long list of things that would represent my recovery It’s like having to start my life all over again from scratch learning social skills which I never really learnt learning not to be scared all the time”*

Recovery seems to be a deeply personal process, which varies from person to person. Sally’s dreams of recovery were grounded in living her life and engaging in day to day life with less fear. So Sally seemed to reject the master narrative of mental health and instead articulated her own counter-narrative, which whilst implicitly talking about being less anxious seemed to be about much more than that. It seemed to be about learning new ways to feel safe around others by starting all over again. She wrote about *moving away* as part of this process, possibly saying that in order to re-author her life and have a different story she needed to remove herself from those who have co-constructed this view of self and others. This seemed an important part of many of the participants’ stories of recovery.

How this counter-narrative seemed to have been adopted and enacted in her life was discussed in her update, when she wrote about the impact of taking up cycling in her life (246-8; Appendix 6): a day to day activity which has possibly come to represent freedom and finding a way to explore the world on her own terms.

In the follow up (see Appendix 6), she also wrote about the impact of writing and sharing her story:

“it has helped me to be able to put all this in writing and made me realise that things that happened to me as a child were really out of my control and it wasn’t my fault that no one helped and stopped what was going on” (263-5)

Mattingly (2004) talked about the link between hope and recovery and how recovery does not necessarily mean being cured; it can mean being seen and cared for. Participating in the research possibly provided Sally with an experience of being heard rather than being dismissed or ridiculed. So making sense and telling her narrative may have become a form of self-analysis in which Sally started to change her story from that of a victim to a survivor.

Janet: Stories of Coherence and Chaos

Janet's story of social anxiety was a cause and effect or genesis story: that the social anxiety (and other types of emotional distress) that she has experienced since adolescence was a direct response to child sexual abuse. She talked about being "*very outgoing, bubbly*" (62) before puberty when "*with all of those changes in your body*" (71) the impact of what had happened to her was realised. She talked about how she then withdrew into herself, stopped trying at school and of how her life then became a relentless struggle to get through the day with others, in which "*you lock everybody out and everything out*" (230) until the next morning when "*it starts all over again... just like a merry go round*" (233-4).

Janet's talk about her emotional distress was reminiscent of Frank's (1995, 2010) chaos illness narratives in which one bad thing happens after another with the actors in the story having no control over events as their efforts to stop things getting worse prove futile. These types of stories are defined as chaotic and essentially anti-narrative as there is no resolution or conclusion. There were many times in Janet's interview where she talked about her struggle to get through life, as "*a merry go round*" or a "*vicious circle*" of being disconnected from others and trying to make it through each day before the struggle starts again the next, as highlighted in Extracts 1 and 2:

Extract 1: *it's just been a long slog, you know of sadness really, it's just like a cloud that has followed me through life really, missed opportunities, you know just things just seem to pass you by, one year goes into another year, goes into another year, goes into another year, it's just very, very sad really* (83-6)

Extract 2: *I thought you know what's the point I'm not going to be here next year and then the next year I would say the same thing again, well what's the point I'm not going to be here next year and then the next year I would be saying the same thing* (101-3)

In Extract 1 Janet talked about her life as “a long slog” and of how this exhausting, slow and heavy plod through life is relentless and never changing, as illustrated in her repeating “another year” a number of times. She seemed to be talking about the abuse when she talked about the cloud which has followed her through life, its impact obscuring and troubling her, with seemingly no escape as she is stalked by this experience and its impact.

In Extract 2 she talked about how she has felt unable to negotiate this trauma and came to protect herself by withdrawing and cutting herself off from others and life. In Extract 2 she specifically was talking about how she went from being an A grade student to no longer performing at school. This was one of many examples in her story of talking about feeling powerless and seemingly giving into the social anxiety and depression which she has struggled with for many years. Yet she also spoke about social anxiety in a different way, as something which is at times hers and which seems to serve a function, as seen in Extract 3.

Extract 3: *I tend to hide behind it (l: mm) you know I also have to watch what I say, how I when describing it, when I'm talking about it, because I notice that sometimes I will say to myself, things like my social anxiety, my, it's not, ah, you know, I keep reminding myself that maybe I should not say that because I'm almost owning it, I'm*

almost saying its mine, I'm not going to hold onto this because its protecting me, I I think I'm using it like a shield, like a protection, oh I can't do that because I've got this and I can't you know and this has happened to me because of it, you know, which I'm trying not to do, trying to kind of, you know, um separate it from me before it takes over who I am (380-8)

There seemed to be a paradox here. In Extract 3, social anxiety protects Janet and can be used by her as a *shield*, suggesting that it is really her who has agency here and can draw upon social anxiety when she needs to. Yet it is spoken about as an uneasy alliance in which she could lose control at any moment if she does not also keep her guard up against social anxiety itself (*before it takes over who I am*). Social anxiety was presented as a constant in an account of a life of feeling disconnected from self and others. In Extract 3, social anxiety is something to almost willingly give into and hide behind, which seemed to protect Janet from the world, possibly from further hurt. It seemed that she feared being left more alone without its constant presence in her life.

In the interview, Janet also appeared to take on cultural stories, including historical stories, to make sense of the abuse and emotional distress. This highlighted how we interact with our own and others' stories constantly, taking on and rejecting these narratives, at times seemingly unknowingly, in our attempts to build a story of ourselves which makes sense.

Extract 4: *I've never shared with anyone what happened, or anything about my social anxiety either, with anyone, just carried it on my own, just thought my shoulders are big enough to carry it... I often call it a black woman's burden anyway my shoulders are big enough to load up with anything (122-6)*

Extract 5: *you don't want to draw attention to yourself, so you tend to take jobs that are menial, that are you know, that are (pause) um subservient you know? So no*

one is looking to you for answers, looking to you or expecting too much from you
(241-4)

Janet seemed to draw upon wider cultural narrative identity in Extract 4 when she talked about a “*Black woman’s burden*”, evoking history of slavery in the African diaspora and endurance over adversity. She later appeared to evoke this historical narrative again when she talked about doing work which is *menial* and *subservient* in Extract 5. She seemed to have taken on racial and gender inequalities as a means to not only explain but also perhaps to find a way to put up with the pain that she has endured.

This talk seemed to identify her as belonging to particular groups with a shared, common history. She also perhaps was saying that part of this shared identity is bearing this pain alone as she talked about carrying the weight of this on her shoulders. I pictured her with a silent, formidable strength, one she has learnt she must hide, almost as if she has come to believe this would be acting above her station, hence why she has taken on jobs which do not require her to share her intelligence or resolve. This ultimately had left her isolated, trying to find a way out but when this has not worked or helped, perhaps drawing upon these cultural stories to reluctantly accept that this is the way life is.

Summary

Despite encountering one difficulty after another in their storied accounts of their lives, Sally and Janet have not given up. Their stories seemed to show how even when someone is caught up in their emotional distress, they seek not only explanation but are constantly looking for a way out of this chaos and confusion to reconstruct and recover. Their stories remind us how important others are to the recovery process. We know that early relational trauma is linked with later mental health difficulties. This tends to act like a vicious cycle. Experiencing emotional

distress tends to isolate us from others. This then limits our opportunities to have different relational experiences which help us to cope and recover as well as reduce the risk of future difficulties (Pilgrim, Rogers, & Bentall, 2009).

Both Sally and Janet have had multiple experiences of therapy: therapy to help them to deal with the after-effects of abuse; and, therapy for their social anxiety. These interventions were separate, rather than joined up, suggesting that the links made between social anxiety and abuse were made by themselves, rather than by drawing upon other stories (e.g. medical, psychological or cultural). Could there be scope in therapies for social anxiety to help clients make better links between their pasts and presents? In these accounts, it seemed important for Sally and Janet to understand the present through looking at what went before. They also seemed to both say that making these links did not go far enough and that they also needed support to reduce their anxiety and change their ways of relating to others now.

11 Quest Narratives: Ways of Authoring Alternative Stories of Social Anxiety?

This section talks about the three stories told by Mia, Samuel-James and Massimo. Williams' (1984) and Frank's (1995, 2010) highlighted how people reconstruct their story so that an origin for illness is found within the past and in doing so, that their lives and sense of selves have an order and purpose now. The three stories were very different examples of reconstructive or as Frank (1995, 2010) named "quest" illness narratives. It was not so much that the resources or narratives that they have drawn upon to negotiate social anxiety were vastly different as much as how they seemed to be at very different points of reconstructing their stories. In all of their accounts there was a realisation or desire for their experiences of social anxiety to have been purposeful, even revelatory, similar to what Adame and Hornstein (2006) found in some accounts of emotional distress.

Massimo's story offered a clear, persuasive account of how social anxiety became problematic and was overcome. This was achieved by drawing on a range of narrative resources and experiences to negotiate a way through social anxiety. In Samuel-James' and Mia's stories, they moved between holding onto an earlier account of their lives as new perspectives started to emerge and how a year later, this new perspective had taken greater shape and moved them closer to a reconstructed narrative of recovery. Without these updates, their stories would have appeared to belong to another illness genre, such as chaos illness stories. The shifts in their stories, reminds us of Frank's (2005) argument about the unfinalizability of people's stories and how as researchers we get a glimpse of someone's life in a particular time and place (Frank, 2005).

Massimo: Recovery as a “Progressive Process of Self-Exploration”

Massimo has been running a self-help group for people with social anxiety for a number of years. In the interview, his story appeared to be told from the vantage point of the “recovered”: of someone who has conceptualised a way of viewing his own and other's social anxiety which has shaped the story of his life and which in turn continues to shape who he is, what he does, and what he wants to represent. It was useful to consider the functions of narrative when analysing Massimo's story: he brought to life, through talking about this process of recovering from social anxiety, how we draw upon resources that are available to us to reject, shape and sustain our stories.

Extract 1: *I've always thought about my social anxiety as originating in my family, especially my relationship with my father and um probably as I was growing up the way my parents, especially my father, responded to me, dealt with me in my changing needs and interests um really had a big impact on the social anxiety that I felt, the self-consciousness.. that's the source of it for me” (36-41)*

In Extract 1, he talked about his relationship with his dad and not feeling allowed to be himself or encouraged to develop this emerging sense of self in relation to others. Why this story and not others? This relationship was presented as the primary reason social anxiety became problematic. Prior to saying this, he had rejected another explanation I asked about (i.e. difficulties managing transitions). Similar to some of the other stories, there was a cause and effect (genesis) narrative (Frank, 2007; Williams, 1984) presented at this point. There may have been a number of possible functions for understanding and presenting his story this way. Having a clear explanation perhaps makes the pain and confusion of what this lived experience felt like at the time, feel more manageable for Massimo now. There was a sense of resolution in his explanation of the genesis of problematic social anxiety. It was useful to consider how this related to recovery and being able to tell a recovery narrative. Presenting a clear, coherent account of how things were and their impact perhaps strengthened his current perspective on what social anxiety is and how to recover from it.

Extract 2: *I would feel immediately that there was something wrong with me and I know this story I know that there is something wrong with me but I can't do anything about it, I don't know what to do about this, I have no, there is no escape here, what can I do, I can't do anything? This was the type of vortex that was going on ah so that would be my response and then I guess over time um I did that process did help me to um not even put words to it because actually it was too early I I couldn't make sense out of that but at least to recognise that there was something to address (118-24)*

In Extract 2 he talked about the impact of his then girlfriend on his social anxiety. He talked about how this relationship helped him to recognise that his social anxiety was something that he could not continue to hide through what he told me was his “cover up” (93-4) of academic achievement. This relationship challenged his way of managing his social anxiety. In Extract 2 when he said “*I know this story*” it suggested that it was the way things were: something confusing but reluctantly accepted. At the time, he had no other explanations available to explain what he was

experiencing, so he drew upon an available narrative (as the nerdy, awkward academic) to try to manage his social anxiety. This relationship was significant as Massimo said she was the first person to look beyond this appearance.

In Extract 2, he said *"It was too early; I couldn't make sense out of that"*. This was one of many examples in the interview when he indicated how he was trying to place himself back into particular periods of his life. There could be many reasons why he did this in the story: it may have re-assured him that his response at the time was understandable/okay as it was all that was available to him. He was in a situation where he was struggling with this *"discomfort"* (21; 77) and unable to find any explanations for how he felt.

In the interview, he then went on to talk about his experience of seeing a psychiatrist and talking to a psychotherapist and why he was unable to access the latter's help at this time, specifically how this was linked to stigmatised views within the family and wider culture, that psychotherapy was for *"mad.. crazy people"* (145-7). The lack of available narratives and support at the time appeared to relate to how Massimo talked about social anxiety as a *"type of vortex"*. A vortex brings to mind a whirlwind which destroys, is turbulent and sucks up everything in its path. So at the time, social anxiety seemed to be all powerful and encompassing as opposed to how he saw himself at the time as powerless: *"I can't do anything about it"*.

Talking about it being *too early* may have also served to reinforce his story, specifically that recovery is a staged process and that one has to go through each stage to get better. So at this stage it was too early, as he had not yet gone through the necessary steps to make sense of it. This could fit with how he makes sense of the various therapeutic approaches (232-72; 286-309) he has used to get to where he is now. So he talked about looking back and his understanding now on what was happening then and that it *"was too early"* then to have had that language or explanation. Perhaps he was saying that the path to understanding is marked by

struggle and confusion, partly because of the lack of wider narratives and hence owns own lack of narratives to draw upon to explain what is going on.

Extract 3: *I've always felt that the problem being the relationship with people that the way the problem would be solved was in the relationship with people (pauses) um I wouldn't have used these words it was um where I would always find myself because on the one hand I really wanted to be around people, I really wanted to be heard, I really wanted to be seen, I really wanted to be me, I wanted to influence other people (226-31)*

In Extract 3, he framed his view on relationships and recovery as how he always had viewed the problem. Does he claim this to strengthen his position now? Frank (2010) talked about how people can be seen to “report their reality as they need to tell it, as well as reporting what they believe their listeners are prepared to hear” (pg.90). He seemed to be talking here about social anxiety being his problem, his embodied self and hence the solution lay in changing his body. It seemed to be about what he cannot do and wanted to do. Others were talked about as serving particular functions to enable his recovery. In the interview, he then talked about how he engaged in a number of different treatments, initially physical, then psychological to understand what was happening and ultimately change (238-51; 286-309).

By distinguishing between then and now, he marked how things had changed for him since this time. For example, saying *I wouldn't have used these words*: denoted a change, perhaps saying that this narrative resource was not available to him at the time. *Where I would always find myself* brings to life all of his efforts to make sense and recover would lead him back to this point. Is he also possibly talking about his current perspective? As he then subsequently drew upon many different treatment approaches, which were focused on changing him; which placed the social anxiety in him and whilst all useful in some way, it appeared that all of these efforts brought him closer to realisation that this was only part of the solution. That he needed others for all of these efforts to take shape and do their work.

Extract 4: *the real thing is in the emotional content in a relationship (l: mm) what touches me about somebody else's expression, presentation and um how I respond and how they respond to me um and that that's where I am (l: sure) right now (282-5).*

The way he talked about relationships in Extract 4 was different – rather than what he wanted to achieve in his relationships with others – he talked about intersubjectivity and what happens between people. It was interesting how he talked about these two different accounts of relationships. Often once we have a position, we defend it in our stories, drawing upon available resources and narratives, to do so. He possibly is doing this by providing two different accounts of relationships, so he and the reader can see how he shifted from there to here. He presented himself as someone who could reflect and talk about how he used to view this issue and what he learnt and wished to inform others about. Telling a story in which the narrator has faced and overcomes adversity is commonly found in quest narratives (Frank 1995, 2010). This narrative seemed to shape not only how he talked about his life but how he lives it, for example by facilitating a self-help group. I got swept up into this story too, concluding the interview by asking him questions which were essentially asking him for recommendations for others, as I too saw him as someone whose story had much to tell others about struggling with this difficulty.

Mia's Story of Social Anxiety: The Way That I Am?

Extract 1: *"I was still the same, nothing had changed and I think that what kind of scares me and gets me down is the fact I might never change, that I'm stuck with this condition for life, I think to an extent I will be, I think it does make, you know a big part of who I am I don't want it to be that way but I think that because I've had it for so long, it's been so relentless, it's never um really got that, I've never felt that it's completely gone away" (128-133)*

At the time of the interview Mia seemed caught up in Western culture's medical narrative. In Extract 1, she talked about struggling with a chronic, medical condition which was outside of her control, with no endpoint or cure. Both physical illness and emotional distress are predominantly framed within this powerful medical narrative. However, emotional distress is often labelled as part of one's identity (Adame & Hornstein, 2006). Mia seemed to be saying in Extract 1 that she understands her social anxiety as both an illness and who she is.

Conceptualizing social anxiety this way as both illness and identity seemed to complicate how Mia negotiated this difficulty. There is a desire to rid herself of social anxiety and a sadness that this will never happen as it is impossible to separate the two: Mia and her social anxiety. In Extract 1 and at various points in the interview (e.g. when she talked about being "*treatment resistant*" (311) and of the impact of living with "*this condition*" (130)), Mia seemed to be communicating her implicit yet problematic acceptance of this master narrative which places social anxiety within and makes it part of the individual.

As found in many of the stories, Mia presented her story with a clear temporal order from early childhood onwards. She went back to the beginning and talked through her struggles with social anxiety, with a particular focus on her difficulties in education and at work.

Extract 2: *"I was really thinking that when I left primary school, secondary school would be a whole new start; you know I'd make friends, be normal this time but that never happened. I just think I find new groups of people really overwhelming like I just can't handle it (71-4)... it's just not ah for me with social anxiety it's completely all wrong for me" (81-2)*

Mia's talk about her difficulties at school in Extract 2 perhaps reflected how we internalise and negotiate dominant cultural stories. Mia felt she was expected as a

child, adolescent and young adult to “*be normal*” and fit in with peers and manage educational demands. She seemed unclear about how to make sense or manage anxiety and build relationships and so the sad image of a child hoping this would magically happen is brought to mind. When Mia struggled in these interpersonal contexts, the felt responsibility for this seemed to be placed onto her as someone with an abnormality (shyness) rather than as resulting from or exacerbated by the environment. Mia seemed to have learnt that there was something wrong with being shy.

This was perhaps understandable given that there had not seemed to have been other resources, whether narratives or support available at this time to negotiate a different way of viewing herself and being in relationships. This appeared to be the accepted way of things within her family, with Mia, mum and grandma all struggling in relationships (“*My mum and my nan, my mum’s mum, they both have spoken about how, well especially my mum, is very introvert, she doesn’t, she doesn’t have any friends*” (157-9)) and seemed to be confirmed implicitly at school. Social anxiety had to be endured and perpetuated the view that the problem lied within Mia and was simply part of who she was.

Drawing on narrative therapeutic idea, I asked about alternative explanations, particularly the role of the environment on her social anxiety. The interview context may have partly facilitated the shifts that occurred during the interview. This may have included a desire to please me that as I commented on similarities in our stories, she seemed increasingly able to shift from viewing social anxiety as something overwhelming that had to be endured, to make recommendations on how to help others with social anxiety.

Extract 3: “*I think it’s so important to actually raise awareness of social anxiety and at least for especially for educational set ups, there should have been more options I think (250-2)... I think for kids that do have it for me it was real painful going through school and uni and I just think there should be more options out there for people that*

have got it even more severe than I have, to have the option to work from home... there should be more awareness about that I think” (254-9)

In Extract 3, whilst Mia seemed to continue to frame social anxiety as something that she has, like a long term health condition, she started to talk about the need for systemic changes to support people struggling with social anxiety. Whilst this may have not seemed a great shift, it seemed considerable for Mia who previously focused on her struggles with social anxiety as solely her responsibility: her secret to hide from others; as a source of shame for what *“it’s driven me to do”* (655). So whilst talking about her experiences in education and work, she drew upon both dominant narratives (social anxiety as a psychiatric illness) and counter-narratives (social anxiety and systemic factors). These shifts in talk showed how through our interaction and being given permission to talk about other understandings, particularly about contested or counter-narratives, Mia became able to start to include these within her talk about social anxiety. This fits with ideas from narrative therapy, in which the therapy encourages people to move away from problem saturated stories, build alternative stories with the support of witnesses and re-author their lives (White & Epston, 1990).

A year after the interview, Mia re-read her story and articulated the three main messages from her story:

Extract 4: *“1. Social anxiety may never completely go away, however it can be managed with therapy or medication so should not prevent people from doing activities or pursuing careers etc. that they really want to do. 2. Acceptance has been a key part in SA (sic: social anxiety) for me, in that it is there but does not mean it has to take over my whole life and that there is a lot more to my personality other than my SA (sic: social anxiety) 3. It’s always worse in your head.” (813-8; Appendix 6)*

Mia seemed to have shifted over the year from a chaos to a quest narrative (Frank 1995, 2010). Mia's emerging alternative narrative seemed to be about finding ways to understand and co-habit with social anxiety rather than being resigned to coming out second best to it throughout life. In the pre-amble to providing these themes, she wrote about how she wanted to provide a message of hope for herself and others that you can live a good life with social anxiety (see Appendix 6), framing her struggles as purposeful, as is commonly found in quest narratives.

Participating in the study may have played a role in her efforts to re-author her story. She had talked about how helpful it was to talk to someone who had "recovered": and, to see that there are ways to make social anxiety no longer solely a source of pain; but also an opportunity for insight and purpose through self-acceptance. The desire for her story to become redemptive would give meaning and purpose to these difficult experiences. It seemed that telling her story had started a process of challenging how she thinks about her social anxiety and what she and others need to manage this difficulty. Shifting to this new story has enabled her to start to see how she can not only negotiate social anxiety but potentially use these experiences to move into a helping role. This process seemed a work in progress: a desire for her story to become redemptive rather than actualized at this point in her life.

Samuel-James: Stories of Finding and Accepting Self through Relationship

Extract 1: *I'd describe it as a hindrance as a, it really gets in the way...so when it's not there I'm like the sunshine and everyone else is on earth but when social anxiety comes, which can be at any time, it's like a cloud comes between me and the earth so people can't, they can see some light coming through but they can't see, you know the warmth or the glow of it.. it um causes a barrier between me and other people (343-50)*

Samuel-James' story of living with social anxiety was framed within his relationships. As seen in Extract 1, even when social anxiety is not problematic, it appeared that he saw himself as separate and disconnected from others. Describing himself as the sunshine denoted warmth; something that others need, like and want. His social anxiety seemed to be experienced as external to him, something that rises up, the cloud that gets in the way and blocks people seeing the "real" him. But as his story unfolded, it emerged how difficult it has been for Samuel-James to work out who he is. He traced the origins of social anxiety to when his sister ran away from home and he took on responsibility for not upsetting his parents by being "*the perfect son*" (97). This involved never making any demands on his parents, such as asking to go out and socialise with his peers. He spent many hours alone, using elaborate role plays to fill his time such as in the following extract:

Extract 2: *"It was a converted attic, one big space (I: mm) and mum and dad put um I had um a four foot snooker table up there, a little flimsy one and I used to play on it for hours on end, by myself, playing snooker with an imaginary person, I'd even have two cues, one for me, one for the other person, I'd play for the other person, it was all very realistic... I look back on it and it was absolutely brilliant, I suppose I just created my own little world (I: sure) it worked for me but looking back at it I can see err there was there was something missing"* (171-8)

In Extract 2, Samuel James provided an evocative glimpse into his social world during adolescence. It was one of many rich examples in Samuel-James story of using role plays during this time in his life (162-9; 236-7; 267-74). Whilst for me, this build a sad picture of a teenager alone and trying to find a positive way to manage loneliness, this is not how Samuel-James spoke about this, describing it as "*brilliant*". However, there was also a contradiction, in which he talked about there being "*something missing*", perhaps as he was reflecting on how not having the opportunities to develop peer relationships impacted on his relational world. His ways of hiding his loneliness had possibly been both self-protective and self-perpetuating. This may have defended him from rejection but may have also made it difficult to form meaningful relationships, as, outside of his wife, many of his

relationships he spoke about seemed to have come and gone. In Samuel-James' story he seemed to tell these stories as part of negotiating an understanding of how these experiences growing up may have related to social anxiety becoming problematic.

Extract 3

I have compensated for it in the past by being you know really (laughs) a nice person (I: yeah) just so I keep everybody happy and then I don't have to worry about it um, so yeah that's one coping mechanism I've used all of the time really (I: yeah) I don't like it, even now it really really upsets me, I don't mean like tears but it can really play on my mind if I have the thought that somebody else is thinking badly about me (352-8)

I hate that falseness when you're being nice but you know full well and they know full well that it's all an act, I can't do that (386-8)

Extract 3 captured the ongoing relational dilemmas that Samuel-James seemed to struggle to negotiate. If we think about how we develop a sense of ourselves through our interactions with others, what happens when we miss out on this? He seemed to be talking about how without a clear sense of who he is and what others think and feel about him, he has been left being unsure about how to act around others and understandably terrified of causing anyone upset. Experiencing this fear as unbearable is often seen in those struggling with social anxiety (Sanders et al., 2003).

This confusion about how to be with others played out in a told life story that was full of contradictions. How can we make sense of the contradictions in Extracts 2 and 3? At the time of the interview, he seemed to be starting to challenge his master narrative: that he had had a brilliant, happy childhood. It did not seem a coincidence that he had recently entered counselling at the time of the interview. Challenging his master narrative was not a straightforward process, so in the telling of each episode

he moved between challenging and maintaining the stories he told himself/lived by. Bruner (1990) and Sarbin (1986) talked about how our narratives provide order, coherence and a sense of self. As seen in Samuel-James' story, we seem to feel compelled to maintain the story of our life.

A year later when Samuel-James' provided feedback on the analysis (Appendix 6), he had a different take on his story:

Extract 4: *"This has become quite clear and apparent to me very recently...Loneliness...(854-5) The reality is I have got friends, but I often spend time by myself and a lot of my negative feelings towards myself stem from the intensity of feeling lonely (857-9)... I learnt how to make it look as though it didn't bother me. But I realise now that I was faking it all the time."* (863-4; Appendix 6)

I was struck how the loneliness he wrote about in Extract 4 may have related to the roles he played growing up. If these personas were ridiculed or rejected was this okay because it was not really him? However, this strategy seemed to have left him feeling lonelier as he felt unable to know and show himself. This struggle seemed to play out in his difficulties making eye contact which he also talked about as a major theme, which he saw as his means of *"pretending and faking and hiding my true feelings"*. Telling his story to me and others (through receiving counselling for a year following the interview) had possibly enriched his process of self-analysis.

There was a clarity and coherence in his feedback that had been missing in the interview. As he negotiated recovery through self-analysis, Samuel-James' seemed to have found a different way to tell a positive story, not by claiming it is a happy one, but by making it redemptive through reconstruction and using this understanding to become a counsellor and set up a self-help group. It was helpful to go back to the original story to look for glimpses of this emerging narrative: of the struggles of

negotiating identity and one's place in the world when experiencing problematic social anxiety:

Extract 5: *because when you are socially anxious you're not really um allowing yourself or you don't feel permitted to be yourself um so then to be able to help other people and the only way you can really help another person is just by, being genuine am um by being, giving that person just the simplicity of your true self um when it's a situation that allows you to be to be who you are for once (l: mm) I suppose that's at the heart of it for me" (474-9)*

In Extract 5, Samuel-James' spoke about what it meant for him to become a counsellor and how this represented an opportunity to be authentic and care for others. I thought about the different careers Samuel-James had been in before moving into a counselling role and what it might be like for a man to take on a helping role, when in Western culture, independence and masculinity are valued cultural norms. How does that impact on someone like Samuel-James who has felt responsible for others' feelings for much of his life?

Men who have internalised cultural demand to be independent may become socially anxious as they come to believe that their self-construal differs from perceived cultural norms (Moscovitch, Hofmann, & Litz, 2005). Samuel-James' considerable efforts to make light of or manage social anxiety on his own could have possibly been his attempts to disown this part of his character. When this did not work and he turned to others for help, he appeared to be talking about embracing this interdependent, sensitive nature, or as described in Extract 5 his "*true self*". It seemed to be about finding a place and community which values these attributes, including within the interview and within therapy, where he can find a sense of self which is valued and embraced and so helps him to start to negotiate a different way of being with others.

Summary

These stories highlighted how the quest illness narrative can take many forms. Unlike restitution illness narratives, people who tell a quest narrative tend to draw on a variety of narrative resources to reconstruct their story of illness (Frank 1995, 2010, 2012). People can be at very different stages of their quest to better health and wellbeing, as seen in these stories. Massimo spoke as someone who had come through the other side of social anxiety. He presented a story in which he went through a number of stages to learn new ways of viewing himself and others and being in relationships. This had been achieved through a number of different means, including self-help, physical and psychological therapies and group work. His story was reminiscent of what Adame and Hornstein (2006) called a purposeful or revelatory story of emotional distress.

Samuel-James' and Mia's stories showed how people's stories change over time. At the time of the interview, both of their stories more closely resembled chaos narratives as they tried to make sense of their difficulties as they moved between old and new accounts of their experiences. At follow up, both seemed to have moved closer to a new account of their lives in which they had started to find ways to make sense and move on from social anxiety. For both, talking therapies, self-help and supportive relationships played an important role in gaining a new perspective on their social anxiety which had promoted an emerging self-acceptance.

12 Storying Lives with Problematic Social Anxiety

The analysis considered 8 accounts of living with problematic social anxiety. Some people talked about how they have found traditional mental health narratives and treatments helpful to make sense of and move towards personal recovery. For others, recovery seemed to have partly involved either rejecting dominant cultural narratives or drawing upon alternative or counter narratives to find ways to live a full

life with social anxiety (Adame & Knudson, 2007). The latter involved looking beyond biomedical explanations to understand and respond to problematic social anxiety. This was rarely clear cut as people merged different voices and available narratives into their accounts of a life with social anxiety.

Drawing on the past to explain the present did not appear to be a simplistic process of recollecting what actually happened. How each person recalled the past seemed to fit with how they story their present and future. By this, I mean that the recollection of the past seemed to not only be done through the lens of one's current view of self and their world but seemed to act to sustain this self and world view. The experience of problematic social anxiety in childhood or adolescence seemed to be marked by chaos and confusion at the time. In people's stories, they referred to their childhoods as confusing but presented the story of this time in their lives in an ordered, coherent way, with clear links made between what had happened then and how their social anxiety had taken shape and was understood now. These findings will be discussed in relation to the research literature in the Discussion chapter.

DISCUSSION

The present PAR study collected life stories of problematic social anxiety to explore the following:

- How do people make sense of problematic social anxiety?
- What can these stories tell us about personal recovery from problematic social anxiety?

A PAR approach was used to incorporate the views of others into the entire research process. This has been done to varying degrees of success, as discussed in the critical reflection section of this chapter. The stories provided rich insights into the lived experience of problematic social anxiety. Whilst there are many research studies on social anxiety (for example a database search on PsycInfo and PsycArticles yields over 12,000 results), there are relatively few that have used a qualitative research method (less than 200 results from the same search). I could not find any research studies on social anxiety which have used narrative analytic approach, nor any qualitative studies which have collected life stories. There is a lack of inductive research in this area as the general consensus seems to be that psychology understands this problem and knows how to treat it effectively. This is true in many respects but, as highlighted in the analysis, there are aspects of our understanding of social anxiety and recovery which could further improve our practice.

The analysis highlighted how there is both uniqueness and commonalities in people's stories. The types of stories told; how people's stories of problematic social anxiety were grounded in experience, particularly during childhood and adolescence when we are understood to be developing our sense of personhood; the ways that people drew upon wider cultural narratives to make sense of their experiences; and, how all of the above were seen to shape people's conceptualisation and often re-

conceptualisation of what “recovery” means and looks like, showed people drew on similar narrative resources but did this in different ways.

This concluding chapter talks about the study’s findings in light of the research literature on social anxiety, narratives, and personal recovery. The chapter then moves onto thinking about how the studies could translate into recommendations for policy and practice. The limitations of the study and recommendations for future research are also discussed.

13 Making Sense of Problematic Social Anxiety

I started analysing the stories by using Adame and Hornstein’s (2006) typology of emotional distress narratives (see Appendix 4) to think about the types of stories told but also considered research on illness narratives, such as Frank’s (1995, 2010). What was striking was how people’s accounts rarely drew on a single narrative genre, as these typologies may suggest. People often primarily told a particular type of story, whether one of restitution, chaos or as a quest towards recovery but they also moved between genres, by presenting parts of their stories in different ways. This tended to change over time, which was the case for those participants who were involved in the analysis (e.g. Sally, Samuel-James, Mia). How this occurred was less clear. Narrative psychologists, such as Bruner (2004), wrote about how little we have attended to or know about the “development of autobiography — how our way of telling about ourselves changes, and how these accounts come to take control of our ways of life” (pg. 695).

The restitution narratives were slightly different in the elicited accounts of social anxiety than what we find in restitution stories of physical illness (Frank 1995, 2010). Restitution stories involve people adopting the medical model’s narrative of illness to be restored to a pre-illness state. In people’s accounts of social anxiety, however, we

saw that most people did not identify a pre-social anxiety stage. Social anxiety was something that people had struggled with throughout most of their lives, similar to the continuity stories found in Adame and Hornstein's (2006) research on emotional distress narratives.

So in the restitution stories told by Alice and Rose, the "restitution" was to an imagined post-illness life. There was no loss or yearning for a pre-illness state or having to come to terms with being unable to return to this pre-illness state. This may instil a sense of hope within a restitution narrative that perhaps does not always occur in physical illness stories. This may partly explain how in Alice's and Rose's stories they were such strong advocates of this narrative, similar to what Adame and Hornstein (2006) identified in psychiatric empowerment narratives. Whilst perhaps Mohamed's counter-narrative had emerged from disappointment at having new hopes dashed.

Everyone's stories talked about how they had grown up struggling daily with social anxiety from some point during childhood or adolescence. This finding bolsters the argument that social anxiety may be better understood as a developmental problem (Bögels et al., 2010). During childhood but also well into adulthood, there were limited, if any, narratives available for people to explain or understand what they were experiencing. Nobody knew about or could name their social anxiety for many years, until they stumbled across an explanation, often via the internet.

The stories indicated that awareness and recognition of problematic social anxiety in health, education and wider society continues to be low, as highlighted in the research literature (NICE, 2013). Spending so many years with no explanation for what they were experiencing had a number of knock on effects for the participants, including low self-esteem and a strong sense of difference from others. This acted to further isolate the participants' from others and often limited opportunities to fully engage in different social realms, at school, work and in their personal lives. This finding adds another dimension to existing studies on the impact of social anxiety on

people's lives and how the wider environment can act to perpetuate and worsen this difficulty (Brook & Schmidt, 2008).

The role of relationships in how social anxiety developed, was expressed and managed permeated all of the participants' accounts. What was striking in the stories was how powerful our relationships are to act as forces for good or bad in problematic social anxiety. In the stories, people talked about how their social anxiety developed in their relationships, often originally in the family, which were then perpetuated further in other social groups, such as with peers at school, university and work. This highlighted how this difficulty is socially and culturally constituted (Stravynski, 2007) rather than a difficulty that simply happens to or within an individual. Social anxiety in childhood was expressed in many different ways, from growing up with others who were themselves socially anxious, or controlling, distant, over-protective, to the abusive. The latter seemed to foster a defensive interpersonal pattern of relating to others (Stravynski, 2007) to protect oneself from further harm and humiliation.

People's stories recalled how their shyness became much more as their early and immediate relationships left them feeling that they lacked the know-how to negotiate relationships. This finding mirrors research discussed in the literature review on the interpersonal features of this problem, in particular about how social anxiety may be understood as not only involving social avoidance behaviours but also difficulties in social approach behaviours (Alden & Taylor, 2011). For example, many of the participants talked about how their inability to manage their anxiety made them appear disinterested or aloof and further perpetuated their struggles.

Some of the participants talked about how they continued to struggle in relationships now. However, for many they had found or started to have different, positive relational experiences which seemed to play an integral part in their recovery journeys. This supported research which argues that recovery may be better understood as a social rather than individual process (Kogstad, Ekeland, &

Hummelvoll, 2011; Topor, Borg, Di Girolamo, & Davidson, 2011). As discussed in the literature review, existing interpersonal research on social anxiety focuses on relational difficulties rather than what helps people to make relational changes. Whilst some participants put this down to luck in meeting and connecting with kind or likeminded others, this process was often linked with a shift in how participants viewed themselves, others and their experiences, from confusing and shaming, to being able to frame and understand social anxiety in a different way. This occurred in a number of different ways, including being able to draw upon mental health narratives to facilitate this process. This in turn, seemed to change how others then responded to the person, leading to different relational experiences. This highlighted the dynamic inter-subjectivity processes that occur between people in relationship throughout their lives (Bowlby, 1988; Mitchell, 1988).

14 Narratives and Personal Recovery

Recovery has been conceptualised in many different ways. Some researchers have argued that recovery is a process of integrating experiences of emotional distress into one's life story (Thornhill et al., 2004). This process is understood to involve moving from incoherence to coherence in the stories we tell ourselves which subsequently changes how we then live our lives (Adame & Hornstein, 2006; Brown & Kandirikirira, 2007; Lieberman et al., 2008). Looking at the participants' stories, there were some accounts which seemed to bring this dynamic process to life, for example Massimo's and Alice's stories of social anxiety. However, this way of conceptualising recovery did not fit the stories told by Sally and Janet, who told coherent, ordered stories about chaos and confusion and not being able to move on from abuse in their childhoods. Or Mohamed's account in which he built a counter-narrative for how social anxiety is understood and treated, whilst continuing to struggle with this difficulty in his own life. So it appeared that making sense of our experiences only tells part of the story of recovery.

Everyone in the study had some experience of treatments, including medication and talking therapies. The latter included some participants who had received therapy specifically for social anxiety. People talked about how therapy had given them a different perspective on their difficulties (not always one that they agreed with) and useful tools for managing or counteracting social anxiety. Different aspects of therapy had been helpful at different times, indicating that not only does one size not fit all across but also within individuals (Cooper, 2008; Cooper & McLeod, 2007).

As highlighted in the personal recovery literature (Slade, 2009) and in the participants' stories, there was no singular way to move on from problematic social anxiety. There were a variety of narrative templates which people drew upon to make sense and move on from problematic social anxiety, including from biomedical and psychological narratives. This was a good reminder that personal recovery does not necessarily mean establishing an alternative narrative or counter-narrative (Adame & Knudson, 2007). The strength of this critical movement is in providing room for various discourses, whether established or novel.

What was problematic for many participants' was the term "recovery". They either directly or indirectly talked about the inherent problems with adopting this medical term to challenge clinical recovery's focus on symptom alleviation. Harper and Speed (2012) argue for conceptualisations of recovery which are framed in people's own words. In the present study, participants used terms such as authenticity, empowerment, self-exploration, acceptance, compassion and connection to others to describe what getting past problematic social anxiety had or could look like. People did not talk about this in terms of symptoms, rather in terms of living a good life (Adame & Knudson, 2007, 2008). As seen in many of the stories, part of how people conceptualised a good life was through moving into a helping role to help others struggling with social anxiety.

There was also something strikingly ordinary about how some of the participants talked about their recovery, for example Sally's talk about cycling. Mattingly (2004)

talked about the small moments in recovery and how these can be grounded in everyday activities and encounters. Both big picture and small, day to day aspects of recovery highlighted how this process looks and mean much more to people than symptom reduction. As argued in illness narrative research literature (Kleinman, 1988) we are people, not illnesses, and as our emotional distress has many different meanings, so will what getting better looks like. A challenge going forward is how to have this recognised in the services we provide to those experiencing emotional distress (Kogstad et al., 2011).

Those who seek a conceptual foundation for personal recovery argue that we still have far to go to understand this complex area and incorporate different aspects of recovery in research and practice (Leamy et al., 2011). Some authors have called for an ecological recovery framework, which recognises that distress and recovery occurs in interactions between the individual, others, and, the society in which they live (Onken et al., 2007). This was the case in all of the participants' stories in which they talked about a difficulty which evolved in relationship with others and in a world which had generally failed to recognise nor know how to respond to this difficulty. The implications for practice are discussed in the next section.

15 Recommendations for Policy and Practice

15.1 Counselling Psychologists' Role in the Therapy Room

The stories highlighted how psychologists may need to consider more integrated talking therapies to help clients make links and use these insights to make changes in their lives. Grounding therapies in individualised formulations is an important step. As psychologists operating within a postmodern paradigm, it is important to remember that our theories on emotional distress offer different ways of conceptualising and working with our clients' problems (Hansen, 2006). Everyone who participated had clear ideas about the problem (social anxiety) and how to

overcome the problem (recovery). Hearing peoples stories highlighted how potentially powerful giving people the space to tell their stories and re-story their lives are to the therapeutic process. The research literature highlights the strong evidence base for CBT, particularly for reducing anxiety symptoms (NICE, 2013), and as seen in some of the stories, changes in this area seemed to then trigger many changes in their lives. This reminds us that for some clinical recovery can be much more than the reduction of symptoms. However, we also need to remember to engage with clients and their understandings of their problems to ensure that we can offer different therapies when the recommended therapy does not fit, as occurs with a significant minority of clients (NICE, 2013). Flexibility in how we work with clients struggling with social anxiety is key, including regularly checking in with clients about how they are experiencing the therapy and whether the work is on track for them.

In all of the stories, participants sought insights into why social anxiety had become problematic for them. The participants seemed to use this information to try to find a way out of being crippled by social anxiety. Stories can both perpetuate and transform our experiences of emotional distress. Our stories seem to be both entrenched as they become the story that we live and identify ourselves by; (McAdams & Adler, 2010) whilst being marked by instability and open to multiple influences (Bruner, 2004). This is part of what makes talking therapies so challenging and potentially transformative. As seen in the participants' stories, our stories of ourselves are shaped and changed by the wider narratives around us. We saw in all of the participants' stories how they drew upon available narratives to make sense and in some cases, move on from social anxiety. As seen in the participants stories we cannot assume that people will respond to information in particular ways. This will always be contextualised by their particular ways of interacting with these narratives and how well the wider environment supports or constrains applying this knowledge. This has reminded me that we need to be beside our clients so that we understand their worlds before seeking to support them to reshape these accounts.

The literature review highlighted the importance of developing a therapeutic alliance when working with people experiencing problematic social anxiety (Alden & Taylor,

2004). The analysis supports this finding, highlighting that the type of relationship needed will not look the same for each client. It seemed important for clients to have the time to develop trust and feel safe to encourage them to open up about something they have struggled with alone their whole lives. Further, whilst people talked about how CBT was helpful, particularly for helping them to manage their anxiety, it appeared that people generally would have liked more time to build a relationship with their therapist and to help them make relational changes outside of therapy. One way forward would be to incorporate relational factors into CBT, such as done in Alden and Taylor's (2011) pilot study. This also fits with recovery oriented therapies which help people make relationship changes outside of the therapeutic relationship. This recognises that an important aspect of recovery is about the person interacting and connecting with others in their social worlds (Tew et al., 2012). In terms of my own practice, it will be important to acknowledge that people are already engaging in a new way of being with others by speaking about a difficulty they have kept to themselves for many years.

15.2 Looking Beyond the Therapy Room

Whilst the recovery process and meaning varied from person to person, it appeared that there are limitations to how much the individual can achieve on their own when negotiating social anxiety. Rather than conceptualising this process as a solitary journey, we need to think about ways of working holistically with clients, including thinking about our clients' relationships in and outside of the therapy room to the provision of joined up services to how to change cultural norms and structural inequalities which perpetuate clients distress (Foster & Tew, 2005; Tew et al., 2012).

The NICE (2013) guidelines highlight how little awareness there is of problematic social anxiety both within and outside of the health profession. This lack of awareness was talked about in all of the participants accounts and had (and often continued to have) an adverse impact on people being able to understand their difficulties as well as access appropriate treatment. This seemed to have played

some role in social anxiety becoming an entrenched and chronic difficulty as people grew up and entered into the world not knowing what was wrong with them and inadvertently blaming themselves for how they felt. As discussed in the literature review, social anxiety disorder is understood to be one of the most prevalent mental health problems and yet when you look for public information on this problem (<http://www.mind.org.uk/information-support/types-of-mental-health-problems/>), little or nothing on this difficulty is included. As discussed in the literature review, it is important to remember that cultural narratives are produced within a dynamic process in which each individual's story both originates from and adds to shared knowledge (Gallo & Mattingly, 2000). Therefore, it is imperative that we find ways to promote our research beyond our own discipline to feed into this process.

Awareness raising and education about problematic social anxiety is needed on various fronts. This could include psychologists providing training to health, social and education staff on how to recognise this difficulty in those they work with and information on avenues for help and support. Public promotional campaigns could also be conducted as part of general awareness raising as well as targeted specifically on anxiety difficulties. This could include sessions in schools for students and educational materials for parents and carers, given that we know that social anxiety tends to become problematic during this period of people's lives.

16 Critical Reflection and Study Limitations

16.1 The Challenges of Participatory Action Research (PAR)

There are different levels of participant involvement in PAR studies. The research has been conducted in an inclusive way but, when assessed against a measure of participatory involvement, sits at the low to medium end of the participatory continuum (Balcazar et al., 2004). This means that whilst people have been involved in an advisory capacity, they have not driven the research agenda nor have they generally acted as co-researchers. I constantly questioned how participatory the study was, and, how participatory it needed to be when it was service user led. The

threat of tokenism in PAR was at the forefront of my thinking throughout the research process. I also needed to think about how to achieve quality in both the research and the participation (Nind, 2011). I tried to build relationships in which people felt supported and encouraged to voice their opinion and disagree with me. Ideally, I would have made the resources and skills to engage others as co-researchers, so that they could be more actively involved in designing the study, recruitment, data collection and in conducting the analysis, writing up and sharing the findings.

In the thesis there has been no screening of participants related to their recovery status. It would have been judgmental of me to decide who had or had not recovered. How would I have judged recovery? If I used available clinical measures, I would have been assessing personal recovery by measuring clinical recovery. This would have been a contradiction that undermined the purpose of the study, which was to look beyond clinical recovery. I also did not feel I could claim that being recovered was essential to be able to talk about these issues. However, having a self-selecting sample was not without difficulties. For example, did participants who felt they were not in recovery or that their journey had only begun look to the researcher as some kind of recovered ideal? How did that influence the story they presented, particularly for those participating in an interview rather than in written form? Did people want to show their best self? Was participating seen as an opportunity to seek guidance from someone (a trainee psychologist) whose wider role is to help people like themselves? (Haverkamp, 2005)

Some participants asked for information on talking therapies or asked about my recovery journey. In most cases I was able to agree with participants that there would be time at the end of the interview to ask questions. This did not adequately address this issue in the second interview as the participant stepped out of her story at various times to ask for a clinical opinion. In future research, the study materials could outline detailed information about this issue, including providing information for those seeking guidance or support for their difficulties.

16.2 Narrative Analysis

As a novice narrative researcher it was difficult to know how many stories I needed to collect. I was overwhelmed by the response from SASH and SAUK and found it difficult to say no to people who wished to participate. So, I collected 8 stories which made it difficult to thoroughly analyse and talk about each story in depth. If I conduct narrative research again in the future I will listen to my supervisors when they tell me I have enough data.

I did not recruit participants via NHS services as we know that over 50% of people who struggle with this problem will never receive any professional help (NICE, 2013). This would have potentially excluded many people struggling with this difficulty and may have also reduced the types of narrative templates people felt able to draw upon to talk about social anxiety. The latter would be interesting to explore in a future study to see whether the narrative conformity found in studies of groups such as AA (Frank, 2010; Holstein & Gubrium, 2004), also functions within this group. The participants were recruited via two non-clinical channels (half via SASH, half via SAUK) but they were by no means a homogenous group. For example, the level of involvement in the self-help group SASH varied considerably from those who facilitated groups and were involved in efforts to change public and professional responses to social anxiety, to those who had attended only one meeting at SASH. Similarly, those recruited from SAUK ranged from moderators to one time users of this online forum. It could be argued that all were seeking alternative narratives to make sense of social anxiety but as seen in the stories, this was not always the case, with many finding established narratives very useful to negotiating recovery. It has been useful to think about my role in the co-construction of people's stories as the participants were aware of my dual role as a trainee psychologist and service user. The study materials (see Appendix 2) explicitly stated my position as someone who takes a critical view on how social anxiety is recognized and treated. This is likely to have influenced the types of people who wanted to be involved (e.g. others who take a critical view; those who also wish to be in this dual role) and the types of stories they told. It is likely that if I had not shared this information then different people would have been recruited who may have told very different stories of social anxiety. This is not necessarily problematic but needs to be acknowledged in our

analyses of interviews which are essentially a social interaction in which stories are jointly constructed (Potter & Hepburn, 2005).

One criticism of the use of interviews in qualitative research is how the interviewer is effectively deleted from the analysis (Potter & Hepburn, 2005) I collected stories using a range of different methods, in acknowledgement that for some, talking to someone is the crux of their struggles with social anxiety. Therefore, whilst all the participants were aware of my position from the study materials, my presence in shaping the stories they told is likely to have varied. Some of the participants responded in writing to a set of questions, others had only verbal cues (on the phone), whilst for some they had both verbal and nonverbal cues (face to face and Skype) on which parts of their stories to elaborate on or talk less about. A limitation of the current study has been to not attend more to these interactional features in the transcript (e.g. using Jefferson transcription) or in the analysis. It would be good to develop the analytic skills to incorporate these features into a future study.

As seen in the results, there were a variety of narrative templates people drew upon to make sense of social anxiety and I hope there was an openness to hear all stories, not just of a critical nature. However, I was more receptive to hearing certain stories than others and encouraged participants, particularly in the early interviews, to elaborate on these stories. It was only as I grew in confidence during the process that I was able to sit back more and allow the participant to tell their stories with limited input from myself. This is not to say that my presence did not still influence the stories told, particularly as I explicitly asked people to talk about how social anxiety became problematic; to start at the beginning; and to talk about recovery. This encouraged stories within a particular narrative template so people tended to talk about the past to explain the present; that recovery needs to be re-conceptualized; and, that this is a process which is helped and hindered by many different factors. This narrative template inadvertently shaped, permitted and constrained the types of stories that could be told about problematic social anxiety.

17 Recommendations for Future Research

A possible future project could publish the full narratives so that others have the opportunity to engage with these lived experiences of social anxiety as this is currently missing in the psychological literature. It would also provide readers with the opportunity to draw their own interpretations of the stories as I have come from the position of a fellow sufferer, trainee psychologist, White, educated, now middle class Australian; married mum etc. so have looked at the stories through these various lens. Others may take very different things from these stories.

A key criticism of current talking treatment research is that it lacks contextual information on how to work with individual clients (Dattilio, Edwards, & Fishman, 2010; Flyvbjerg, 2006). Whilst some outcome research studies seek to understand the processes underlying therapeutic change, they can only provide us with general information on these processes. To obtain this type of knowledge, qualitative research studies are integral to understanding how treatments do or do not work (Dattilio et al., 2010). Future research could look at how to include clients' narratives in assessing therapeutic outcomes, rather than relying on quantitative clinical outcome measures only.

Another area for future research could be to more actively involve those affected by a mental health problem in determining what therapeutic outcomes should look like and how this can be assessed within services. There has been some participatory research with people who hear voices to develop personal recovery outcome measures. Similar projects could be done with people who experience problematic social anxiety; other anxiety difficulties; or, depression etc. The survivor movement has tended to include people who have experienced in-patient services and/or experience chronic, often stigmatised, mental health difficulties. I hope that this study, particularly the response to the PAR aspects of the project, have shown that there are many different groups of people who use mental health services who would like to have their voices heard.

CONCLUSION

The present PAR study collected life stories of problematic social anxiety to explore how people negotiate this difficulty. I was particularly interested in whether people who had struggled with this difficulty for many years (a minimum of 10 years) experience personal recovery and if so, how this has occurred. Each stage of the study has reminded me of our potential for self-actualisation and how we strive for this throughout our lives, even when our social and cultural worlds do not adequately support this. How people responded as advisors and co-researchers also reminds us of our capacity to think critically and empathically about problems that we also face.

As we strive to define what personal recovery is, there is a danger that we may inadvertently return to a mechanistic conceptualisation of distress and recovery. Recovery as co-opted by healthcare providers and services, seems to have taken factors, such as hope, empowerment, agency, self-determination and self-management (Roberts & Boardman, 2014) as a new set of criteria to measure improvement in clients. Is this a case of old wine in new bottles? Roberts and Boardman (2014) argue that whilst services can “provide the pre-conditions of recovery.. it [recovery] needs to be discovered by the individual themselves” (pg. 37). In this conceptualisation of recovery, practitioners and services are in place to support this process. Recovery factors seem to be understood as a set of personal attributes, something that people have or can acquire, like traits rather than often fleeting states. What, if any, changes are required by services in this model? How are these factors defined and measured within services? In particular, if narrowly defined so as to fit within existing services and overarching paradigms, how does this constrain clients? My fear is that whilst well intentioned, the dominant, positivist biomedical model prevails in this visioning of recovery. I hope that this project contributes to the critical movement which wants us to consider more than symptom reduction when determining what our work with clients looks like and how it is critiqued.

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APPENDIX 1: Ethics Procedures and Checklist

The study requires ethics approval via UEL. NHS ethics approval will not be required as participants will be recruited via self-help groups and online forums.

Informed consent: Information about the study in plain English will be provided to all participants. Introductory sessions will be conducted by the researcher or delegated to appropriate staff at user network events to introduce the study to service users. The contact details of the Research Team (the student and supervisor) will be provided so that potential participants can find out about the study in further detail. Before interviews commence, the researcher will discuss and outline the consent process with participants and obtain informed consent. Information for participants outlines the purpose and nature of the research, what involvement in the research means for participants (in terms of times, activities), voluntary participation, anonymity and confidentiality (including explaining in what circumstances confidentiality would be breached and how this would occur). Participants will be provided with a minimum of 2 weeks' notice between introducing the study and conducting data collection. A draft information sheet is attached.

Participants will be told in all written materials and in discussions of their right to withdraw from the study at any time. As this is a participatory research study, if a participant chooses to withdraw from the research, any data collected will be destroyed and not used in analysis. If there is any information that arises which is relevant to participants continued participation, this will be shared via key contacts (e.g. shared with user network leads) with the Research Team's contact information to find out further information.

Anonymity and confidentiality: The type of personal information that is likely to be gathered will include first names (participants can use pseudonyms), email addresses and phone numbers for those participating in a telephone interview. This personal information, audio recordings and transcripts will be saved on computer files. This information will only be accessed by the researcher and be password protected on the researcher's laptop. This information will be destroyed at the end of the research project. To ensure confidentiality, real names and any identifying information will be removed from transcripts and the reporting of data. Write up of

findings may include the use of direct quotations where they reflect key themes but any use of quotations will not include any identifiable information. Participants will be informed about the possible use of quotations during consent process. Anonymised transcripts and audio recordings will be kept on computer for up to three years after the study ends. Paper copies of transcripts will be kept in a locked file in the researcher's home or at UEL. Audio recordings will be erased from the audio recorder once audio file has been saved on computer.

Protection of participants: The interviews will cover sensitive, potentially upsetting issues, such as the consequences of having social anxiety, which may include experiences of mental health stigma and recalling distressing feelings, thoughts and events. The information and consent form outlines options for participants who are upset by the interview questions, including withdrawing from the interview, asking the researcher to change the topic and talking to the researcher after the interview to access further information and support. The researcher will ensure that all participants are provided with this information before participating in the interview. Before the interview commences, consent will be discussed and participants invited to raise any issues. The mental health recovery research literature highlights the potential benefits to participants of being able to talk about their experiences of mental ill health and recovery.

Debriefing for participants will include checking in to see whether they have been upset by talking about their recovery with appropriate signposting to services for further support. Participants will be provided with the opportunity to review and amend their transcripts. It will be made clear that this is optional and not a requirement of participating in the study. This approach is commonly used in participatory research and is an opportunity for participants to revise anything that they feel does not convey what they were trying to say in the interview. It also allows participants the opportunity to remove any information that they in retrospect do not feel comfortable disclosing.

Potential risks to the researcher have been considered and may include exposure to distressing information and to health and safety risks in a variety of community settings. A number of strategies have been put in place to minimise risk, including conducting interviews at UEL rather than in participants' homes. The researcher will

have access to regular supervision to raise any issues as they arise over the course of the study. Additionally as a service user researcher, any personal issues that are raised in the course of the study will be dealt with within weekly personal therapy sessions.

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)
--

SUPERVISOR: David Kaposi

ASSESSOR: Amanda Roberts

STUDENT: Catherine McCarthy

DATE (sent to assessor): 22/11/2011

Proposed research topic: Narratives on Living with and Recovery from Social Anxiety

Course: Professional Doctorate in Counselling Psychology

- | | |
|--|-----|
| 1. Will free and informed consent of participants be obtained? | YES |
| 2. If there is any deception is it justified? | N/A |
| 3. Will information obtained remain confidential? | YES |
| 4. Will participants be made aware of their right to withdraw at any time? | YES |
| 5. Will participants be adequately debriefed? | YES |
| 6. If this study involves observation does it respect participants' privacy? | N/A |
| 7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? | NA |
| 8. Is procedure that might cause distress to participants ethical? | YES |
| 9. If there are inducements to take part in the project is this ethical? | NA |
| 10. If there are any other ethical issues involved, are they a problem? | NO |

APPROVED

YES, PENDING MINOR CONDITIONS

MINOR CONDITIONS: Recruitment will occur through self-help networks including Social Anxiety Self Help (SASH) groups in London and online forums, such as Social Anxiety Support and Social Anxiety UK. **Please obtain written permission from the network**

administrators to do this before recruitment.

REASONS FOR NON APPROVAL:

Assessor initials: AR

Date: 22/11/11

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: David Kaposi

ASSESSOR: Amanda Roberts

STUDENT: Catherine McCarthy

DATE (sent to assessor): 22/11/2011

Proposed research topic: Narratives on Living with and Recovery from Social Anxiety

Course: Professional Doctorate in Counselling Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

- | | | |
|----|-----------|----|
| 1 | Emotional | NO |
| 2. | Physical | NO |
| 3. | Other | NO |

(e.g. health & safety issues)

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: AR Date: 22/11/11

Please return the completed checklists by e-mail to the Helpdesk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,



Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



APPENDIX 2: Study Information Sheets



UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

The Principal Investigator(s):

Catherine McCarthy

(Email: u1021646@uel.ac.uk. Tel: 07986 456 445)

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate in Counselling Psychology degree at the University of East London.

Project Title:

Involvement Research with People with Social Anxiety

Project Description

Social anxiety is a common mental health problem. It is the most common type of anxiety disorder and third most common mental health problem. It typically develops in late childhood or early adolescence and is understood to be a lifelong, often chronic condition, which can have many detrimental effects on people's lives. The research literature to date has largely omitted the stories of people with social

anxiety, particularly the resilience of people with social anxiety to live a meaningful life, often without any professional help. This research is informed by my own experiences of living with social anxiety. As a trainee psychologist I am interested in ways to improve talking treatments for people with social anxiety. I am interested in the development of social anxiety and how experiences in childhood can lead to social anxiety. I am also interested in what helps people to get better and ways that therapy could better help to facilitate this process.

I would like to talk to people who have experienced social anxiety for a minimum of 10 years. As a first step I want to talk to people with social anxiety about my research ideas and get them involved in shaping what exactly the research will explore. Once that has been agreed, it is likely that the next step will involve an interview, either face to face or on the telephone or Skype or MSN. However, if this is too anxiety inducing, written responses are also welcome. Face to face interviews will be held at UEL's Psychology Department's Research Suite in Stratford. Alternatively, if you are attending a self-help group, such as Social Anxiety Self Help (SASH), then the interview can be arranged around a scheduled group. The interview will take about one hour and will be audio recorded. When written up, there will not be any records of people's names, so there will be nothing to identify you personally. Once the audiotapes have been transcribed, they will be erased.

Interview questions will be shared with you before the interview so that you know what we will discuss and can think about what you would like to say. I am also happy to share your transcript with you once it has been typed up so that you can make any changes.

The interview will include discussion of your experiences of living with social anxiety which you might find upsetting. If this happens, you can take one or all of the following actions:

Let the researcher know you would like to change the subject.

Talk to the researcher after the interview and s/he will tell you about places you can go to for more support.

You can leave the interview.

There will be additional opportunities to be involved in the research, outside of sharing your story, such as providing advice on emerging findings and helping to shape the dissemination strategy. If you would like to find out more, please contact me to discuss.

Confidentiality

Any personal information that is collected, such as phone numbers, email addresses or names will be securely stored on password protected computers and this information will be destroyed at the end of the project. In the write up of the study, direct quotations may be used but your name or any other identifying information will be removed.

Disclaimer

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation.

If you have any questions or concerns about how the study has been conducted, please contact the study's first supervisor Dr David Kaposi, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8823 2760. Email: d.kaposi@uel.ac.uk)

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Please retain this invitation letter for reference. Thank you.

Yours sincerely,

Catherine McCarthy

May 2012

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Study Title: Narratives of Living with and Recovery from Social Anxiety

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date:

APPENDIX 3: Interview Topic Guide

To begin we will run through a few key points. You will have received the information sheet and consent form for the study. I'll check if you've had a chance to read it and if not, we can spend some time at the beginning so you can look at this and ask any questions. Some key points about the interview include:

- Anonymity: your name will not be written down on the tape or the transcript of the tape. Your name will not be linked to the transcript in any way.
- Confidentiality: however if you disclose that you may be at risk of harm or of causing harm to someone else, I may not be able to guarantee confidentiality. I will discuss this with you if this comes up.
- Withdrawing from study: it is your right to withdraw from the study and/or not answer any questions you are uncomfortable with.
- I will audio record the interview so that I can transcribe and not miss anything that you have told me. No one else will listen to this tape and I will delete it at the end of the study.

I will have sent you this topic guide too so before we start I'll check if there is anything about the interview topics that you want to ask me about.

If you are happy to go ahead, I'll ask you to sign the consent form (if you are participating by phone; Skype; MSN; or in writing, I will arrange for you to send this back to me before you tell your story).

1: Your experiences of social anxiety

This section of the interview will explore your experiences of social anxiety. I do not want to be prescriptive. I am interested in what has been important for you so will be guided by what you want to talk about, rather than run through the following questions. The types of things you may like to discuss include:

- How would you describe your social anxiety?
- What was your life like at the time you started experiencing social anxiety?
What was happening in your life at the time?
- What do you think your social anxiety has been due to? I am interested in why you think your social anxiety came about and how it has affected your life. You might want to talk about issues relating to your childhood and growing up; your relationships with others; the impact of life events and changes; the role of wider society and culture; and, also any personal characteristics or views of yourself and others that may have played a role.
- How has social anxiety affected your life?

- Have you used health services? If so, have you been given a diagnosis?
What is your opinion of this diagnosis?
- Are there any other factors that may have played a role?

2: Recovery

Recovery is a term that is now commonly used within and outside mental health services. I'd like to find out your views on this concept, such as:

- What does this term mean to you?
- Is this a term you like to use?
- Do you consider yourself to be in recovery now?
- Is there anything that might represent recovery for you? (e.g. do you have any goals or aims or images of what recovery means to you?)

3. *What helps or hinders recovery from social anxiety*

Looking back over your life so far, what has helped or hindered your recovery from social anxiety? You may not feel like you are in recovery, which is fine, you still will have ideas about what may help and will have things to say about what has not been helpful. Things you may want to talk about here include:

- Turning points in your life where things got better or worse
- What have you found helpful? You might want to talk about medication; mental health services and treatments; people, including family, friends and professionals; peer support; cultural and environmental factors; education, work, interests, hobbies, activities; spirituality; self-help.
- In what ways have these things been helpful to you?
- Have different things been helpful at different times?
- What has been unhelpful? This could include problems with any of the above factors, such as difficulties accessing help; but also can include things like discrimination and stigma and lack of professional and public awareness of social anxiety
- Is there anything that you wish had been there to help you? Do you have any recommendations to others experiencing social anxiety on what helps?
- Have you gained anything from your experiences of social anxiety? This could be things you have learnt or changes about the way you live; think or feel about yourself/others/life in general

Thank you

APPENDIX 4: Adame & Hornstein's (2006) Typology

Subjective experiences of emotional distress

Does s/he identify specific cause/origin of emotional distress?

Does s/he explain this cause?

Diagnosis?

Describe her/his story in medical/psychiatric terminology?

Use of metaphors; symbolism?

“mental illness” as separate or a part of self?

Impact on daily life?

Impact on relationships?

Crisis/breakdown?

Types of treatments (evaluated as good or bad):

Recovered?

Turning points?

End point to distress?

Wisdom/lesson learned?

Narrative structure

How is narrative organised?

Past or present tense?

Narrative form:

Genre:

How is plot structure organised?

Narrator's perspective:

Preface or commentary from medical/academic source?

Where does story begin?

Turning point from pre to post distressed?

Intended audience?

Narrative Voice

Distinction b/w distressed vs non-distressed self?

Does voice change through experience of distress?

Victim? Survivor? Witness to suffering? Deviant?

Reconstruction of concept of self?

Reintegration?

Purpose

Told to expose psychiatric system? Expose abuse?

Written to refute stigmas/stereotypes of the “mental illness”? To reveal abuse/discrimination of those labelled with a mental illness?

To create order out of a chaotic experience? To reconstruct the disrupted life story?

To recover narrative voice after losing it during emotional distress?

To come out about their experiences of “mental illness”?

Is narrative written to describe narrator’s problems in living in terms different from those used by doctors and mental health professionals?

To propose an alternative viewpoint about origins/concept of “mental illness”?

Written as a means to self-analyse?

Assert sanity explicitly or implicitly?

To share a divine message, religious experience or revelation?

APPENDIX 5: Example of Analysis

Alice's analysis notes

Frank's (2010) questions on meaning in stories: who continues to tell this story, to whom and to what effects? I was thinking about the story presented and how episodes are presented which have also been shared on her blog, she pointed this out when telling a story about her childhood and social anxiety. Her story was non-confessional as this story has now been told many times to various people. In the story, there are clear links made to events and problematic social anxiety so that it fits together neatly.

How does she hold her own in the story? (Frank, 2012)

Aligning herself with dominant mental health (CBT) narrative of social anxiety; one of the voices in the story is that of health professionals as this gave her a language to explain her experiences which has not only facilitated recovery but many other changes in her life, including ending her marriage, losing and making new friends; and, her career change. The latter in particular is possibly the greatest which influenced the story that she told me as another professional as I could be seen to belong to the group she wants to join? I was not so much thinking that the group is the socially anxious but more joining with a sub-group of people who have tackled this problem and now work in mental health. If anything, she seemed to have very clear idea about what is acceptable and non-acceptable emotional distress (419-423; 673-6) and helping people like herself: *a gap for people like me who are in recovery* (423-4)

As similar to some of the other narratives, there was a shift from a story about one's self to talking for others; again this was encouraged by my questions – why did I do this? Did I get swept up in her story?

Her social anxiety framed within relationships – shift from genetic perspective to grounding it in relationships (as case; exacerbation; and cure); like some other stories, whilst she talked about shifting from passive to active in relationships (e.g. people pleaser to saying and doing what she wants – perhaps more from non-

demanding to demanding?); it was mostly spoken about as what people do to/how they react to the participant; acknowledges that people in her life have different perspective on what has happened.

She made me think also about how integral our relationships are to our sense of selves: she explicitly talked about this when she said about reducing contact with people who knew her in the past to the new friends in her life who *“know nothing about my past so are not reminding me about how I used to be”* (432-3) – help her to re-author her life or to co-construct this re-authoring; on the flipside of this, she talked about how her mum (who she described as very anxious) would say they were the same *“my mum always said, oh you’ve got my genes or you’re just like me, you’re a chip off the old block”* (181-2); *“my mum says I have McLaren bad luck because that is my maiden name”* (569-70) and how this family script had shaped her views on her distress as inherited/genetic

What voices are in the story?

The confused child and adult, dealing with dad's illness and mum's over-protectiveness; mum's seeming complicity in her anxiety; attracting relationships in which she is saved/protected (friendships at school; with mum; her marriage); getting by seemingly be accident yet when she spoke about this it was in comparison to her sister who she framed as having “worse social anxiety” and reliant on medication to cope – so perhaps was saying that even before she found out about CBT and took on this narrative template, she still was in better psychological/social shape than her sister? Her ways of coping – overworking to avoid mistakes = humiliation; people-pleasing (helping peers (30-2); teachers' pet (29))

From passive to active in relationships – talked about *“all through my childhood I expected people to come rescue me... accept me... nurture me”* (118-9); talked about how with hindsight, she can now see the *“connection”*: to do it myself (119-20). What is she talking about here? Being different in relationships? Or relationship with herself? Seems to be the latter at this point but then later on when talking about the breakdown of her marriage, talks about different types of relationships too (271-280)

And now? Presented herself as the enlightened one – CBT provided her with *“the facts”* (102) as she looks back on how things were for her with amazement (94);

using language of CBT (e.g. rumination) (82) to explain what she understood at the time to be dysfunctional (96) weakness, wimpy (98), weird (99); uses the first voice to reinforce the second?

The professional (the expert service user becoming a coach)

When she talked about not understanding why she couldn't cope, perhaps framing this as skill based achievement? (which she has gained through CBT) – Yes there are numerous references to skills building as the way to recovery

Talked about other changes too – such as narrative shifts when she talked about her 20s and learning to cook but understands this improvement now through the lens of CBT (e.g. skills building (125); pushing yourself forward (126)

I wondered how being a relatively recent recruit to psychiatric and psychological understanding and treatment for social anxiety impacted on her allegiance to these master narratives? I was thinking about the fervour of a new recruit. Do we then try to fit our entire story into this new way of seeing things? She talked about what it was like to get the description of social anxiety disorder (one of her Eureka moments) (379) and her CBT therapist normalising and explaining her experiences (467-72); going through CBT process (370-3) as a process of enlightenment which then permeated other areas of her life.

Adame and Hornstein's (2006) typology

Qs around subjective experiences of emotional distress

Does s/he identify specific cause/origin of emotional distress? Interplay of genes and environment, particularly impact of early familial relationships

Does s/he explain this cause? Yes talked about predisposition (170) and environment eroding her chances of being herself/progressing (170-1)

Talked about being “carbon copy” of mum when she was a child (175) and then used re-enacted direct speech from mum talking about her inheritance of her genes; begrudgingly being just like mum (180-4); then goes on to talk about environmental and systemic factors – how do these voices fit together?

Diagnosis? Yes via clinical psychologist; self-referred; private therapy

Describe her/his story in medical/psychiatric terminology? In psychological terms, specifically language of CBT (e.g. rumination; NATs etc.)

And yes when talking about inheritance/genes/predisposition - she stated that “I’m a little bit biased by stuff that I’ve read” before beginning this section of her story

Use of metaphors; symbolism? Sometimes; to illustrate periods of distress and impact of CBT

“Mental illness” as separate or a part of self? She talked about shift in viewing herself as the problem to the social anxiety as a mental health problem or an illness (within medical discourse) which she has found a cure from

Impact on daily life? Yes

Impact on relationships? Yes – significant within family; relationships with peers at school; ex-marriage; and post-social anxiety

Crisis/breakdown? Yes

Types of treatments (evaluated as good or bad): CBT – very good; life changing and enabling: “got to the nub”

Recovered? There is something about recovery and movement (not progressing; pushing myself forward etc.); she also talked about how CBT has enabled her to achieve much more than change her thoughts and behaviours – it has facilitated her finding her “authentic self” which she prefers to use rather than the term recovery (as this links the latter with social anxiety disorder and the stigma of having a mental health label)

Diagnosis as saviour and marker

Turning points? Yes clear temporal order working through childhood, adolescence and adulthood to denote crisis and breakthroughs

End point to distress? Yes

Wisdom/lesson learned? Yes, once she got the facts or “*the nub of it*” of social anxiety through CBT

Qs Analysing narrative structure

How is narrative organised? Clear temporal order from early childhood; speaking about events (e.g. parental roles) with authority when she would have been too young to remember or understand it in this way at the time. Made me think about how we take on family scripts, that we can present them as facts/unquestioned accounts about the way things were, particularly when it reinforces how we view ourselves and those relationships now

Past or present tense? Both and often distinguishes between how she saw things then and how she sees them now to reinforce her position

Narrative form: interview; done via skype video; sound went out sometimes so had to ask her to repeat. How did this impact on storytelling?

Genre: Restitution (Frank’s illness narratives) but with aspects of chaos (to describe pre-treatment perspective) and quest (to describe how she has drawn on the CBT narrative template to make sense of her life and change it). Alice seemed to use restitution narrative to frame her story as a quest/enlightened narrative.

How is plot structure organised? From point that social anxiety became problematic; including talking about early childhood with authority even though too young to be able to remember this herself – power of family scripts!

Narrator’s perspective: Adopted psychological/CBT narrative following CBT; has identified to extent that was then training in psychological coaching to offer adjunct to CBT for the socially anxious

Preface or commentary from medical/academic source? N/A

Where does story begin? At point, that looking back, social anxiety became problematic but then imagines pre-points (e.g. when dad became unwell when Alice was 2 years old and role changes for mum and dad. Spoke about this as if she was there to see and understand this at the time rather than as bits and pieces told by someone else and/or guessed by the narrator as she looks back on her experiences)

Turning point from pre to post distressed? Somewhat, from shy to socially anxious

Intended audience? That's what I'm wondering about - think it is very important to the story told; what role did I play? I was very active in framing her experiences according to this model too – recruited to the cause?

She is moving into mental health role, working specifically with people with social anxiety and sought my advice after the interview on this work. What impact did wanting to build this professional relationship have on the story told?

She referred to how some of the stories she was telling me were from her blog (34) – non-confessional? The story has been told before; this is the new script? Everything fits neatly together and builds an argument for what she did; thinks; feels; does; future focused too

Qs Analysing narrative voice

Distinction b/w distressed vs non-distressed self? Yes, social anxiety ongoing problem but gets caught up/exacerbated by low mood and struggles at home, school and work

Does voice change through experience of distress? Yes

Victim? Survivor? Witness to suffering? Deviant? n/a

Reconstruction of concept of self? Yes, absolutely

Reintegration? Not really – she talked about how social anxiety was problematic from childhood but that she was able to appear normal (e.g. married; had a career etc.) and then when these aspects of normality started to fall apart, social anxiety increased and she came across disorder explanation and found a CBT therapist

Qs Analysing purpose of narrative

Told to expose psychiatric system? Expose abuse? No

Written to refute stigmas/stereotypes of the “mental illness”? To reveal abuse/discrimination of those labelled with a mental illness? Not really outside of revealing social anxiety is problematic and needs to be recognised and picked up more often

To create order out of a chaotic experience? To reconstruct the disrupted life story? Yes very much so: as discussed above there are two distinct voices in the story

To recover narrative voice after losing it during emotional distress? Rather than recovering a voice, perhaps more about finding a narrative voice

To come out about their experiences of “mental illness”? Yes – possibly strategic? As moving into coaching role and to provide opportunities for “people like me” to practice in between therapy sessions

Is narrative written to describe narrator’s problems in living in terms different from those used by doctors and mental health professionals? No it’s provided a way to understand problems of living which has been (generally) very helpful for her to move from chaotic, shaming view of her distress to understanding her problems in relation to CBT model – it seemed to have been a non-shaming experience for her which has promoted self-compassion and acceptance

To propose an alternative viewpoint about origins/concept of “mental illness”? No but argues for early intervention and better recognition of this difficulty

Written as a means to self-analyse? No; very clear about position and her story post therapy/analysis

Assert sanity explicitly or implicitly? Explicitly – distancing herself from people who are more distressed (why might she do this? To take on professional role?) Or people with a different perspective, such as those from her past (to re-author)

To share a divine message, religious experience or revelation? CBT can do much more than change your thoughts, feelings and behaviours. It can lead to many other changes; has been catalyst/ revolutionised her life; job; sense of self; relationships

APPENDIX 6: Participants' Contribution to the Analysis

Mohamed's feedback on story themes

September 2013

I think the main three themes of my story are:

- 1) Temporary cognitive dysfunction (the temporary reduction in key cognitive functioning, such as memory, arithmetic, logic etc. as a result of anxiety, which leaves you with a strong sense of vulnerability)
- 2) Vulnerability - a sense of a severe lack of control over social situations for any number of reasons
- 3) Lack of socialising in childhood development

Looking back over my answers, I did put a lot of emphasis on the idea of trauma. However, on reflection, whilst this is an important aspect, I think that perhaps even more important is a lack of socialising at key stages in childhood. Whilst trauma and fear can definitely cause mental harm - I think that it will not necessarily lead to severe adulthood social anxiety without accompanying social isolation of some sort, I think. I'd definitely be interested in hearing your analysis of the feedback and the future progress of your project.

Mohamed's feedback on draft analysis

March 2014

I found your analysis very interesting. I have a few points I'd like to share with you: One of the reasons for my use of technical-sounding descriptions like "depersonalisation", "trauma" and "low self-esteem" - as well as discussion about speech impediments - are, perhaps, my attempts to understand and express social anxiety as more complex, multi-faceted and obscure than sometimes presented in popular understanding and CBT. Use of such terms are also, perhaps, my attempts to explain large differences in symptoms I have perceived between myself and other social anxiety sufferers that I have met - thereby, to explain and comfort me about my perceived weaker social performance.

I agree that my use of technical language is also an attempt to gain credibility and understanding with the medical community, as represented by you. I always have the fearful sense, especially when talking to my therapist, that use of normal language and personal anecdotes is ineffective to communicate my experiences. I have the sense that normal language is open to greater interpretation and that the qualified listener will miscategorise or just disregard what I say to fit established models - whilst, more specific, technical language is harder to dismiss or misinterpret.

The fear of my expressed experiences, even when couched in technical terms, being misinterpreted or overlooked is supported, I feel, by your omission of my discussion on depersonalisation in your analysis. As far as I am aware, the idea of depersonalisation (or disassociation) is not a defined medical term and, therefore, one, I feel, that the medical profession instinctively reject. I understand why this is the case - undefined and untested terms are hard for the therapist to work with any confidence. However, I strongly feel that the idea of feeling depersonalised in social situations or, in more normal terms, suffering brain fog/zoned out/hazy/blank is important to my social anxiety. However, in my courses of therapy, I have not successfully expressed this to my therapist. I have occasionally raised it, very hesitantly, or in writing and my therapists have tended to overlook the concept - whether I have expressed it 'technically' by calling it depersonalisation or informally, as feeling hazy.

My quite extensive and personalised discussion about my childhood experiences, particularly, relating to my father, were discomfiting attempts at purging shame. As I wrote them, I appreciated that some of it was quite emotive - which I felt reduces my credibility with others who may doubt or misinterpret my words because of its emotional quality (and, in fact, on re-reading, I doubt myself for this reason). Nonetheless, I made myself write those paragraphs to try and be more open about myself, to confront fear of expressing emotion, to challenge my self-doubt and fear of being misunderstood - and, thereby, confronting my social anxiety.

Regarding the part of your study relating to practical steps for helping SA sufferers - I feel that that CBT treatments might benefit patients more if there was more regular interaction between patient and therapist. Usually, sessions are once a week with

'homework'. After sessions, I have struggled to retain, apply or, even, think about the previous therapy session. Hence, why I feel that more regular contact, perhaps, by email would be helpful. Obviously, resource limits may make this difficult to apply.

I also think that therapists need to directly address patients' lifestyles - and try to encourage the patient into more regular social activity - even, perhaps, to the point of jointly investigating activities that the patient could involve themselves in. Perhaps, such a 'life coach' remit for a therapist would be considered to detract from the actual therapy - but I feel that it is vital for the isolated patient. I have wanted to tell my therapist about the extent of my social isolation but have found it to be too shameful.

Thanks for your work which I feel is very important. I was glad to participate and hope that I have been of some use. I'd love to hear about anything that you publish or share in the future.

Sally's feedback on story themes

September 2013

I have read your email and have read my story again and am a bit unsure as what you mean by themes in the story, the way I understand it's the main themes of my own story are

1 - Abuse - This was one of the biggest causes of my social anxiety and what made me petrified of people

2 Traumatic childhood experiences - which also lead me to not trust anyone through my fear of getting hurt if I got things wrong

3 Depression - This can cause a person to see everything in a very negative way and in my case it caused me to see people in such a negative way

These to me are the 3 main themes of my story (I hope this is what you meant). If this is not what you mean could you let me know as sometimes I find it difficult to understand. I will say too that some of the problems I have reading back on my story are medical through the physical abuse I feel I have damage to my brain and was told that by the test I had done for my dyslexia this causes me to struggle with

processing information quickly but because I am so aware of myself this in turn causes me to worry about what other people think of me as I do get laughed at because I do not understand things so I hide my disability I have asked the doctor for a diagnosis but his reply was the only way to prove the brain damage is to have a brain scan and they are not willing to refer me to this so even though I have problems which effect work and everyday living I will never have a diagnosis as I cannot get a doctor to help, but I thought I would add that on to story that I have already given you not sure if that helps in any way with your research.

I would love to know your initial analysis on my feedback and would find this most interesting. Also since writing my story for you I have begun cycling, this may not seem much to most people but it has opened a door for me into the world and I have started to go out on my own and it has given me some confidence, it is a slow process as I am fighting to have my bike at home as I live in a block of flats but have applied for a residents grant to improve the cycling shed they provide as it is not secure enough, this will then help me to start going out on a daily basis on my own, and am doing my first camping/bike touring trip next week for a couple of days on my own and next year am planning some longer trips. I'm not sure why cycling is changing my life but it's something I can do for myself and it means I am able to go anywhere I want and for the first time be in control of something which no one can take away it has saved my life I still have a long way to go but it's a step forward. I still have received no help for my condition after I insisted on another assessment with the mental health team was told in writing that there is nothing available to help me so I have been with nothing for over a year now. Anyway I thought I would update you a little as to progress in case you can use it in anyway.

Please do not hesitate to contact me again if you need anything else as I am quite happy to give you any information you need for your research it has helped me to be able to put all this in writing and made me realise that things that happened to me as a child were really out of my control and it wasn't my fault that no one helped and stopped what was going on. It's funny but the one thing I still search for even now is for some to say well done, or to clarify that I'm doing ok which is something I still do not get in fact I still get the opposite when I tell people I know about my plans for a world travel by bicycle I get laughed at and told not to be so stupid which yet again

contributes to my social anxiety but at 43 I am now learning to ignore it and am going to follow my dreams of world travel.

Feedback on draft analysis

March 2014

Thank you for your email. It's great to know the work and writings are progressing for you and, was great to read what you have sent me. I read through it and it all seems pretty great to me, I would like to add my own thoughts to this. On the first page you added my part about playing a victim etc. I would like to add for your own use if you need it that I feel when you are abused as a child (and this is just my opinion from my own experiences) you are brought up in a life of abuse, it is really all you know so you attract abuse because it is familiar, like say a child who comes from a normal loving nurturing family with lots of hugs, cuddles and love, that to these normal children is familiar as is abuse to me its normal and it's what I was taught about which is why I attract abuse, love cuddles and nurture is not normal to me which is why any relationship I have with a friend or a boyfriend that is not abusive does not feel normal and can be perceived as boring for someone like myself from an abusive back ground.

I would like to update you on my progress since our last communication in case you feel you can use this too. I'm not sure where I got up to in my last email but since I then life went downhill. My relationship ended and although we are still friends I found that I am unable to deal with relationships especially physical ones (I feel this is due to bad experiences of rape which I think I told you about) I also spend 9 months changing my doctor and having to work with the surgery manager to do this as my old doctor kept telling me 'I'll never be normal' and ' what did I need a diagnosis for' this question seems to be asked a lot amongst the health profession, yet someone who pays for private therapy can get a diagnosis in the first session as I have found out recently. I have also had my 3rd assessment with my local mental health clinic. The first one I was told "I had just had a bad life" was given 6months of 1hr a week of talking therapy and was told this should have been enough even though my childhood issues where never talked about in any depth. My second assessment I was told "there is nothing available and that I should pay for

private therapy out of my benefits” then I fought for nine months for another doctor and now actually have a lovely one who understood completely why CBT therapy was no good and why 6 months of therapy was not enough she then referred me back for another assessment who have now referred me to the brief intervention team and told me I may be able to get therapy to go into depth of my childhood as this seems to be the issues behind my lack of recovery and relapse so I am hopeful about this though yet again I’m on a waiting list and am unsure if they will cater for me being able to go out again.

I feel recover is not only hindered by myself not being able to learn or understanding coping strategies but also by the lack of professional help, I have been asking and fighting for help for 5 years now and keep being told we will not give you a diagnosis (yet on my doctors notes it says Extreme anxiety and agoraphobia but they haven’t told me this I have had to find this out for myself) and there is nothing available as I am not in the ‘At risk’ category. No organisations in the UK cater for individuals with agoraphobia the only one who deals with anxiety have said I have to pay to join and I cannot afford to do that even on their reduced amounts and even this because I am unable to get out they cannot help. I have spoken to a few people in the UK who also have agoraphobia and most of them cannot get any help but just are pumped full of numerous tablets, I myself chose not to go down this route but I think this contributes to the lack of help and support.

I have stopped cycling as I have had to fight for the last 8 months to get my bicycle home, luckily I have won a funding grant last month to get a secure bicycle shed for the 15 residents where I live from the housing association which I am hoping is step forward for them to put these secure sheds in all their block of flats in the future but it has been 2 months since I won this and am still waiting for the work to be carried out so again I’ll have to fight for this to go ahead, and then I can get my bike home and re start my recovery.

So at the moment my anxiety is through the roof due to lack of help and support again and to be honest I’m so tired of the fight it’s no wonder suicides are on the rise as it seems that it is a huge fight to get anything even just a little help to get some help. I am a strong person and have realised this but there are people out there who

do not even know they suffer with anxiety because they are unable to get help or the doctors will not help and just constantly prescribe medication which in my opinion isn't always what is needed.

So I'm afraid my recovery is again on hold but I am using my time to complete qualifications and am presently undertaking a Alcohol and drug counselling course level 3, basic counselling course, understanding drugs course, and now just signed up for to become a NLP life skills registered coach and A quit smoking therapist (both diplomas) obviously these are home study courses which means I can gain qualifications while hopefully getting the help I need to get out. I think the motivation to help others in the same situation as me will help in my recovery, I want to stop the stigma on mental health and help those who suffer with agoraphobia this is a help with my recovery as it takes the focus off my own anxiety.

I hope this can help in some ways, and yes please do share with me any future things which you feel you would like my opinion on or you think may help, and please feel free to ask any questions you may feel helps.

I also want to add which I'm not sure if I've mentioned before, I do believe that with the physical abuse I received as a child I think that some damage was caused to my head at some point as I have awful difficulty sometimes with speech, and have problems with processing information quickly. I talked to my old doctor about this but he said that unless they do a brain scan it would be unable to tell and he refused to send me for one as it costs too much. I do feel that this has also been a contributing factor of my anxiety because I forget my words sometimes or do stupid things and am extremely gullible, I also have problems with short and long term memory, this has also been a cause for bullying as people say I'm stupid and thick because I'll do things which can seem a bit thick sometimes, this is another reason why I do not like being around people as I am so scared of doing or saying something wrong or if I get a job forgetting what they have told me to do. I know it's not my fault and am pretty sure part of it is damage to my brain as a child but yet again stigma on mental health will provoke people's nasty comments even though it could well be a brain issue which is physical. Without a diagnosis I am unable to know if it is brain damage or not but I know this contributes to my anxiety more and more and as I'm

getting older the problems like memory etc. seems to be getting worse so the anxiety is getting worse.

Mia's feedback on story themes

As for my 3 key messages, I know this may sound a bit clichéd but I think generally I'd like it to be a message of hope, so this is what I've come up with so far:

1. Social anxiety may never completely go away, however it can be managed with therapy or medication so should not prevent people from doing activities or pursuing careers etc. that they really want to do.
2. Acceptance has been a key part in SA for me, in that it is there but does not mean it has to take over my whole life and that there is a lot more to my personality other than my SA.
3. it's always worse in your head. What I've found is that I may have been dreading an event for weeks, imagining that I'll be tongue tied or ignored/laughed at by people but in reality it's never been as bad as I've anticipated.

Samuel-James' feedback on story themes

September 2013

It has been good to read through it all again. I think over the last 12 months I have expanded my knowledge of myself and my processes and the social anxiety. I am not free of it but I have taken steps to improving, including face to face counselling. Of course, this is something that has been with me for many years so I'm not going to be able to rid myself of it overnight, but progress is being made slowly.

Three main themes? I would say...and this has become quite clear and apparent to me very recently...Loneliness...I have become aware at my own fear of other people thinking that I have got no friends. It was this thought that triggered the SA back in 1998 for the first time. The reality is I have got friends, but I often spend time by

myself and a lot of my negative feelings towards myself stem from the intensity of feeling lonely. Lonely for me means not having people I like or love or trust around me...it means not having that support around me...it means not feeling protected...it means not feeling at one with others...it means not feeling liked and feeling vulnerable to other peoples' judgement. Not having this leaves me feeling very very insecure and I learnt how to make it look as though it didn't bother me. But I realise now that I was faking it all the time. I really do need this around me and I would love nothing more than to have a best friend or a number of friends who I spend a lot of time with and am seen with.

Another theme? Eating...I used food as a way to control my feelings and to escape from the social anxiety. It was my alcohol and consequently became (and still is to some extent) a tool for me to use to help me feel better about myself. I am working on this currently.

A third theme? Eye contact - pretending and faking and hiding my true feelings caused the quality of my eye contact to be severely hampered so that I had to learn how to fake good eye contact too. But even though I managed to do this, often I just couldn't hide. My eyes would always shout the truth...that I am feeling very very insecure and in need of others.

Feedback on analysis

May 2014

It's taken me some time to reply...sorry for this. I read with interest the analysis and completely happy with everything. Thanks for keeping me posted. Must be very time consuming and you probably know the scripts off by heart! I am well and continuing to learn and progress. I set up Social Anxiety NW, a therapy group for people with this issue in their life, and held my first group recently which was an excellent experience. You may be interested in having a quick look at the website. Many thanks and just let me know if there is anything you would like to know.