EXPERIENCE OF DISTRESS AND USE OF PSYCHOLOGICAL THERAPY: PERSPECTIVES FROM USERS OF AN IAPT SERVICE

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ABSTRACT

This study explored the experiences of people who attended therapy at an IAPT service. It focussed on how distress has been understood by people who have had this experience, and how this understanding in turn shapes their experience of psychological therapy.

Individual, semi-structured interviews were carried out with nine individuals who had completed High Intensity therapy at an IAPT service. The data was analysed using Interpretative Phenomenological Analysis, generating three themes: "Looking to my self", exploring identity and emotional world; "The role of others", exploring experience of distress in the context of relationships; and "'Outside forces': Contextual influences on the experience of distress". The analysis suggested that participants made sense of their distress in varying and complex ways, with implications for their experience of therapy.

Findings are discussed with relation to the existing literature, and implications for clinical practice are suggested.

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1. INTRODUCTION

1.1. Overview

In this chapter, I outline the subject of the study: how distress has been understood by people who have had this experience, and how this understanding in turn shapes their experience of psychological therapy. I discuss the service of focus for this research – an Improving Access to Psychological Therapies (IAPT) service. IAPT is a relatively new approach to delivering mental health services in the UK, providing psychological therapies for a range of different forms of distress. I discuss the results of a literature review conducted to look at research that has investigated how people conceptualise distress. I summarise the gaps in the literature to provide a rationale for the current study, and finish with the research questions.

1.1.1. Terminology

I have used the word 'distress' to refer to the experience of sadness and worry, or what is commonly referred to by the diagnostic terms 'anxiety', or 'depression'. These experiences are also sometimes referred to as 'common mental health problems'. The Oxford English Dictionary (2013) defines distress as 'extreme anxiety, sorrow or pain'. I have chosen to use the broad term of distress rather than focussing more narrowly on one particular type of distress to encapsulate a range of experiences. I recognise the significant overlap between different diagnostic categories and the debates surrounding their utility (such as debates around whether 'anxiety' and 'depression' should combine into one diagnosis due to their significant overlap – Shorter & Tyrer, 2003).

I use the term 'service user' to refer to people who are using, or who have used mental health or psychological therapy services. I acknowledge that people have different ideas about the best term to use. Campbell (2013) states that 'service user' is a 'neutral term now commonly used' (p.140) and notes that it is often used in literature written by service user activists.

Terminology in relation to mental health is problematic. It is often loaded with meaning, and as the above examples show, terms are often debated. Some of the terms I use here I consider problematic (e.g. 'treatment' as a term for psychological therapy, with its relationship to the medical model) – however I have tried to remain faithful to the research I am reviewing here by using the same terms as it uses.

<u>1.1.2. How I came to this research</u>

My interest in carrying out this research was influenced by a number of experiences both during clinical psychology training and prior to training. I am interested in personal narratives of psychological distress, and what influences these – for example, cultural background, family stories and media representations. I am also interested in the way that personal understandings interact with professional explanations where help is sought. I have worked in services where I feel there has been careful exploration and consideration of a person's own understanding of why they are feeling the way that they are, and services where I have felt like professional understandings have been dominant and personal understandings neglected. I am aware of the multiple lenses through which distress can be viewed, and of the (often polarised) debates that exist in clinical psychology literature about the strengths and weaknesses of different therapeutic approaches. Of particular interest is the debate around the extent to which context (such as people's circumstances, and their interactions with the world – Boyle, 2012) should be taken into account when conceptualising distress. I have found that the views of people using mental health services tend to be much less present in these debates. I therefore hoped to explore how people experience psychological therapy, and how it fits with their personal understandings of distress.

1.2. Frameworks for Understanding Distress

In this section I consider some of the ways distress has been conceptualised from different perspectives, to begin to consider some of the frameworks that

people experiencing distress might have available to them to understand their experience.

<u>1.2.1. Theoretical Perspectives</u>

1.2.1.1.'Biopsychosocial' Model

A dominant approach in recent years has been the 'biopsychosocial' model, originally proposed by Engel (1977). This aims to understand distress through combining biological influences (e.g. hormones), psychological influences (e.g. thought processes) and social influences (e.g. family relationships). The biopsychosocial model has acted as a framework for considering the different realms that may contribute to a person experiencing distress. It has been criticised for assuming that biology, psychology and social influences are separate entities when in reality they are likely entwined, and for not considering the relationships between each influence enough (e.g. Cromby, Harper & Reavey, 2013). Read (2005) argues that mental health research has predominantly focused on biological, and, to a lesser extent, psychological influences, so that in reality a 'bio-bio-bio' model exists. Potential social influences have been explored far less, meaning there may be fewer discourses available for people to consider their own distress in terms of how it is affected by, or located in, their social context.

The vulnerability-stress hypothesis (e.g. Zubin & Spring, 1977) has much in common with the biopsychosocial model – it also seeks to understand the interaction of biological and social influences. The model suggests that mental health problems are more likely to occur in people who are biologically 'vulnerable' (i.e. people who are less able to tolerate stress evoked by external stressors, such as life events – Zubin & Spring, 1977). Boyle (2012) criticises the vulnerability-stress hypothesis for downplaying the role of life events, by implying that only 'the vulnerable' are affected and that 'normal' people are able to cope (p.32). The focus is still primarily on biology and the locus of distress is still firmly placed within the person. Boyle (2012) points out that downplaying the role of context is not a neutral endeavour, and that both psychiatry and clinical

psychology potentially stand to gain from ignoring the impact of context. Within psychiatry, taking context into account may threaten to abolish its very subject matter – the idea that distress is an outward symptom of an internal pathology, to be treated by medication (Boyle, 2012). Within clinical psychology, consideration of context may threaten its attempts to be scientific and value-free (Boyle, 2012). Ignoring the impact of context may also be in keeping with psychology's long history of working with individuals.

1.2.1.2. Psychiatric Approaches - the 'Medical Model'

Psychiatry, and the medical model, is the dominant discourse in mental health (e.g. Rogers & Pilgrim, 2005). Psychiatric approaches to mental health are based around the idea that biology, or changes in the brain, are the primary cause of distress. The 'medical model', upon which much of psychiatry is based, has a variety of definitions. A recent definition by Shah and Mountain proposes that it is 'a process whereby, informed by the best available evidence, doctors advise on, coordinate or deliver interventions for health improvement' (2007, p. 375). More traditionally, the model has been taken to mean that people who are distressed are suffering from biologically caused illnesses, for example from changes to brain structure or chemistry (Johnstone, 2013, p. 102). Psychiatric treatment is based around diagnostic categories, such as those described in the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5, 2013).

Clinical psychology is divided on the utility of psychiatric diagnoses. In response to the DSM-5, the British Psychological Society (BPS) issued a statement critiquing psychiatric diagnosis for being presented as objective fact, arguing instead that it is based on clinical judgement and therefore subject to variation and bias (BPS, 2013).

Diagnoses are commonly used in mental health services such as IAPT, and have been influential in shaping public and professional understandings of mental health.

1.2.1.3. Clinical Psychology Approaches

Clinical psychologists commonly use formulation as an approach to understanding distress. Sometimes formulation is used alongside diagnosis, and sometimes it is used on its own (Johnstone, 2013). In its 'Good Practice Guidelines on the use of psychological formulation', the BPS's definition of formulation includes that it is 'a hypothesis about a person's difficulties, which links theory with practice and guides the intervention [...] it summarises and integrates a broad range of biopsychosocial causal factors' (2011, p. 2).

Formulation forms a core part of many therapeutic approaches used by clinical psychologists, including cognitive behavioural therapy (CBT), psychodynamic therapy, systemic therapy, and cognitive analytic therapy (CAT) (BPS, 2011). Training courses are obliged to teach at least two approaches, and many psychologists describe themselves as integrative or eclectic in their overall approach (BPS, 2011).

Psychological approaches differ in how they conceptualise distress – what they consider to be the causal factors of distress, and where they see distress to be located (e.g. within the person, within relationships, within the wider societal context). Below I offer a brief summary of the main therapeutic approaches in clinical psychology, and how they conceptualise distress. This is only a brief summary, and does not fully capture the significant diversity in the way that psychologists practise within each approach.

A CBT Perspective: CBT sees that distress occurs when people are stuck in unhelpful patterns of thinking and behaviour, sometimes as a result of difficult childhood experiences. Intervention is based on the idea that evaluating and modifying these thinking patterns can ameliorate distress and improve wellbeing (Dudley & Kuyken, 2006, p. 17).

A Psychodynamic Perspective: Broadly speaking, at the core of a psychodynamic approach is the idea that distress is a result of 'failing defences', or unconscious attempts to avoid pain (Leiper, 2006). Therapy aims to help the person become in

touch with those thoughts and feelings that were previously unconscious, or repressed, and to develop a new understanding with the therapist that opens up new ways of managing conflict (Leiper, 2006).

A Systemic Perspective: A systemic approach sees problems as being located in relationships, or in interactions between members of a system (such as a family). It therefore acts to 'shift[…] the focus from the person in isolation to the person in context' (Baum, 2006, p. 38).

A Community Psychology Perspective: A community psychology approach sees that distress, and wellbeing, can only be understood through analysing social context (e.g. Kagan, Burton, Duckett, Lawthorn & Siddiquee, 2011). Context is taken in the broadest sense to encompass areas such as: organisational and work settings; geographical communities (e.g. neighbourhoods); communities of identity based on gender, ethnicity, and class (Orford, 2008).

There are therefore a range of different ways that distress is conceptualised, according to which therapeutic approach is being used. A key distinction between different approaches relates to whether they look to the individual, or to their context, to locate the distress.

An important part of any psychological therapy is the relationship formed between therapy provider and user. Studies exploring the effectiveness of different types of therapy consistently show that the therapeutic relationship between therapist and service user is the biggest predictor of successful outcome (e.g. Blow, Sprenkle & Davis, 2007; Horvath & Simonds, 1991), over therapeutic model or model-related techniques. More recently, qualitative research has explored the types of interaction within a therapeutic relationship (such as reflections signifying an understanding of the other) that might contribute to a stronger or weaker therapeutic relationship (Roy-Chowdhury, 2006).

1.2.2. Public Understandings

Surveys of public attitudes in England suggest that many people still understand psychological distress as a medical problem. An annual report by 'Time to Change' (a mental health anti-discrimination programme) in 2012 showed that out of 1727 adults interviewed, 76% agreed with the statement that 'mental illness is an illness like any other' (Time to Change, 2012). Fifty percent agreed that 'someone who is born with some abnormality affecting how the brain works' describes a person with mental health issues (Time to Change, 2012). Notwithstanding the predominance of medical language throughout the report and questions posed (e.g. 'mental illness'), this implies that people conceptualise 'mental health' as a medical problem, rather than a social one. Other research suggests that medical understandings of distress are not necessarily incompatible with social understandings. For example, Priest, Vize, Roberts, Roberts &Tylee (1996) found that respondents in a doorstop survey were likely to link the cause of depression with life events (such as unemployment (77%), or relationship breakdown (67%)). However, this view did not prevent respondents from agreeing that depression was a medical illness comparable to physical illness (73%).

Coverage of mental health in the media has been shown to link clearly with public attitudes (e.g. Philo, 1997). A number of researchers have analysed portrayals of distress in the media and have suggested that negative depictions tend to predominate in both print media (e.g. Coverdale, Nairn & Claasen, 2002) and television media (e.g. Philo, 1997). A review by Wahl (1992) concluded that mental health is displayed inaccurately and unfavourably across different media types. Rose (1998) showed that on UK television, the most common theme associated with 'madness' is violence. Bilic and Georgaca (2007) showed that key discourses surrounding mental health portrayals in newspapers included 'bio-medicalisation', constructing mental health as a medical disorder associated with 'dangerousness', for instance, portraying people with mental health problems committing violent crimes. Studies exploring mental health problems typically show very low rates of self-depiction; for example, Nairn and Coverdale (2005) showed that only 0.8% of articles discussing mental health included direct reports

from people with a mental health problem. This research may be less applicable to articles written in the UK as the study was based in New Zealand.

Findings discussed in this section suggest that biomedical understandings and stigma shape public understandings, and the voice of people experiencing mental health difficulties is little-represented.

1.2.3. Service User Perspectives

Research exploring the views of people who have used mental health or psychological therapy services in the UK has tended to focus on views and perspectives of treatment, rather than conceptualisations of distress itself (or the relationship between the two). For example, Rogers and Pilgrim (1993) studied service users' evaluations of different interventions and found that talking therapies were preferable to Electro Convulsive Therapy and drug treatment, implying a psychological approach was preferable to some medical interventions. Campbell (2013) cautions that, while there is scepticism towards the medical model generally amongst service users, this is predicated on different conceptualisations of the medical model – some service users disagree with the fundamental concept of a mental 'illness', while some are more interested in promoting choice in intervention throughout services. Some researchers (Beresford, Nettle & Pering, 2010) have argued for a 'social' model of mental health, which is discussed later on in Section 1.4.1. Caution needs to be taken to ensure that 'service user views' are not seen as a homogeneous collective, and the diversity and range of opinions needs to be accounted for (Campbell, 2013).

1.2.4. Personal Accounts

There is a growing body of publicised first-person narratives of distress, both in literature (for example, Sylvia Plath's (1963) 'The Bell Jar'), and on the Internet (for example in blogs such as 'Hyperbole and a half', on which the author describes her experiences of depression Brosh, 2011). Gail Hornstein (2011) has collated a bibliography of first-person narratives of madness which include more than 700 titles. Whilst the considering the implications of this growing area further

is outside the realm of the current study, it is important that its existence is acknowledged.

1.3. Policy and Service Context

<u>1.3.1. The IAPT Programme</u>

The Health and Social Care Act (2012) equally emphasises mental health and physical health .The current mental health strategy emerging from it, 'No health without mental health' (Department of Health (DoH), 2011), sets out aims to improve the mental health and wellbeing of all citizens. A key objective is that support for mental health 'should offer access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives' (DoH, 2011, p. 6). To this end, £400 million was invested between 2011 and 2015 in making psychological therapies readily accessible across England, largely through the IAPT programme, originally launched in October 2008 (DoH, 2011). The drive for IAPT was based on an economic report often called the 'Layard Report' (London School of Economics, 2006) which argued that psychological therapies could save money by helping people return to work and thus reduce their dependency on Incapacity Benefit.

The aim of IAPT is to ensure access to psychological therapies for all who require them (DoH, 2012). IAPT services mainly deliver interventions approved by the National Institute of Health and Clinical Excellence (NICE), which include CBT, Interpersonal Therapy, and Dynamic Interpersonal Therapy. Some services offer further choices, such as systemic therapy with families and couples. In addition to providing psychological therapy for adults, a standalone IAPT programme has recently been developed for children and young people. Plans are also underway to extend IAPT to those with long-term conditions, medically unexplained symptoms, older adults, and people with 'severe mental illness' (DoH, 2012, p.12).

People accessing psychological therapy services in the NHS in England for distress (perhaps more often referred to as 'common mental health problems'

such as depression or anxiety) are most likely referred to an IAPT service. IAPT services tend to use a 'stepped care' approach, meaning there are different levels of support available according to a person's needs: 'High Intensity' offers support from therapists who are trained in using CBT with people with 'moderate to severe anxiety and depression'; 'Low Intensity' offers support from therapists who are trained in using CBT with people with 'mild to moderate anxiety and depression' (IAPT website, 2014). 'Low intensity' often involves fewer therapy sessions, and therapy may take place within psycho-educational groups (IAPT website, 2014). Stepped care is based on the idea that a person starts with the most efficient and least intensive form of intervention, and can be 'stepped up' to other forms of intervention if necessary (e.g. White, 2008).

1.3.2. Current Debates in IAPT

The IAPT programme has been instrumental in: achieving more funding for (traditionally underfunded) mental health services; for expanding psychological therapies and emphasising effectiveness; and for increasing accessibility of psychological therapies to people who would previously not have had any (Marzillier & Hall, 2009). Furthermore, a summary report of its first three years (DoH, 2012) outlines that over 1 million people have been treated, with over 680,000 people completing treatment. Recovery rates (measured by a significant change in scores on routine outcome measures) are consistently in excess of 45% (DoH, 2012, p. 5).

Debates have ensued about different aspects of the IAPT programme and its implementation. Some have argued about the dominance of CBT in IAPT services (e.g. Hall & Marzillier, 2009). IAPT services largely use therapeutic approaches supported by NICE, which only selects therapies that have been evidenced through the 'gold standard' of research, the randomised controlled trial (RCT). The idea that RCTs are the best method of assessing the effectiveness of psychological therapy has been criticised. For example, Roy-Chowdhury (2013) states RCTs are based on psychiatric diagnoses, for which validity is poor (e.g. Bentall, 2009), and they rely on the premise that therapy is stripped of all elements of human interaction. RCTs therefore tend to negate the crucial

importance of the therapeutic relationship (e.g. Blow et al., 2007), and have little resemblance to real life practice. CBT is often favoured by RCTs, as it aims to facilitate behavioural change, which is easily measurable (Roy-Chowdhury, 2010). Other approaches (such as systemic therapy), which aim to facilitate changes that are harder to measure (such as changes in relationships) have therefore been marginalised. A published exchange of letters between Andrew Samuels, Professor of Psychoanalytic Studies at Essex University, and Dr David Veale, Chairman of the British Association for Behavioural and Cognitive Psychotherapies debates the nature of interaction and therapeutic relationship in CBT (Samuels & Veale, 2009). Samuels describes it as 'mechanistic', requiring clients to be 'passive and obedient'; Veales in response states that CBT in recent years has been focusing on how to deliver an 'efficient, compassionate and caring' relationship (Samuels & Veale, 2009). Their exchange illustrates the often polarised nature of such debates surrounding CBT.

Some have argued for greater choice in the therapeutic approaches delivered through IAPT services, as a result of the tendency for CBT to be used over other approaches. The process by which an approach is decided upon has also been debated. Hall and Marzillier (2009, p.407) propose that plans for intervention in IAPT are based on the following:

- a comprehensive problem assessment and formulation (including personal history, the influence of family, the presence of financial and social constraints on change, and the person's expectations based on their previous contact with services)
- a subsequent 'decision tree' for options for intervention, including choice of intervention with a diverse range of therapies (with no intervention at all being an option); creating a therapeutic alliance; and social and community support where social and financial factors are prominent in the formulation.

This argument is based on the idea that people will engage better with therapy that is consistent with their own values and beliefs.

Desire for choice is echoed in service user evaluations of IAPT. An evaluation by Mind in 2012 showed that 58% of the (over 1600) people they surveyed who had accessed psychological therapy from the NHS were not offered choice in the type of therapy they received, and 43% did not have different types of psychological therapies explained to them at referral. People who had a full choice of therapeutic approaches were over four times more likely to report 'feeling well' after treatment than those who were not offered choice (Mind, 2013). In a service-user led evaluation of IAPT commissioned by Rethink (Hamilton et al., 2011), satisfaction with IAPT services generally was high. This was particularly true when service users felt that therapists adapted and responded to their individual needs and circumstances, but less true when it was felt a less flexible 'text book' therapy was received (Hamilton et al., 2011, p. 3).

Choice and diversity in approach is particularly important when providing a service that meets the needs of all members of a community (e.g. different ages, ethnicities, cultural backgrounds, religions). Moloney and Kelly (2004) argue against the suitability of 'quintessentially Western' (p. 5) CBT for individuals from ethnic minorities. Only one in ten service users surveyed by Mind (2012) felt their cultural needs were taken into account by the service they were offered, although many identified that this was not important for them. Adaptations that make IAPT services more culturally sensitive have since been proposed (Roy-Chowdhury, 2013). However, there is still some way to go, and a key goal in the delivery of IAPT is to become more responsive to the needs of diverse communities (DoH, 2012).

Many have argued that focusing intervention on individuals ignores the effects of the wider context. Hall and Marzillier suggest that:

> *'anxiety and depression should be seen in the context of growing income inequalities, changing patterns of family life, increasing job insecurity, the influence of the media on people's expectations and wants [...] for many depression and anxiety are products of the society in which they live and are not an individual fault or pathology'*
>
> (2009, p. 406).

The continued use of individually-focused therapies may therefore ignore the root causes of distress and focus only on its effects (Patel, 2003). Some have argued that the focus in IAPT of getting people back into work does mean the wider social context is acknowledged, but this is based on economic rather than humanitarian grounds (Roy-Chowdhury, 2010). White (2008) has shown that IAPT services have the potential to work with communities, not just individuals and suggests a population-level approach for IAPT, including raising awareness of mental health and combating stigma. However the approach he outlines still has CBT as its focus. John and Vetere state that:

'CBT has an enormous potential to reframe, as do many of the other individual psychotherapies, and this can help life mood and re-energise us for a different approach to problem solving. But it does not have social action at its focus'

(2008, p.27)

They further argue for services that support community collaboration, through developing social support and building trusting relationships, alongside determination to focus on individual, resonating more with a community psychology approach. Yet with the continuing focus on NICE guidelines, which recommend predominantly individual approaches, it remains to be seen how their ideas could be implemented at present.

1.3.3. Summary and Key Issues for IAPT

The IAPT programme therefore represents a major step forward in mental health services. Specific issues it faces include the issue of choice in intervention; the extent to which context is focussed on and considered a part of intervention; and how accessible it is to different parts of the population.

Qualitative research focussing specifically on the views of IAPT service users has been limited. Hamilton et al. (2011) suggest that there is an appetite amongst service users for more opportunities to become involved in planning services, or in providing feedback. Currently, quantitative outcome measures remain the

predominant measurement of change. Hall and Marzillier (2009) argue that such measurements are predicated on the idea of symptom change, and ignore changes in the wider context.

It is less well understood how people accessing IAPT services experience the interventions they engage with, particularly in relation to the issues of context and choice in approach, as discussed above. More specifically, there is little research into whether the approaches offered fit with service-users' own personal understandings of distress – indeed there is little research into what these understandings are. I now turn to a review of literature which explores personal conceptualisations of distress, and how these conceptualisations influence experience of therapy.

1.4. Literature Review: Understandings of Distress

I conducted a literature review into how people who have experienced distress make sense of it, and what factors might shape people's understandings. See Appendix A for further information about the search strategy used.

I noticed that despite using different search terms linked to common mental health problems (e.g. depression, anxiety) the majority of studies focussed on depression.

Below is a summary of key themes that emerged through my reading of the literature found:

- Understandings of psychological distress held by individuals may differ from those suggested by a biomedical, or psychiatric model;
- Individuals who have experienced distress appear to believe that it has a variety of causal influences – including biological, psychological and social influences;
- Understandings of distress tend to relate to a person's social position – for example, factors such as culture/ethnicity, gender,

age, socio-economic status and spirituality seem to influence understandings of distress;

- There appears a link between a person's conceptualisation of distress and the way in which they seek support;
- Having a 'fit', or congruence, between personal understandings of distress and treatment approaches may be linked to increased satisfaction with treatment.

Each theme and its supporting research will be discussed in further detail later on, alongside its relationship to mental health more generally. Several of the above themes are supported by a significant body of literature. For example, cultural influences on mental health have been extensively researched. However, due to word constraints I have limited the below discussion to focus specifically on research into factors that help our understanding of how people conceptualise distress.

It is important to note the different terms for 'understandings' or 'conceptualisations' that have been used in the research presented below. The term used largely depends on the theoretical background and epistemological framework of the study. For example, health psychology research tends to use terms such as 'health beliefs' (based on Rosenstock's 1974 'Health Belief' model). Here 'conceptualisations', 'understandings' and other related terms are used interchangeably, and taken to mean the way that people experience, describe, and attribute causality to distress.

1.4.1.Conceptualisations of Distress

Qualitative studies have tended to focus on the experience of specific types of distress (e.g. depression, anxiety) as they are experienced by particular groups of people. Findings suggest that experiences and understandings of distress are diverse and wide-ranging, and influenced by a number of factors. I discuss these two topics in turn, first exploring the variety of ways in which distress has been conceptualised, and then what factors have been shown to influence its

conceptualisation. I then turn briefly to research which looks at how personal understandings influence help-seeking and experience of therapy.

One of the challenges of summarising and synthesising this research is that qualitative research is, by its nature, influenced by the interests and positions of the researcher, and therefore findings are often presented as seen through a particular 'lens' or framework. For example, Rafique (2010) explores South Asian women's experiences of depression, drawing on a cognitive behavioural framework and explicitly exploring rumination. Their findings are therefore presented through a 'meta-cognitive framework', shaped by the types of questions they asked and the corresponding answers participants gave. I attempt to address this challenge in my own research through reflexive practice and considering the assumptions and values that I bring to my analysis, considered further in Section 2.7.

Descriptions of distress tend to draw upon different aspects of experience, including:

- Physical aspects – such as sleep problems, sexual difficulties (e.g. Amini, Negarandel, Cheraghi & Eftekhar, 2013)
- Emotional experience – e.g. unwanted emotions, fear (e.g. Sisley, Hutton, Goodbody & Brown, 2011), sadness, (e.g. Gramling & McCain, 1997)
- Thoughts and disturbances to thoughts (e.g. Amini et al., 2013)
- Relationships with the world and other people, such as withdrawing from friendships (e.g. Sisley et al., 2011)
- Diagnostic labels given by a medical professional, such as depression (e.g. Gramling & McCain, 1997)

Research suggests that different features of distress alongside levels of conceptualisation form an inter-connected whole. For example, Rhodes and Smith (2010) explore the experience of depression in a single-case study. The participant, 'Paul', describes difficulties in his life in the lead up to depression, such as money worries, working late, and reduced contact with his family. He goes on to describe his experience of depression, in terms of a set of

interconnected features such as lack of motivation, helplessness, fear, and related difficulties in his relationships. An interaction of different types of experience and understandings are therefore present in his account.

Rafique (2010) found that people understood there to be inter-relationship between emotions, thoughts, physical health and behaviour when speaking about their experience of depression, consistent with a cognitive model of rumination. As discussed previously, the questions asked of participants were consistent a CBT paradigm (e.g. 'tell me about your experiences of rumination'), which may have shaped participants' responses and the conclusions drawn. Feely, Sines and Long (2007) interviewed participants about their experiences of living with depression and found that they tended to blame personal attributes for the way they thought and felt – for example, the belief that they were 'people-pleasing' and could not say no to things. Rafique (2010) and Feely at al.'s (2007) findings suggest that one way of understanding distress is to look internally to the self. Notwithstanding the methodological issues outlined, the accounts they explored focus primarily on ways of thinking, personal attributes and the self, and see distress as being located intra-psychically.

Locating distress intra-psychically has parallels with studies that explore experiences of taking psychiatric medication, and how medication influences constructions of distress. Fullagar (2009) found that women taking anti-depressants tended to construct themselves as 'neurochemically deficient' (p. 389). Taking medication was linked to restoring normality and overcoming the 'biologically deficient and morally failing self' (Fullagar, 2009, p.389). Seeing the self as deficient chemically and biologically is one approach to understanding depression that may be shaped heavily by the 'emergence of molecular science and the push for pharmacological solutions' (Fullagar, 2009, p. 389). These findings also suggest that there is a relationship between a person's conceptualisation of distress the type of intervention sought.

Other studies have found that people look externally to their relationships and social context in order to understand their experience of distress. Granek (2006) interviewed graduate students about their subjective experience of depression,

and found that they often spoke about it in terms of their relationships to other people. For instance, many described a lack of connection, loneliness, difficulty finding support, or loss. Martin, Jesus Mari and Quirino (2007) interviewed women diagnosed with depression living in poor, high-crime suburbs of Sao Paulo. The authors found that these women attributed the causes of their depression to their relationships with other people, including (sometimes violent) marital relationships, and difficulties within families. Martin et al. (2007) acknowledged that they selected highly articulate and informed individuals; the same could also be argued of Granek's (2006) research given she interviewed graduate students. Further research with people from a range of backgrounds and levels of education is therefore needed.

A range of studies cross-culturally has suggested that people link the experience of distress to the circumstances of their lives – both past and present experiences, drawing on a range of influences and experiences. This has been described by some as a 'social' model of distress (Beresford, Nettle & Pering, 2010). Beresford et al. (2010) spoke to a large number of UK mental health service-users about their personal understandings of distress, focussing primarily a 'social' or 'holistic' model, and asking participants whether they felt that the social model of disability (e.g. Oliver, 1983) offered a helpful way of understanding mental health issues. Participants tended to view medical or individual models of mental health as dominant within public domains and professional understandings, and furthermore felt that these models were largely unhelpful. The view that 'mental health was affected by and a response to broader social and environmental factors' was popular amongst participants (Beresford et al., 2010, p. 16), locating experience of distress in the wider societal context, rather than locating it solely within the individual. Views on whether the social model of disability was a helpful way of understanding mental health issues were divided. Participants described fearing the association with disability and impairment, and questioned whether the social model of disability was a useful framework for understanding mental health.

The idea of locating the experience of distress in the wider societal context has featured widely in other studies. Brown and Harris's (1978) seminal research

showed a clear link between psychosocial factors and the experience of depression in women. Participants commonly associated depression with difficult life events, particularly bereavements, but also specifics of their circumstances (such as living in an urban setting). Brown & Harris concluded that:

> *'a woman's own social milieu and the broader social structure are critical because they influence the way in which she thinks about the world and thus the extent of this hopelessness; they determine what is valued, as well as what is lots and how often, and what resources she has to face the loss'*

<div align="right">(1978, p. 270).</div>

Since Brown and Harris's (1978) research, a range of studies have looked at how people make sense of their social circumstances when exploring their own distress. For example, Sisley et al. (2011) interviewed African-Caribbean women living in London about their experiences of distress, finding that a key theme that emerged from their accounts was the attribution of distress to social factors. Examples of this included performing gender-specific roles, stressful life events and lack of support from others. These findings have been replicated in a Taiwanese population (e.g. Fu & Parahoo, 2008) and Brazilian population (e.g. Martin, Mari & Quirino, 2004) – participants in both studies linked the causes of their depression to difficult social circumstances, both past and present.

The process by which social circumstances influence understandings of distress has been shown to vary according to a person's social position; for example, one's gender, cultural background, socio-economic status. I therefore now turn to research focussing on these different areas. I acknowledge that there are other social positions that may influence understanding that are not explored here due to word constraints (e.g. age, educational background). The areas discussed below were included in the main findings from my literature search.

1.4.2. Which factors influence understandings of distress?

1.4.2.1. Cultural Background

As discussed in Section 1.2.1.2, research has suggested that the medical model is dominant in our explanations of distress in Western society. Whilst NHS information sheets about anxiety and depression (NHS, 2014) – widely available on the Internet – discuss both biological and psychosocial causes, the language used is still predominantly medical (e.g. 'diagnosis', 'symptoms', and 'treatment'). Access to help for distress is primarily through GPs, intrinsically linking mental health, and its treatment, with physical health and medical understandings.

The expression, understanding and interpretation of distress have been shown to vary cross-culturally. Research suggests that other cultural groups may understand distress differently, and their understandings may not be influenced to the same extent by the medical model. For example, Karasz (2005) explored differences in conceptual models of depression between South Asian and European American groups living in New York by asking the groups to discuss vignettes describing depressive symptoms. South Asian participants identified the symptoms largely in social and moral terms, referred to as a 'situational' model, locating the 'problem' within difficult life situations. European American participants on the other hand, were more likely to identify with a biological model, where explanations for the symptoms ranged from 'hormonal imbalance' to 'neurological problem'. Their responses suggested that they conceptualised the 'problem' as a disease process, located within the individual. The authors conclude that there was a separation in conceptualisation between depression-as-disease, and depression arising from social context. Karasz (2005) also found between-group differences in the type of help sought for depression. European American participants were more likely to recommend professional help, particularly psychotherapy or psychiatric medication, whereas South Asian people were more likely to recommend self-management or drawing on the support of family and friends. Such findings imply that conceptualisations of depression and how help is sought are interrelated, and that a person's cultural background may influence both.

Karasz, Garcia and Ferri (2009) explored conceptual models of depression in other ethnic groups. They used the 'Illness Representation Model' (Levanthal, Nerenz & Steele, 1984) as a framework to interview participants from European American, Hispanic American and African American backgrounds and elicit a narrative of their experience of depression. Analysis showed that the groups differed in key aspects of their conceptualisations of depression. For example, European American people were more likely to give a technical label for their depression, make internal causal attributions (i.e. either biological or psychological), and see internal changes relating to the self as key to success in therapy. They appeared to conceptualise depression as the problem of the individual.

It could be argued that the use of a pre-existing model such as the Illness Representations Model is problematic as it assumes that 'representations' of distress exist and that these can be used to structure participants ideas, rather than enabling participants to describe distress in their own words. However the model adds value through highlighting potential cultural differences in where people locate distress – either seeing it as arising from within the person, as a disease or biological process, or from their social context, or life situation.

The tendency to draw on one or the other is shaped by multiple factors. For example, the community psychologist Mark Burton has argued that in Britain, the prevailing capitalist ideology of an 'individual who enters into contracts with other individuals in a market system' (Burton, 2010, p17), has infused British psychology. He argues that psychology focuses on individual factors over and above societal factors, and that this focus explains our current obsession with 'de-contextualised cognitive behaviour therapy' (p17). This suggests that understandings of distress can be influenced by cultural background and what the prevailing understanding in that background is.

1.4.2.2. Gender

Differences have been found in the way that men and women describe experiencing distress. Danielsson and Johansson (2005) explored the way in

which men and women diagnosed with depression construct and made sense of their experience of depression. They found that men talked about physical distress more easily than emotions, whereas women verbalised emotional distress, such as shame and guilt, more easily. This finding suggests that people working with distress need to be aware of the way that gender roles might influence the experience and expression of distress.

Research in this area heavily suggests that social and contextual factors are key in understanding the differences experience and expression of distress in men and women. For example, Mackay and Rutherford (2012) interviewed feminist women who had been diagnosed with depression, to explore their lived experience of it. They found that the majority of the women's subjective accounts drew upon social factors (such as relationships), and framed depression in terms of social context. Social understandings appeared to be more compatible with a feminist perspective. For instance, participants often related their experience of depression to social factors, such as relationships with family, or belonging to a certain cultural group. In drawing upon social factors, the authors argued that participants were situating their experiences within a systemic framework - 'externalising their experiences, rather than internalising stressors as personal deficiency' (Mackay & Rutherford, 2012, p. 185). These accounts challenge dominant psychological and medical accounts of depression as they draw explicitly on the effects of social conditions on women's lives.

Other studies have shown an intimate relationship between the social construction of gender roles and the experience of distress in men and women. Research by LaFrance and Stoppard (2006) showed that the experience of depression in women was influenced by their gender identity – women were 'consumed by domestic practices and governed by the needs of others' (p. 307). Recovery was tied to participants relinquishing their 'good woman practises' (p. 307) and attending to their own needs. Emslie, Ridge, Ziebland and Hunt (2006) demonstrated that men's accounts of depression were influenced by discourses of hegemonic masculinity, defined as the idealised form of masculinity at any given place or time (Connell, 1995). When describing recovery, men incorporated hegemonic masculine values, such as 'being one of the boys' (Emslie et al.,

2006, p.2246) into their narratives, or resisted them, by finding alternative approaches to masculinity. Newberger (1999) considers messages that men receive from an early age, for example, 'boys don't cry' – these may lead to decreased help seeking, which may be seen as a sign of vulnerability.

Indeed, research shows that men are less likely to seek help from mental health services (e.g. Andrews, Issakidis & Carter, 2001). It is arguable that such gender discrepancies in help-seeking relate to gender discrepancies in suicide rates. For example, women are diagnosed as depressed twice as often as men (World Health Organisation - WHO, 2002), yet men kill themselves twice as often as women (WHO, 1999). Social constructions of gender, and social roles associated with gender, therefore, appear to influence the experience and expression of distress as well as the tendency to seek help.

Research looking at the specific needs of social groups within gender categories has highlighted the need to tailor interventions to the particular needs of these groups. For example, Silverstein et al (2009) explored how low-income mothers explain feelings of sadness and stress, and considered how a tailored community-based intervention might be developed in line with their conceptualisations. A theme of 'aloneness versus loneliness' was interpreted, whereby participants spoke of wanting reprieve from the chaos of their lives. Considerations for intervention therefore included supporting participants to have time alone, away from the chaos. This study can be criticised for drawing upon individualised ideas to overcoming difficulties that appeared contextually-driven – for example, it used 'brief cognitive restructuring' to increase participants' sense of control over their lives, rather than exploring ways to increase the power and resources that participants have. A study exploring depression in British Pakistani women (Gask, Aseem, Waquas & Waheed, 2011) found that persistence of depression linked to a number of social factors , including sense of entrapment driven by difficult social circumstances (e.g. seemingly inescapable family conflict, and social isolation). The authors suggested that a successful intervention will address the psychosocial origins of depression in this group, 'identifying and addressing both the underlying cause(s) and the specific consequences of depression and associated social isolation for each individual

person' (p.54). These ideas have parallels in community psychology, outlined earlier, which locates distress in its social context and sees that intervention involves empowering communities to act upon the root causes of distress.

1.4.2.3. Socio-economic status

Several studies listed above (e.g. Silverstein et al.'s (2009); Martin et al. (2007)) point to the potential influence of socioeconomic status on the likelihood of a person experiencing distress. This resonates with Wilkinson and Pickett's (2010) extensive research into the influence of income inequalities on a range of physical health and mental health issues. For example, they demonstrated that there is a strong relationship between income inequality and a range of mental health issues, concluding that 'a much higher percentage of the population suffer from mental illness in more unequal countries' (Wilkinson & Picket, 2010, p. 66-67). Wilkinson (1996) elsewhere argues that differences in income within countries rather than absolute wealth or poverty influences health – it is 'not whether you have a larger or smaller house or car in itself, but what these and similar differences mean socially and what they make you feel about yourself and the world around you' (p.75).

Research examining how people perceive inequalities and their influence on wellbeing, particularly psychological wellbeing, has however remained limited. To this end, Davidson, Kitzinger and Hunt (2006) used focus groups to explore how people discuss their sense of relative deprivation, and their sense of its impact on their health and wellbeing. They found that people from more deprived backgrounds spoke in a way that suggested that inequalities profoundly affected their wellbeing. The authors linked accounts of polarised income distribution to lower self-esteem and the challenges of being able to 'keep up' (p. 2179), thus supporting Wilkinson and Pickett's (2009) argument of a relationship between mental health and inequality. Stress was identified as a potential mediator between poor socio-economic circumstances and poor health. For example, one participant in Davidson et al.'s study identified that:

'The poor get poorer, or poorly, it's because we don't have – you're fighting to get your benefits. You get yourself into a state, you get depressed, stress sets in, because of the circumstances you're in'

(2006, p. 2175)

Interestingly, the participants from more affluent backgrounds spoke much less about the effects of living in an unequal society, which the authors suggested implied that they were less 'affected'. Davidson et al.'s (2006) results differed from previous research in the field (e.g. Blaxter, 1997) which suggested that people rarely talk openly about the influence of inequalities on ill health. Blaxter (1997) questioned whether 'to acknowledge 'inequality' would be to admit an inferior moral status for oneself or one's peers' (p.754). This proposition could potentially explain the paucity of research in this area – in other words, people may be reluctant to talk openly about their social status, and perhaps researchers may be reluctant to ask.

1.4.2.4. Spirituality

A person's spiritual beliefs offer an additional framework from which to explore their conceptualisations of distress. A wide body of literature exists on the relationship between spirituality and mental health, which due to word constraints is out of the scope of the current study to review.

As an example, Black, Gitlin and Burke (2011) explored constructions of experiences of depression in older people from African American heritage. Participants rejected more medical conceptualisations of depression and preferred to contextualise the emotions they felt in terms of their self-view and belief system, such as describing how their relationship with God shapes their responses to depression. They preferred to seek help for feelings through turning to God, and praying. They also interpreted and experienced depression through the context of their lives – such as through negative life experiences that they saw everyone as enduring. This interpretation led Black et al. (2011) to conclude that 'ultimately a strong faith in an ultimate deliverance by God underlie their interpretation, experience, expression, and resolution of depression' (p. 655).

Previous research with this group has shown that they attribute depression to 'experiencing difficulties' such as loss, isolation, and a lack of resources rather than to an illness that requires treatment (Black, White & Hannum, 2007). Exploring the way in which spiritual beliefs interact with conceptualisations of distress is therefore important.

1.4.3. Summary & Synthesis

The above research taken together implies that our social positions (including gender, cultural background, socioeconomic status and spirituality) and the way that society responds to us within these positions all have the potential to influence experience of distress, and in turn how distress is described to others. This idea is encapsulated in Burnham's (2011) 'Social GRACES' theory, which looks at social differences and how they shape our understandings of the world and each other. It also suggests that services need to be responsive to how social context may a) increase the likelihood that someone experience of distress and b) influence the experience of that distress, in order to effectively ameliorate it.

This implication links with a wider body of research that suggests the importance of taking social context into account in therapeutic work. As discussed earlier, there is a well-demonstrated link between social inequalities and mental health. For example, research by the (WHO) in 2007 showed that there was 'very convincing' evidence that low socioeconomic position, low education and unemployment were all risk factors for depression (WHO, 2007). Hall and Marzalier (2009) argue for psychological distress (e.g. anxiety, depression) to be conceptualised in the context of social factors such as growing income inequalities, changing patterns of family relationships, and the influence of the media on people's expectations. They also advocate that mental health services become less focussed on individual pathology and a person's internal world, but instead understand distress as a product of the society in which we live.

As discussed previously, research exploring distress has tended to be polarised. Brown and Harris (1978) caution against individually-oriented and socially-

oriented research about distress ignoring each other, stating there is a 'need for each to remember the other' (1978, p .293). The research outlined above has typically focussed on the perspective of a particular group, and what is lacking is a broader analysis of people's differing understandings taken together, outside of a pre-existing theoretical framework.

1.4.4. How do personal understandings of distress influence how help is sought?

Research suggests that people seek support for distress in a way that is compatible with their own explanatory framework. Karasz et al (2009) explored explanatory models of distress and subsequent support choices in three different ethnic groups, and found that within each group, a person's explanatory model determined the help that they sought. If participants had a medical understanding, they sought medical treatment. If they had a spiritual understanding, they chose complementary treatment or self-management. Other influences included the type of distress they felt, and the resources that were available to them. Waite and Killian (2008) adopted the Health Belief model (e.g. Rosenstock, 1974) to explore beliefs about depression and treatment amongst African American women. The health belief model emphasised the importance of considering individuals' subjective beliefs about depression when understanding decisions made about accessing help. They found that participants' conceptualisations of depression were shaped by attitudes towards seeking help for depression and vice versa. For example, one participant discussed how s/he believed that depression arose from stressful living conditions (living in an area with high crime rate, shootings and death) and therefore medication could not help, only living somewhere where you can feel safe would help.

How then might this be drawn upon in service provision to help identify what might be a helpful approach for a person at any one time? The 'explanatory map' provides one idea (Sisley et al. 2011, Williams & Healy, 2011) as it draws upon both internal and external experience, and links current and newly-encountered knowledge to coping and help-seeking. This idea has much in common with that of psychological formulation, which draws together personal and professional understandings about the nature and experience of distress, and is used as a

map to guide intervention. The extent to which a service takes into account a person's own understanding of their distress, and their preferences for treatment, is variable.

1.4.5. How do personal conceptualisations of distress influence experiences of treatment?

Previous research has focussed less on the influence of personal understandings on experiences of therapy. As described above, personal understandings have been shown to influence help-seeking, but the experience of support provided in relation to personal understandings has been less explored. Furthermore, research into experiences of therapy has focussed largely on therapists' experiences and understandings, leaving service users' experiences far less researched (Elliott & Williams, 2003).

Within research that has explored service user experiences, some studies have looked at how people experience specific therapeutic techniques. For example, the homework component within CBT has been experienced as challenging (e.g. Barnes et al., 2013; Bru, Solholm & Idsoe, 2013), whereas psychoeducation and behavioural activation have been experienced more positively (Bru et al., 2013).

Other research has looked at how people understand the process of change in therapy. For example, Elliot and Williams (2003) showed that clients attribute change to the therapist, or the therapeutic relationship, whereas therapists attribute change to specific techniques. The first finding links with research touched upon earlier which highlighted the importance of the therapeutic relationship (e.g. Blow et al., 2007). Sometimes this relationship is held as what is most important regardless of the approach used and how it may fit with the service user. Collaboration with the therapist and a sense of control over therapy has been linked to positive outcomes (Westra, Aviram, Barnes & Angus, 2010) and positive experiences of therapy (Gostas, Wiberg, Neander & Kjellin, 2013).

There is some evidence that people will engage better with therapies that are conceptually consistent with their own understandings (Hall & Marzilier, 2009).

However, the processes and mechanisms by which this occurs remain less clear, as does the experience of engaging with therapy that is incompatible with personal understandings of distress. The current study therefore sought to explore these issues.

1.5. Rationale for Current Research

Research exploring how people conceptualise distress has focussed on the experiences of particular social groups, as discussed in Section 1.4.2, or on particular ways conceptualising distress, such as Beresford et al.'s (2010) study. Gaps in the literature include:

- A broader analysis and exploration of conceptualisations of distress, including the extent to which context is taken into account;
- Exploration of how people experience psychological therapy in relation to their personal conceptualisation of distress.

These questions are central to the IAPT initiative and services that function within it. IAPT is a relatively new, and celebrated, approach to psychological therapy service delivery. Qualitative research exploring experience of therapy in IAPT services has been limited, particularly in relation to the debated issues of choice in approach, and the extent to which context is taken into account. Therefore the current study sought to explore these issues within an IAPT service.

1.6. Research Questions

1. How do people using psychological therapy at an IAPT service make sense of their own distress? To what extent do they draw on contextual factors?

2. How do people experience the 'fit' between their personal explanations of distress and the explanations they encounter in therapy?

2. METHOD

The chosen method for the study was individual semi-structured interviews with people who had completed therapy in an IAPT service, which were then analysed using Interpretative Phenomenological Analysis (IPA).

2.1. Why choose a qualitative methodology?

I chose a qualitative methodology for the study, due to the exploratory nature of the research questions, which seek to explore personal, subjective accounts of distress and look at how people make sense of their experiences. Barker, Pistrang & Elliot (2002) assert that qualitative research is well suited for exploratory research that focuses on an individual's personal experiences. In addition, qualitative research has the advantage that it allows for detailed exploration of the subject at hand, rather than focusing on specific variables or factors as in quantitative research (Yardley, 2000). It also considers the particular circumstances of the participants involved, rather than seeking to make generalizations across large numbers of participants (Yardley, 2000). For these reasons, I judged that it is better suited to the research questions of the current study.

2.2. Epistemological position

Epistemology has been defined as 'the study of the nature of knowledge and the methods of obtaining it' (Burr, 2003, p. 202). Willig (2013) highlights the importance of clarifying which epistemological position is being taken up in relation to a piece of research. This determines the theoretical framework that is used, (in this case IPA), and allows for evaluation of the research. Willig (2013) posits that there are three main epistemological frameworks from which qualitative research can be conducted: realism, phenomenology, and social constructionism. One key factor across all three frameworks is the extent to which the data collected is seen to mirror reality (Harper, 2012). This has been conceptualised as a continuum, moving from realism (where the data collected

are seen to mirror reality) to relativism (where the data are not seen to directly mirror reality and there are many valid interpretations) (Harper, 2012, p. 87).

Lying between these two extreme positions is a position of critical realism, which was adopted for the purposes of the current study. This assumes that the data collected can tell us about reality, but does not directly mirror it (Harper, 2012). It also takes into account the social, historical and situational context in which the data has been collected. Critical realism has been suggested to be a helpful framework for research in emotional distress (e.g. Ussher, 2010; Pilgrim & Bentall, 1999) as it allows that there is a material 'reality' of the subject, but sees that this is shaped by social, political and historical context. In relation to the current study, it therefore permits an attempt to explore the 'reality' of subjective experience of distress as it is described by participants, and the importance of interpretation in situating the experience in context.

I also held in mind the idea of 'contextual constructionism' (Madill, Jordan & Shirley, 2000) in carrying out the research. This position asserts that results will vary according to the context in which the data are collected and analysed. For the purposes of the current study, it permits exploration of the fact that the data were collected in an IAPT setting, by a Trainee Clinical Psychologist, at a time when IAPT is still relatively new, and CBT is the preferred approach to therapy. I consider the potential impact of this further in the section on 'Reflexivity' and in the Discussion. Madill et al. (2000) suggest that contextual constructionism has much in common with a position of critical realism.

2.3. Method of Analysis: Interpretative Phenomenological Analysis

2.3.1. Why IPA?

I chose IPA as the methodology for analysis. IPA is defined as being 'committed to the examination of how people make sense of their major life experiences' (Smith, Flowers & Larkin, 2009, p. 1). It aims to explore personal experiences and accounts of life events or processes (or phenomena) and how people understand and make sense of them. IPA therefore fits well with the aims of the

current study, which are to explore how distress, and therapy, were understood and experienced by the participants. It also permits close exploration of each case before moving on to the next, allowing for a fuller understanding of each participant's account.

At the same time it recognises that it is not possible to access personal accounts directly or completely, and interpretation of the account is therefore necessary, situating it in its wider social, cultural and historical context. A two-stage interpretation process, or 'double hermeneutic' is therefore involved, whereby the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2003). I recognised the importance of my assumptions and understandings in carrying out the research (which I discuss in more depth in Section 2.7, titled 'Reflexivity'), and appreciate the way that this is fore-grounded in IPA.

It is possible to conduct IPA focusing on any type of experience, but it is most commonly used to explore experience that is of existential importance to the participant (Smith, 2011). IPA is increasingly being used to examine the experience and context of psychological distress (Smith et al., 2009).

IPA connects with theories of phenomenology, hermeneutics and idiography (Smith et al., 2009).

1. Phenomenology is concerned with the way that things appear to us in experience (Eatough & Smith, 2008). Husserl, a key phenomenological philosopher, called for us to look 'to the things themselves' (cited in Smith et al., 2009, p.12), suggesting that we should focus on each and every particular experience in its own right, on its own terms (Smith et al., 2009).

2. Hermeneutics refers to the theory of interpretation. In trying to understand individual experience, we need to understand that it cannot be accessed directly, from the perspective of being another person. Heidegger suggests exploring phenomenology is an explicitly interpretative activity, and emphasizes the relationship between interpretation and the assumptions

of the researcher, which therefore need to be explored (Smith et al., 2009). In doing IPA, the researcher therefore has to be constantly reflexive, to be aware of his/her own preconceptions and attempt to 'bracket' them off, in doing so allowing for greater receptivity to the experiences of the participant (Finlay, 2011). The process of interpretation places a participant in its broader social, cultural and theoretical context (Harper, 2012).

3. Idiography – concerned with the need to be particular. IPA is idiographic in the way that it commits to analyse each case in detail, with sufficient depth – and in the way that it is committed to understanding how *particular* phenomena have been understood and experienced from the perspective of *particular* people in a *particular* time in a *particular context* (Smith et al., 2009).

2.3.2. Consideration of other Qualitative Methodologies

In deciding on which methodology to use for the study, I considered my research questions, and the epistemological position taken. Three other methodologies with versions that are also compatible with a critical realist epistemological position are Thematic Analysis, Grounded Theory, and Narrative Analysis.

I considered Thematic Analysis (e.g. Braun & Clarke, 2006) to be less appropriate than IPA as it does not have the same commitment to exploring the phenomenological world of participants. Thematic analysis also does not foreground the role of the researcher in interpreting experience in the same way as IPA. This was felt to be of importance given my role as a Trainee Clinical Psychologist who has worked with, and learned about, distress, and therefore holds a set of beliefs, assumptions and values about it. I wanted to use a methodology where both these issues are explicitly taken into account.

Grounded Theory (e.g. Glaser & Straus, 1967) has much in common with IPA, and has similarly been used for research exploring psychological distress. It relies, however, on larger, and less homogenous samples, and is primarily used

for developing explanatory level accounts of processes and phenomena. While this is one possible avenue the current study could have taken, I was more interested in exploring the experience of distress itself, and how people make sense of it, than developing an explanation of why people accessing IAPT therapy feel distressed.

Narrative Analysis (e.g. Riessman, 1993) similarly has been likened to IPA and the two methodologies have significant overlap (Eatough & Smith, 2008). While both IPA and Narrative Analysis look at narratives, and how things are talked about by participants, Narrative Analysis tends to focus on 'the ways in which people make and use stories to interpret the world' (Lawler, 2002, p.242), where as IPA is more focused on subjective experience. The two methodologies lend different weight to what is 'real' – IPA gives greater precedence to internal, or 'real' subjective experience, and therefore was felt to be better suited to the research questions.

2.3.3. Why Conduct Individual Semi-Structured Interviews?

Individual interviews with the researcher and participant were chosen for a number of reasons. Firstly, as it was felt that this would be the optimal environment for participants to be able to speak openly about their experiences, with a degree of confidentiality that might not be possible in other formats, such as focus groups. This level of confidentiality was felt to be important, given the potentially sensitive and personal nature of the research questions. Secondly, they allow for exploring experience, for a rapport to develop between researcher and participant, and for a space to be created where participants can think, speak and be heard (Smith et al. 2009).

A semi-structured format was used in order to create a guide for questioning and ensure that questions were asked that would aid in generating material that would be useful for exploring the research questions, but also allow flexibility and space to follow up on participants' concerns and interests. See Appendix B for the interview schedule. Smith et al. (2009) suggest that semi-structured interviews are useful in exploring IPA questions as they allow for setting a loose

agenda, anticipate potentially sensitive issues, and frame questions in suitably open forms.

2.4. Participants

2.4.1. Recruitment

Participants were recruited from all individuals who completed High Intensity therapy at a London-based IAPT service. Three separate strands of recruitment took place:

- Invitation letters containing a brief overview of the study (see Appendix C) were included with the questionnaires that therapy attendees complete at the end of therapy, the 'Minimum Data-Set'. Letters included a response slip whereby individuals interested in taking part could give their contact details to be passed back to the researcher. Therapists checked with attendees if they had seen the letter, and answered any questions as necessary. Completed slips for interested participants were then placed in boxes held at reception across three main service sites either by therapists or therapy attendees. Seven participants were recruited in this way. I attended team meetings in order to speak about the research and discuss the recruitment process and inclusion/exclusion criteria with therapists.

- I attended the service's 'Service User Forum', (a forum for service users to give feedback about the service) to speak about the research. Two participants were recruited in this way.

- Posters containing information about the study were put up in the waiting room at the service. No participants were recruited through this method.

2.4.2. Inclusion Criteria and Rationale

The inclusion criteria were for participants to:

- Be over 18 years of age. (Individuals accessing the IAPT service are generally over 18.)

- Be able to speak English to a level that means that an interpreter is not required for the interview. This reflects approximately 85% of individuals currently seen at the IAPT service (Personal Communication, 15th September 2013) and was therefore not felt to exclude a significant proportion of the service's users. Non-English speakers were excluded due to the challenge that this places on interpretation, and the fact that it adds an extra hermeneutic layer - a 'triple hermeneutic'. I recognise that this is a limitation of the study, and explore the potential effect of excluding non-English speakers further in the 'Discussion' section.

- Completed individual 'Step 3' psychological therapy (either CBT, Dynamic Interpersonal Therapy (DIT), Interpersonal Psychotherapy or Integrative Therapy) at the IAPT service. Individuals who received systemic therapy were excluded, due to the challenges interviewing more than one person presents to research using IPA.

- Not be experiencing high levels of distress. As mentioned above, I attended team meetings to discuss recruitment with therapists. This inclusion criterion, along with therapists' discretion in mentioning the research only to individuals who they felt would not be likely to become highly distressed by taking part in the interview were emphasised.

- Have completed the full course of proposed therapy sessions, to allow for an assessment of the effects of full course of therapy.

<u>2.4.3. Participant Characteristics</u>

Nine individuals who had completed therapy at the IAPT service were interviewed. Demographic information, and brief information about the type of therapy participants received, was collected at the beginning of the interview (see Table 1).

Homogeneity of the sample is important in IPA (e.g. Smith & Osborn, 2003). Participants were chosen because they offered insight from a position of shared expertise, i.e. having experienced distress which led them to seek therapy, and subsequently receiving therapy from the same IAPT service.

Name	*Gender*	*Age*	*Ethnicity*	*Employment Status*	*Type of therapy received*	*Number of sessions (approx)*	*Time since therapy finished*
Ravi	M	40-49	Asian British	Employed, FT	CBT	20 initially, 12 further	1 month
Jamie	M	30-39	White British	Unemployed	CBT	16	1-2 months
John	M	60-69	White British	Employed, FT	CBT	6	1 year
Faiz	M	30-39	Asian British	Unemployed	CBT	16	1 week
Claudia	F	40-49	German	Employed, FT	CBT	13	1 month
Margarita	F	30-39	Spanish	Employed, FT	CBT	20	1 month
Tom	M	30-39	American	Employed, FT	DIT	16	1-2 months
Debbie	F	-	White British	Employed, PT	CBT	20 initially, 25 further	1 month
Yvonne	F	30-39	Black British	Employed, FT	CBT	8 initially, 10 further	1 year

Table 1: Participant information

2.5. Ethics

Ethical approval was granted from the University of East London Ethics Committee (see Appendix D), a London-based NHS Research Ethical Committee (REC – see Appendix E), and the Research and Development Office (R&D) of the local NHS Trust (see Appendix F). The main ethical concerns for the study are discussed below.

2.5.1. Informed Consent

Participants gave their informed consent to take part in the research through signing a consent form (see Appendix G) prior to the interview. Prior to signing the consent form, the research was explained fully to them, using the Participant Information Sheet (see Appendix H).

2.5.2. Confidentiality and Anonymity

Confidentiality, and its limits (if something the participants said caused me to be concerned for theirs, or someone else's, safety) were explained in the Participant Information Sheet.

Anonymity was assured through giving each participant a pseudonym, which was kept alongside their consent forms, contact details, and demographic information in a locked cabinet that was separate to the digital recordings of interviews, and transcribed materials.

Digital recordings were transferred from a password-protected audio recorder to a password-protected computer on the day of the interview, and erased from the audio recorder at this point. Any identifiable information such as names, locations, and dates was removed/anonymised from the transcripts.

Data was stored according to the Data Protection Act (1998). Participants were made aware via the Participant Information Sheet that audio and paper records

would be destroyed once the thesis had been examined, and transcriptions after 5 years.

2.5.3. Payment

All individuals who took part in an interview were offered £10 for their involvement. This was in keeping with the Service User Reward and Recognition Policy at the IAPT service, whereby individuals who take part in feedback events about the service receive £10. The IAPT service provided the money. I was aware of debates around the ethical implications for paying participants to take part in research (e.g. Head, 2009) but also felt that paying individuals who took part was important to acknowledge their contribution.

Two participants stated that they did not want to take the money, giving the reason that they were grateful for the service they had received and were taking part in the interview in order to be able to give something back.

I consider the potential impact of paying participants in this way in the 'Discussion' section.

2.5.4. Potential Distress

I considered the potential for participants to become distressed by the interview, given that it involved talking about reasons for seeking therapy, and how therapy subsequently met their needs. I was aware that both for people who felt therapy did meet their needs, and for those who felt it did not, speaking about the content of therapy could be a potentially emotive experience.

Throughout the interviews, if I noticed that participants might be finding it difficult to talk about something, I checked with them how they were finding speaking about it, for example by asking 'is it ok for us to be talking about this?' I also considered the way that I asked particular questions in an attempt to not evoke unnecessary distress or unhelpful reflection on therapy. I noticed that with some participants, I needed to 'check' more than with others. For example, at the

beginning of Margarita's interview, she appeared to be upset, and was crying while talking. I asked her how she was finding my questions, and gave her several options for continuing – that we could continue to talk, or stop the interview, taking it up another time if she so wished. Margarita said firmly that she wished to continue with the interview, saying that she wanted to be able to give her account of therapy in order to be able to help other people.

Time was given at the end of each interview to reflect on the process, and speak about any issues that arose. Prior agreement was sought with the service to rapidly re-enter any individuals who were still experiencing high levels of distress. This was not necessary for any participants.

2.6. Data Collection

2.6.1. Interview Process

Once individuals had expressed their interest in the study, contact was made either by telephone, email, or writing, to check if they met the inclusion criteria, speak in further depth about the study, and answer any questions they might have. Following this, an interview was arranged, at one of the four bases of the service, and participants were sent the Participant Information Sheet (see Appendix H) to read prior to attending the interview.

Upon arriving for the interview, the Participation Information Sheet was revisited, and participants were given time to read the sheet and ask questions. Particular emphasis was placed on consent to audio-record the interview and the right to withdraw at any time. Following this, participants completed the Consent Form (see Appendix G).

Prior to starting the interview, the process of the interview was discussed with participants, and, as Smith et al. (2009) recommend, I explained that I was interested in hearing their understanding and experiences. I also explained that the interview would feel quite different to therapy, as it would be a more one-

sided conversation, and that some questions may seem self-evident (Smith et al. 2009).

Interviews lasted between 41 and 91 minutes, with the mean time being 58 minutes. A digital voice recorder was used (Olympus VN 8600PC) to audio record all the interviews.

After the interview, participants were asked for their reflections on the interview process, and were offered time to talk about how they had found it.

2.6.2. Interview Schedule

A semi-structured interview format was used. I developed a draft of the schedule using Smith and Osborn's (2003) guide for constructing semi-structured interview schedules:

1. thinking about the broad range of issues I wanted to cover,
2. putting the topics in the most appropriate sequence,
3. thinking of appropriate questions in each area and
4. thinking about possible probes and prompts for each question.

I then piloted the schedule in supervision, and amended it following feedback from my supervisor. Ideally I would have liked to pilot the interview schedule with a potential participant (someone who had taken part in therapy at the IAPT service). However due to initial difficulties with recruitment, and concerns I initially had about being able to interview enough people, this was not possible. I therefore carried out an additional pilot interview with an acquaintance who had completed personal therapy, who provided feedback on the schedule and process which was incorporated into the design.

Smith et al. (2009) describe the interviews as a 'conversation with a purpose' (p.57), aiming largely to facilitate an interaction in which participants can tell own stories, in their own words. I used the schedule flexibly as a guide, in order to be able to able to move through questions, but not to restrict or constrain

participants' accounts. I considered Smith et al.'s suggestion that the interviewer is an 'active co-participant' (2009, p. 64), and at times it is necessary to move away from the schedule completely. Trying to balance asking questions and probing to ensure that the interview covered material in a way that would help me to answer my research questions, and yet also be led by participants, exploring their experience and hearing their story presented a challenge, which I discuss in further depth in the 'Discussion' section.

2.7. Reflexivity

Reflexivity is important in qualitative research, to enable us to 'explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research' (Nightingale and Cromby, 1999, p. 228). It is of particular importance in IPA, given the commitment it makes to hermeneutics.

Personal reflexivity is defined as the extent to which the researcher's beliefs, values, experiences, shape the research (Willig, 2013).

In line with this, I considered the different positions I hold in relation to the research, and how they might influence the process, including my positions as a:

- White British female
- Person who has not received psychological therapy
- Person who has been close to people who have sought support from mental health services, including IAPT services
- Person who has worked in an IAPT service
- Person who identifies as being middle class
- Person in her late twenties

I was aware that these identities might affect what was talked about, or not talked about, in the research interviews. For example, my position as a White British person might influence the way that people from other cultural backgrounds speak about their experiences to me. Similarly, my self-identification as a person who is middle class may influence how people from other socioeconomic

backgrounds feel able to open up about any potential influence of this factor on distress, particularly given the research discussed in Section 1.4.2.3. which suggests that people may be reluctant to speak about their own perceived social status. My own experiences of knowing people who have experienced distress to the extent that they have sought support from mental health services may influence the way that I understand how services offer support, and therefore how I ask questions about this.

In addition, I am currently training to be a Clinical Psychologist, a profession that places importance on the psychological formulation of distress. My training experiences have focused on critical and social constructionist approaches to distress, and understanding distress within its social and cultural context, rather than focusing solely on the individual. In my own clinical work I am drawn to systemic and community psychology approaches, exploring the influence of relationships and the wider context of people's lives in understanding their experiences. I considered how this might sensitise me to focusing on context in both the interviews and the analytic process, and sought ways to ensure that I was able to listen to other explanations too.

I kept a reflective diary throughout the research process – including after each interview, to 'bracket' my own ideas related to the above issues, and to attempt to listen more fully to participants' accounts (Smith et al., 2009) – see Appendix I for an extract. I also spoke about my own assumptions and clinical preferences in supervision and with peer researchers to consider the ways that they might influence how I interpreted the data.

2.8. Data Analysis and Interpretation

2.8.1. Transcription

I followed Smith et al.'s (2009) and Smith & Osborn's (2003) guide for transcribing the interviews, including:

- Creating a semantic record of the interview, transcribing all the words that are spoken by everyone who is present
- Spelling words conventionally
- Including notes of non-verbal utterances

See Appendix J for transcription key.

2.8.2. Procedure for Data Analysis

Smith et al. (2009) suggest guidelines for carrying out an IPA analysis, which is suggested to be set of common process and principles which can be applied flexibly, according to the research task at hand.

The stages I followed in my analysis were:

I.   Reading and re-reading

      I read through each transcript with the audio recording playing at the same time, in order to capture the experience of the interview and of the participant. I also read the notes that I had taken after the interview to remind myself of my intial impressions of the interview and remain open to new ideas. I re-read the transcripts several times, to become more familiar with the data.

II.   Initial noting

      This stage involved making exploratory notes on the interviews. I wrote notes on the right hand margin of the page, exploring different levels of the data, as Smith et al. (2009) suggest. This included:
- 'Descriptive comments', focussing on content of what was said;
- 'Linguistic comments', focussing on the person's verbal and non-verbal communication (such as pauses, or laughter), and linguistic devices that might tell me about the participants' experience, such as metaphor;

- 'Conceptual comments', moving to a more interpretative level and considering the meaning of what was said for the participant.

See Appendix K for a worked example.

III.   Developing emergent themes

I used my exploratory comments to identify emergent themes, writing these on the left side of the transcript. At this stage the analysis moved to consider the interview as a whole.

IV.   Searching for connections across emergent themes

I typed out the emergent themes developed in Stage III on to separate pieces of paper, with supporting quotes and laid them out spatially to search for connections between themes (see Appendix L). At this stage, I kept in mind many possible different overall themes, in order to not narrow down too quickly. I then created a 'mind map' for the participant, containing clusters of the emerging themes from the analysis of their transcript (Appendix M), and a table summarising their emerging themes with supporting quotes (Appendix N).

V.   Moving to the next case

After completing steps I-IV for each case, I moved to the next case. Similarities, and differences across scripts were noted.

VI.   Looking for patterns across cases

I laid out each participant's mind-map, and theme tables and looked for connections across cases. I wrote out emerging themes for all participants on pieces of card, and laid them out spatially, to explore the best way of arranging them. I had a large number of emerging themes, and it took considerable time to consider the best way to organize them. Themes with only a small number of participants, or that were not relevant to the research questions, were dropped at this stage.

I first clustered the emerging themes into sub-themes - see Appendix O for an example of one theme cluster. Theme clusters were drawn onto an initial master mind-map (see Appendix P). These were then further arranged into three super-ordinate themes, each with two or three sub-themes (see Appendix Q). Conversations with peers and in supervision aided this process. I present a narrative account of the themes in the 'Analysis' section.

2.8.3. Approach to Interpretation

Eatough and Smith (2008) suggest that interpretation takes place at different levels. For example, it can accept what a participant says at a surface level, or it can be more 'critically probing' (Eatough & Smith, 2008, p.190) exploring accounts in a way that participants might be unwilling to do themselves. Eatough and Smith describe this as not necessarily disputing participants words, but 'doing more psychological thinking about them' (2008, p. 191). During the analysis, I first considered what participants were saying, and what this might mean for what the experiences they were describing felt like to them. I then moved to a more 'critically probing' approach, for example in considering what social, cultural and contextual ideas might inform participants making particular statements, or considering what might be being left unsaid in interviews as well as what was being said. Taking a more critical approach fitted with my epistemological position, and the research questions. Striking a balance between being descriptive and being more interpretative initially presented a challenge, and I explore my experiences of interpretation in IPA further in the 'Critical Review', in Section 4.3.4.

2.9. Criteria used to evaluate the study

Yardley (2000) sets out criteria for evaluating qualitative research. I return to these criteria in the 'Discussion' section.

3. ANALYSIS

3.1. Introduction to Section

This chapter outlines the Interpretative Phenomenological Analysis I carried out on the transcripts of nine interviews. I have chosen to organise the results by the three super-ordinate themes found. I present each theme here, with supporting quotes from participants underneath in italics, which are referenced in the form *(Participant name, Line number of quote in transcript).* The themes are summarised in Table 2.

Whilst the analysis presents the themes separately, I see all themes, and their corresponding sub-themes, as being inter-related.

Super-ordinate theme	Sub-theme
Looking to my self	An 'emotional rollercoaster' – Making sense of changes
	'This is me' – Who am I with, and without, the distress?
The role of others	'It usually has to do with the people that you interact'
	''Connection' in therapy
'Outside forces': Contextual influences on the experience of distress	'Feeling better' or 'functioning better': Expectations and social roles
	'Negative event chain reaction': Things that happen in life and how therapy can help

	The meeting of cultural understandings and personal understandings

Table 2: Results of analysis

3.2. Super-ordinate theme 1: Looking to my self

This theme explores the ways in which participants make sense of their distress at an individual, or intrapsychic level.

3.2.1. An 'emotional rollercoaster' – Making sense of changes

Participants described the range of emotions they felt prior to coming to therapy. For some people, the sudden, almost inexplicable nature of their distress was emphasised, such as in Margarita's description of her 'stress explosions' (line 30), or Tom's description of an 'emotional rollercoaster' (line 577). The sense of being somewhat out of control and overcome by emotion is conveyed through their accounts - an 'explosion' and a 'rollercoaster' could both be understood as times when a person feels powerless. Ravi's description of feeling 'hopeless and helpless' (line 149) conveys this sentiment. Similarly Yvonne's account of the time when her 'panic attacks' started:

> *I was a normal person and just suddenly out of the blue I had a panic attack. (Yvonne, 7-8)*

Gives the impression of the sudden, inexplicable nature of her distress. Yvonne's subsequent search for meaning was made more difficult by the apparently 'random' nature of her panic attacks,

> *So it was really random and that's what made it worse I think (Yvonne, 237-238)*

An important part of therapy for her was learning CBT theory about why the panic attacks affected her in the way that they did. For others, the experience of

distress was likened more to a more gradual, physical phenomenon such as 'continuous toothache' (Faiz, line 236). The pervasive, all-encompassing nature of distress is evoked through its comparisons to a 'densely clouded sky' and 'shadows' (Tom and Margarita respectively).

Debbie's extended metaphor of a plant for the 'system of thought' she conceptualised as underlying her distress illustrated the mixed feelings she described about letting go of it:

> *I kind of envisaged it you know like the burrs on a tree, it was really really beautiful, you know. And it had sort of invaded itself into the whole thing. And if you cut it open it would be beautiful, with all these swirls and baroque sort of things, sort of like just sort of taking in any other information and making it a part of itself. But, it's killing the tree and if you cut it out, you just don't know whether the tree is going to survive or not. I really felt like that, I really felt like, if you take this out of me, what's left of me? (Debbie, 518-525)*

Debbie uses images which starkly contrast with each other: 'beautiful' burrs on a tree, and ornate-sounding 'swirls', against what sounds like a parasite, 'killing' the tree (and her?). This is suggestive of the conflict she feels around starting to let go of the system of thought. For her the experience of it seems to be both appealing and terrifying in equal measure. Her reluctance to name the system of thought in this extract, referring only to 'it' or 'this' adds to the sense of its power. Debbie seems to understand it as something that is both 'in' her (through her description of her therapy as taking it 'out of me') and outside of her. Her vivid, visual description appears to give shape to her understanding of her system of thought as a living, organic entity. This is later extended by her comparison of her system of thought to human relationships: she describes it as an 'imaginary friend' (line 332) and a 'horrible abusive relationship' (line 582). In the final sentence of the above extract Debbie seems to be describing feeling somewhat bereft without the 'system of thought'. She is keen to emphasise to the interviewer the depth of her feeling, shown by her repetition of 'I really felt like'. The implications of letting go of something that has been a part of her life for so

long are significant for Debbie. Her question 'if you take this out of me, what's left of me?' can perhaps be interpreted as being directed to the therapy process, or the therapist. It seems important that the complexity and depth of her relationship with the system of thought is recognised. Debbie refers to her therapist's attempts to call it 'OCD' as 'tussles':

> *Debbie: Yeah and we had a few sort of like, um, tussles about that. [Laughs.]*

> *Amy: Mmm. Can you say a bit more?*

> *Debbie: Well just, um. [Pause.] I remember one time, I was saying well I don't even know if I've got OCD. And she said um, I do. [Laughs.] I was like, OK. [Laughs.] (Debbie, 687-694)*

Throughout Debbie's interview, laughter happened at points where she appeared to feel uncomfortable, or was saying something that she found particularly hard – I therefore wondered if these 'tussles', and the therapists' assertion of her diagnosis, was hard for Debbie to hear. There seemed to be a conflict between Debbie's way of understanding distress, and her therapist's. Debbie seemed to ultimately feel moved to accept her therapist's understanding, rather than challenge it, indicated by her saying 'I was like, OK' – this could be interpreted as her feeling pressure to forgo her understanding for her therapist's. The (presumably difficult) experience of someone labelling her rich, complex conceptualisation of distress for a clinical diagnosis ('OCD') is somewhat minimised through her use of the playful sounding description of 'tussle'. Perhaps Debbie is re-playing in her interview the way that she felt her experiences minimised through her therapists attempts to re-label her 'system of thought'. Her conceptualisation of it as a living, organic system seemed to be a prominent way of way of making sense of how she was feeling, and her therapist's attempt to re-label it as 'OCD' may have clashed with Debbie's own understanding.

Experience of diagnostic labels in helping and hindering understanding was interwoven through participants' accounts. As Yvonne's earlier extract describing

her 'panic attacks' shows, some used them unquestioningly as shorthand for describing the distress they felt. Others' relationship with diagnosis shifted over time, and learning about symptoms was important in understanding and eventually seeking help:

> *a couple of months ago, a couple of friends of mine, they told me that I might have some elements of depression. And I was like yeah right, I cannot be depressed. Um so I opened the leaflet and like all the bullet points it was describing like, if you feel like this, like that, it was all matching. And I call them, and they arranged an appointment (Margarita, 147-152).*

Matching her own experience with what was described in the leaflet about depression that she read therefore seemed to be important step for Margarita, more so than hearing the label 'depression' itself.

3.2.2. 'This is me' – Who am I with, and without, the distress?

Distress was described as part of identity in two key ways – firstly, a 'flashbulb' moment of realisation or recognition of distress and a subsequent shift in participants' sense of who they were:

> *there is a stark realisation that shit, this is – this is me, and I potentially will carry this label for the rest of my life (Tom, 241-242)*

Secondly, a more gradual, continual shift to a point where participants realised they were different to how they had been before:

> *I got shouted at horribly, and that day, er when I went home, I – I felt like collapsing, and my um brother and my sister-in-law, they were both – they knew this was all building up for some time, [short pause] and er what they saw was a complete broken down man, and they said you are not going to work tomorrow, you are going to the doctor's. And I felt ashamed, really*

embarrassed, I thought – how can this be, I felt really embarrassed to
have to seek help, I really really – I felt dignity taken off me (Ravi, 37-44)

Ravi's description here of himself as 'broken down', and the links that he makes with his dignity and a sense of embarrassment suggest a gradual change in his sense of self, to a new, more reliant self who has to seek support from others. He describes this as having been 'building up for some time', and the event of being shouted at at work appears to act as a catalyst to this new way of being.

Others considered the way that their actions and behaviour changed as a result of distress. Yvonne considered the way that the panic attacks she experienced when driving necessitated a change in her behaviour, thus causing her to be a 'different person':

so it was affecting me because I wasn't, you know like, I became a
different person so I had to every time I was invited somewhere: 'where is
it? how far is it?' I gotta have a look at the postcode, you know if it involves
an A-road then I would make excuses not to go (Yvonne, 25-28)

Thoughts about distress being a part of identity were linked into participants' own understandings of their distress, and the factors they identified as contributing towards it. Jamie, for example, understood his 'depression' as being related to his upbringing and family, and something that he was therefore 'predisposed' to.

I think I'm just predisposed to it to be honest, um. Cos I've had it so long
that if I didn't have it, I don't think I'd be me any more. (Jamie, 953-955)

His assertion that he would not 'be me any more' without 'depression' suggests that he understands it as a core part of his identity, and he later goes on to describe:

I don't really feel like I'm ever going to really, fully, break away from it
(Jamie, 964-965)

Links between identity and distress were present throughout participants' accounts, suggesting that they considered distress to be part of them, whether this be temporarily or more permanently. Holding this in mind seemed to be helpful for some (for example in Jamie's assertion that he can 'cope with it more' (line 948) knowing that it won't go away). For others, questions were raised as to who they would be without the distress, leading to clear ideas about what they wanted from therapy. For example, the idea reducing the extent to which she relied on her 'system of thought' through therapy led Debbie to compare herself to a 'newborn' (line 650), questioning her basic likes and dislikes:

> *Like I had to decide whether I liked tea or coffee in the morning, and I had to decide how I liked my eggs, and I had to decide what music I liked, I kind of just had to re – just go right back to the beginning and kind of re-think everything. (Debbie, 650-654)*

It seems that the system of thought had been a part of her for so long that she was not sure who she would be without it. Timing, and the pace of therapy was therefore key for Debbie, and other participants:

> *because then what she did, very carefully, very slowly (Debbie, 550-551)*

Ravi described feeling like a different person following therapy, feeling that the CBT tools he had learnt were now 'embedded' (line 765) into his thinking and he could question things in a new way. This led him to conceptualise his new 'self' and approach to life following distress and therapy as 'scarred but stronger', a preferred identity for him:

> *I do ask myself would I have preferred not to have fallen ill? And have the old mentality? Or, scarred but stronger mentality? And I think I'd choose the latter, yeah. (Ravi, 951-954)*

Ravi's description evokes comparison to a battle that he has been through, left 'scarred' – his experience of distress has had a lasting effect on him, even if he is left feeling 'stronger'. This is a stark contrast to Debbie's comparison of herself to

a 'newborn'. Their different accounts of the changing self through therapy highlights the importance of therapy being understood as a process that has the potential to change a person's identity and sense of self, and the importance of understanding distress as a part of identity.

3.3. Super-ordinate theme 2: The role of others

Participants explored their experience of distress in the context of their relationships with other people. This included both the role of the people around them (friends, family, colleagues) in contributing to feelings of distress, but also their role in understanding and support. 'Connection' in therapy – both with therapists and the approach used – is also included in this theme.

3.3.1. 'It usually has to do with the people that you interact' – The role of other people in the experience of distress

Many participants linked their experiences of distress into the influence of the people around them, both in the past and present. This idea is conveyed in Margarita's exploration of her 'personal theories' (line 292) of distress:

> *It's like usually it has to do with people that you interact. [Clears throat.]*
> *And like how they're dealing with your own personality and how they*
> *actually accepting you who you are. In which way. (Margarita, 197-199)*

Many described having experienced difficulties in their personal relationships, both in the past, and present, which they linked into their experience of distress and therapy.

Ravi described 'bullying and intimidation' (Ravi, line 56) at work, leading him to have an 'experience of lots of immense horrible fear' (Ravi, line 61). Such was the extent of the bullying that Ravi tried to drink disinfectant in order to end up in hospital:

> *you know I wanted to be in hospital because it would have been more*
> *comforting than bullied, being bullied (line 54-55)*

Ravi mentions wanting to seek 'comfort' from bullying at different points during his interview, which he considers seeking in different ways – by going to hospital, as outlined above – through considering death, and, as is elaborated on in Section 3.4.2, through describing wanting to be in a 'cocoon' or a 'coma'. For Ravi, the experience of other people at work has become so difficult and aversive that he wants to shut himself off from the world completely – an enforced and total separation from the people who are targeting him. The ways in which he describes wanting to do this a drastic, and give a sense of the extremity of the 'fear' and horror he felt from the bullying.

For others, the effect of fractured relationships is considered in subtler ways. Jamie talked about difficulties in his personal relationships at home, living with his sister and her boyfriend:

> *we have a lot of arguments and that, don't really like it [intake breath,*
> *pause] but it's not too bad really (Jamie, 303-304)*

His intake of breath possibly indicating that this is a difficult thing to say, or that he is being insincere in his suggestion that it was 'not too bad'. Jamie later went on to describe how a previous therapist contacted social services due to the extent that she was concerned about their relationship, which was something he described as initially difficult, feeling that the therapist was 'pushing too hard' (line 411). He later reasons that

> *I suppose it needed to happen in a way but it did get – it did get quite*
> *stressful (Jamie, 420-421)*

Perhaps suggesting that how far therapy should go was a question for Jamie. Faiz, Claudia, Tom, Debbie, Margarita and Jamie all looked to their past relationships with family in understanding their distress. The extent to which they understood the past as relating to their present difficulties, and the amount that

they wanted it to be covered in therapy, varied. Claudia described the 'toxic environment' (line 78) that she grew up in, with difficult and fractured relationships with her family, and replicated itself in the 'toxic relationships' (line 241) that she had in adulthood. Faiz explored how he felt many of the issues he experienced related to his difficult relationships with members of his family:

Er mainly my relationship with my father, my mother, my siblings, er I think that everything branches off from that in my experience, that's where everything branches off from so it was predominantly about that (Faiz, 543-545)

His experience of his distress 'branch[ing] off' from his family suggests that relationships are a significant cause of distress for Faiz. He later goes on to describe an internal conflict around how family are supposed to be and how they are in reality:

you know family's supposed to mean everything, but the reality is like, it doesn't mean they're always right, you know what I mean, they can also be detriment to you (Faiz, 70-71)

This suggests there is something particularly difficult about understanding family to be the reason behind his distress. He seems to be searching for meaning on these issues, and his questioning exploration that 'it doesn't mean they're always right' sounds almost child-like. The potential for family to harm is something that it seems is hard to come to terms with, and Faiz' reversion to an almost child-like way of talking when rationalising this may be an indication of how hard he finds it to accept.

Questions were raised about the extent to which different therapeutic approaches allowed for exploration of past relationships, and participants' perceptions of this. For example, Claudia compared the utility of psychotherapy and CBT in understanding the influence of her upbringing, suggesting they both had use for understanding different aspects of experience:

So, obviously I've been there for many years in psychotherapy but not CBT, […] obviously it helped me a lot, but […] It's like er you dwell on the negative things in psychotherapy […] you talk about how nasty your father is (Claudia, 493-496)

I like about CBT the fact that they had a pragmatic approach, you know. <Amy: Right, OK> With all these exercises, you explore, you tackle your negative thoughts, and you find out why, what kind of feelings does it bring you, and is it supported by real fact or not. You know. And that's this rational approach I needed you know basically. (Claudia, 503-507)

The practical focus of CBT as opposed to the open-ended exploration, or 'dwelling' nature of psychotherapy appears to be experienced as helpful by Claudia for exploring her past difficulties in relationships. Its 'methodical' (e.g. line 597) nature appears to contain the challenge of talking about past relationships and allows her to review different stages of her life in the controlled way she seems to be seeking. Claudia describes the 'strong feelings' (line 573) that were 'still there' following her psychotherapy. Her description of the CBT approach as something that she 'needed' therefore gives a sense of her appreciation of being able to discuss her past in a more measured way.

For some participants, the experience of being alone, or disowned by others was understood to be a key cause, or consequence of the way that they felt. Jamie talked about losing the people closest to him:

I only not only I lost my girlfriend I lost my friend as well (Jamie, 170-172)

Jamie's bleak account of several relationships with others ending, and his subsequent sense that he is 'falling backwards again […] not progressing' (line 176-177) gives a sense of how he feels that others are needed to move forwards in life. He appears to be counting the relationships that he lost ('not only') and his use of 'I' indicates the sense of agency, or responsibility that he perhaps feels for having lost these relationships.

John contextualised his depression, anxiety and panic attacks in terms of loneliness and fear, also comparing their loss to going 'backwards':

I just fear. And this fear is happening, and it's going to be loneliness, I suppose I kind of feel. And I suppose, is that loneliness going to bring on depression, is depression going to bring anxiety, and anxiety going push […] the panic attacks ongoing, and is it all going to go backwards to square one ago, like I was about four year ago. (John, 397-401)

John's account of therapy suggested that a key benefit for him was having someone to talk to:

knowing that person's there and all. Somebody you can turn to, I suppose. (John, 918-919)

Faiz described being a more active creator of his loneliness, both being disowned by others but also choosing to cut ties with people:

so I was really like, and then I got disowned by everyone, you know they – they not just disowned me, but they basically were participants in it? (Faiz, 71-72)

That's a very lonely place when you say to everyone fuck off. Sorry about that. [It's alright]. Mind my French, but when you tell everyone to eff off, it's a very lonely predicament, you know what I mean? (Faiz, 190-191)

The idea of being 'lonely' or alone, whether this is through personal choice of through the actions of others, is therefore clearly linked to the experience of distress. This is summarised by Tom's exploration of the 'exacerbating' effect of a lack of social support:

all of the social support that you might expect in a big progressive city wasn't there in this small town. And I think that sort of exacerbated some of the situation. (Tom, 118-120)

Many participants explored their experiences of the people in their close networks recognising and understanding their distress. For Ravi, John, Claudia, Margarita, Tom and Debbie, friends or family first suggested to them the idea of seeking support for their distress, helping them to take the first step towards therapy. It was implied in their accounts that other people recognised the distress before they did.

> *And it sort of came out of nowhere, so clearly there was some picking up of how I was feeling that wasn't apparent to me (Tom, 108-109)*

Many described continuing to rely on the support of friends and family during therapy. In Margarita's account, alternative therapies from a friend were sometimes described as being more helpful than psychological therapy, making her feel 'immediately' better:

> *she told me like Margarita, I know about therapy. But you've just programmed yourself to believe that you've got buttons and these buttons are going to be pressed. That's wrong. You can just make it schoom. It's gone, it's past. Why you have to press a button to bring up all your past experience. Er and she gave me a reiki – a distant reiki therapy, and I felt definitely better. Immediately. (Margarita, 447-452)*

The above quote also highlights the compatibility of her friend's way of viewing distress with Margarita's own way, and in contrast her lack of compatibility with her therapist's viewpoint. Yvonne contrasted support that she received from different family members – her sister tried to normalise her experience by talking about celebrities who have experienced mental health issues:

> *she was like, you know 'don't worry it happens to so many' because she's into all celebrities and stuff she was naming all the celebrities that it happens to and you know, so she knew and she went you know, don't worry just, she was a bit more sympathetic (Yvonne, 248-251)*

whereas her mother drew on a religious understanding of distress, encouraging her to 'just pray on it' (line 195) which 'wasn't much help' (196-197).

Understanding, or lack of understanding, from health professionals (e.g. GPs) was 'pivotal' (Debbie, line 1015) in the next step towards seeking help. Debbie talked about how a change in GP meant that she was referred for psychological therapy immediately, after having waited for years with her previous GP:

> *I mean I think the first thing, the massive massive breakthrough, and I think that anybody, like looking for help, I think that the GPs is the most important thing. Because that was actually a massive barrier at the beginning. And as soon as that door opened… (Debbie, 996-1000)*

Debbie's call to 'anybody looking for help' and her repetition of 'massive' suggest that this was a significant moment for her, opening up a new pathway to receiving support.

3.3.2. 'Connection' in therapy

Participants described their experience of feeling 'connected' and disconnected during different parts of therapy – to their therapist, to the approach and techniques used, and to other parts of the IAPT service, such as phone triage assessments. 'Connection' was linked to therapy that was collaborative, supportive and tailored, with a therapist whose therapeutic approach and related techniques seemed to fit with the client's own conceptualisation of their distress. Experience of the therapist and experience of the technique were spoken about in a way that suggests that they were highly related to each other.

Debbie described her experience of mapping out her 'system of thought' with the therapist, describing it as an 'amazing moment' (line 421) of being able to 'see it' and understand it:

> *She drew, er I was explaining kind of how things were, de de de, and she drew it on the wall, um and um [pause] and then she said um, so do you*

*find yourself doing this? And I was like well how do you know? And er OK,
so then after that do you find yourself doing this? And I was like yeah,
that's what I do, de de de (Debbie, 491-496)*

Her quick swapping between 'she' and 'I' and assertion that 'yeah, that's what I
do' indicate that this was very much a collaborative process where she felt
understood by her therapist. Tom and Ravi's use of language in their accounts
also indicates the sense that they felt that therapy was a 'we' process:

we identified together as something I had control over (Tom, 772-773)

*Well we'd get, I would give myself some self-tasks, so we started off by
doing the bed up you know every day, and er, we would start off by tidying
the room, move on to tidying up the room (Ravi, 483-485)*

Ravi's use of 'we' in the above extract extends to homework tasks that he carried
out at home by himself, indicating that he very much felt 'with' his therapist at
these times.

Other participants used the metaphor of a 'journey' or 'path' that was being taken
with the therapist to represent therapy either as it was (Tom) or they would have
liked it to be (Margarita):

*say this is going to be a difficult journey, but I'm here to support you
through the conversation (Tom, 453-456)*

*Or guiding. Like with very strong words, and do you know actually giving –
showing the path to someone, not actually grabbing someone and taking
them to the path, but you can show them the path. Um. (Margarita, 483-
485)*

The journey metaphor suggests an understanding of therapy as a process of
tentatively moving to thinking about the future, and what the different 'paths'
might be. In the above extract, both Tom and Margarita seem to be referring to a

similar experience of this journey – one that is gently guided by the therapist. One way of 'guiding' in such a way is by using psychological theory:

> *The process for me was a structured way of talking through things with somebody who had the right level of psychological training to sort of – almost take you by the hand through it (Tom, 450-452)*

Therapist expertise was talked about by Yvonne, Debbie, John, Tom and Margarita – the sense that they were speaking to an 'expert' with knowledge about 'theory' helped them to have confidence in the therapist's understanding of their difficulties

> *maybe because of all the background of what she was doing and all of the theory stuff which helped to put me at ease (Yvonne, 573-574)*

> *This is a thing? [Laughs.] But it's a really big thing, it's really important, people have written papers about it, you know people go to university and study doctorates. (Debbie, 1072-1075)*

In a contrast to the above accounts of therapy as a collaborative, joint process, Margarita described feeling at times that the therapist was not 'with' her in the room:

> *I was like, OK, it might be a language barrier, I might not being understood, or – worst case scenario, she might not be here, like thinking something else (Margarita, 528-530)*

This was a worse prospect for her than not feeling understood, emphasising the joint nature of therapy and the importance of having someone with you and listening to you. Debbie contrasted her largely positive experience of her therapist with a difficult phone call she received between her first and second group of sessions from an administrator, who, in contrast to the connection she had felt in therapy, felt disconnected - 'just a voice on the end of the phone' (Debbie, 1149) making her feel 'defensive'. Taken together, Margarita and Debbie's comments

suggest that there is something important about the embodied presence of a therapist whose mind is 'with' you in the room.

For Yvonne, feeling as though her first therapist was reading from a script meant that she felt therapy to be unnatural, and a lack of connection with the therapist was experienced:

> *its like if you're reading from a script its hard to deviate, so, um. It wasn't like, it didn't seem natural or we weren't able to be creative or just talk about something different or, yeah, and it didn't feel at ease with her or you know, yeah. (Yvonne, 592-596)*

There seems to be a mutual influence of the 'scripted' feel of therapy with the uneasy relationship with the therapist, leaving Yvonne feeling uncomfortable talking with her. Tom also describes feeling as though his first set of CBT sessions had a somewhat mechanical flavour:

> *And I'd reinforce my sort of by rote application of CBT as being rather unhelpful […] I felt that this was a bit textbook, and you know, tick this box, look at this, read that, think about this (Tom, 930-933)*

DIT, the second therapy modality offered to Tom appeared to 'fit' better for him:

> *So I guess that approach, I connected with that approach (Tom, 847)*

An interpretation of his choice of the word 'connection' here, which is usually used to describe human interaction, could be that it is difficult to separate out what was connection with the therapist, and what was connection with the approach used. Tom's contrasting experiences of CBT and DIT led him to question the use of the questionnaires and the triage assessment in finding an approach that fitted for him:

> *was my – was my evaluation process robust enough to get me to the right therapy sooner, than it was. Because I felt like it was very quickly into the*

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> *CBT slot, without any wider considerations of my needs. Despite two*
> *phone interviews. (Tom, 943-947)*

This suggests that elements of the service as a whole may have a role to play in making sure people receive a tailored, flexible therapy that they are able to feel 'connected' to. In the above extract Tom questions the breadth and pace of the triage, as well as its robustness, and seems to feel that it did not work for him on multiple levels.

In addition to questioning the process by which a therapeutic approach is selected, some participants described their experience of specific techniques within a given approach as particularly difficult. Margarita described feeling 'really upset' (line 428) following a therapy technique that she experienced as not fitting with her preferred way of understanding distress. She described a preference for seeking new 'positive' ways of understanding herself, whereas she felt her therapist wanted to take an alternative approach, in working with schemas. Margarita's own interpretation of schemas was that they were

> *big massive shadows that were going to be above my head for the rest of*
> *my life (Margarita, 596-597)*

Her use of the word 'insists' in the following extract suggests that she felt pushed using schemas:

> *But my therapist insists that – that if we're going to find the schemas, we're*
> *going to start controlling them. But the thing is like, I don't want to control*
> *them (Margarita, 437-439).*

Parallels can be drawn with Yvonne's use of the word 'force' in the following extract:

> *it was like she was forcing me to, in those, because that's it, after three*
> *sessions you know, if I haven't made the appropriate, its like I'm on my*
> *own. She would say those things but um, sometimes, I don't know, I just*

didn't think, yeah, I don't think she realised how bad it was (Yvonne, 329-332)

Implying that both women perhaps felt coerced into aspects of therapy that they felt less comfortable with. Yvonne seems in the above extract to be experiencing not only a lack of feeling understand by her therapist ('I don't think she realised how bad it was') but also a pressure to carry out a behavioural experiment she felt uncomfortable doing or risk the therapy ending ('I'm on my own'). A stark contrast was drawn with Yvonne's experience of her second therapist, who Yvonne described as 'really encouraging' (line 444), resulting in a different response :

I really wanted to do it for her, if that makes sense. Because like, not that, not because she was like a tyrant and wanted to see what you done, but just because I wanted to give her some good news say 'I've done this, I've done that'. (Yvonne, 440-443)

Other participants reported having new, positive understandings of their difficulties following therapy, shaped by their experiences of the approach they had received:

And then er this psycho – CBT, um for some reason, through this CBT I realized that I felt very trapped and that this feeling was my mother's one, not necessarily mine, you know? Didn't correspond so much to the reality. (Claudia, 691-693)

Or that the specific techniques used had had positive effects on them feeling safe and understood:

what really helped it was the thought record sheet, and do you what made me feel – every time I had a dip, what mostly did it for me was ask yourself, you're leaving your cosy bedroom, what's the worst that can happen and do you know what, every time the answer was nothing (Ravi, 530-534)

Ravi here describes the impact of a particular technique on how he feels. The simplicity of the technique appears to be both powerful and reassuring for him ('every time the answer was nothing'), and seems to have shifted his understanding of his anxiety at leaving his room.

3.4. Super-ordinate theme 3: 'Outside forces': Contextual influences on the experience of distress

This theme explores the way that participants made sense of wider contextual influences – the roles they occupied, the expectations placed of them in these roles; time pressures and build up of demands; and the ideas that they had about what therapy's role was in helping with this. This theme also includes how participants contextualised their own distress against cultural depictions and understandings of distress.

3.4.1. 'Feeling better' or 'functioning better': Expectations and social roles

The influence of gender roles and the expectations that participants (and others) had of themselves in these roles was implied through a number of accounts. Jamie talked about ideas around being the 'sort of man' that helps (line 314), connecting this to different men in his family (father, step-brother) and how they did and did not help and support the people around them. His admission of his own sense of inability to help his mother with rebuilding her house:

> *Well I wish I could do more to help um but knowing I can't cos I can't take the schoolkids there, that doesn't help (Jamie, 276-277)*

Therefore could be interpreted as being linked into this idea of being a 'man' and consequent self-blame when he cannot fulfil this role and 'help'. Ravi's description of himself as a 'broken down man' similarly invokes a sense that there is something particular about being a 'man' in the experience of feeling 'broken down'. He later pauses frequently when talking about his sense of 'failure', which perhaps could be taken as an indication of the difficulty of 'failure' and being 'broken down':

> *I believed I was a failure [pause] um in the workplace but then I believed*
> *[pause] I was a failure to the family as well, um and – yeah, it [pause] but*
> *basically, normality just disappeared (Ravi, 251-254).*

In this extract Ravi appears to internalise his sense of failure, separating it from the 'bullying and intimidation' (line 56) he earlier describes. His focus is no longer on the actions of others, but solely himself, and what he now sees is his own personal failure. This sense of failure then seems to become all-encompassing, spreading to other areas of his life, to the point that he feels as though 'normality' has gone.

Debbie talked about what being 'better' meant to her, saying that it was not about emotion, but more being about to function better:

> *it wasn't about me at that stage, it was about me being a better mother, a*
> *better partner, you know. So it's still actually I'm lying, I didn't want to feel*
> *better, I wanted to be better, do you know what I mean, in terms of to*
> *function better. I still I think wasn't seeing the point of feeling better,*
> *because that just was not a priority (Debbie, 348-352)*

It seems possible for Debbie to artificially separate emotions (to 'feel better') and roles (to 'function better'). Like Ravi, Debbie seems in this extract to be internalising the expectations of others, and treating meeting others' expectations as the priority, instead of her wellbeing. Being 'better' is represented by being, at least on the surface, fully functioning in her social roles as a mother, or partner.

Margarita talked about feeling that she was failing to meet the expectations placed on her in her role as a partner in a sexual relationship, understanding her distress as partly being a result of feeling that she was failing to meet these expectations. Her choice of words in describing that she felt 'very little' invokes a sense of comparison, of what she could be, or what other women are, in relation to how she felt – unable to fulfil her expected role as a sexual partner.

And at the same time I was feeling that I was very little for him [starts crying]. Because it was cervix surgery so we couldn't actually [pause] have like a sexual life (Margarita, 23-25)

Other participants echoed this idea of sensing that there was a way that a person *should* be, or a comparing themselves to this to feeling that they were not meeting expectations as being linked to the causes of their distress:

Just that I'm worthless is the main thing um yeah just that's the main thing really just worthless or nothing just like I'm not contributing or doing anything or [pause] just makes me feel down (Jamie, 194-196)

It seems that Jamie has an idea of a wider expectation that he should be 'contributing' and 'doing'. The fact that he was not (Jamie was unemployed and receiving benefits at the time of our interview) was linked heavily to his mood and sense of self. I wondered if his later exploration of his feelings about 'costing' something to other people was perhaps a reflection of his experience of being on benefits too:

I couldn't provide anything I didn't want to do anything I didn't want to eat I didn't want to drink I didn't want to [pause] cost anything to anyone else (583-586)

For John, similar ideas were conveyed through his discussions on the idea of being 'normal' (line 310) and wondering whether he was 'normal':

Cos everybody I know always drink and smokes. And I don't. And I feel like – not an outcast but I feel – I don't feel right sometimes, is it not – is it right is what I mean, for me to be like that. You know. And then I'm on my own again, and it all starts, and the panic attacks starts again. (John, 335-338).

Amy: Are there any feelings associated with those thoughts of am I normal?

John: Mm I just get depressed I suppose, makes me depress – bit depress what do call if they call it depressed, cos I don't want to do nothing again, I've – just want to go home and just go to bed and just don't want to do nothing, it's how I feel, again. (John, 340-346)

In the above extracts John describes sensing a gap between his idea of 'normal' (represented here through 'drink[ing] and smok[ing') and how he sees himself as being. He seems to be searching for meaning ('is it not – is it right'), and this appears to be a process he has been through before ('I don't feel right sometimes'). This then affects how he feels, either triggering 'panic attacks', or making him feel 'depressed'.

Faiz talked about his experience of being a second generation Indian immigrant, and how this caused him to feel that he had to play a 'double role' (line 304), leading to being rejected from all sides:

when you go to the people who are from your country, they look at you with a resentfulness. So you're already rejected by them, and then you try to fit into this country, you know, and the English can be very harsh as well in their treatment, then can be very. You don't really fit the picture, you understand that, you don't really fit the role (Faiz, 305-309)

He described the expectations placed on him by people based on his parents' country of origin, and how he did not meet these stereotypes due to having been brought up in England:

But you can't be you, yourself, you've gotta be, you've gotta play the role we want you to play, do you understand that. So you've gotta be either extremely religious, or you've gotta be you've gotta speak a certain way, so you know it's like, for me it's like hold on I was born in Essex, yeah? (Faiz, 350-354)

Negotiating this 'double role' therefore meant that he was rejected from all sides, not feeling that he truly 'fitted' anywhere. His repetition of 'gotta' in the above

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quote is perhaps indicative of the pressure that he felt to be, or at least act, in a certain way. Faiz was clear that he did not feel therapy was a place that he wanted to discuss these issues, which he described as 'prejudice', stating

> *Amy: Do you think it's important to talk about those kinds of things in therapy?*

> *Faiz: No no what it is, basically is I don't think these sorts of things will ever change (Faiz, 991-995)*

Participants therefore seemed to have different relationships to the social positions they occupied. Expectations felt in these positions are internalised, leading to a sense of pressure to be a certain way, or at least behave a certain way, as shown through Debbie's and Faiz' extracts. Others explore the effect of a gap between perceived expectations and how they see themselves as being, leading to feelings of distress, as shown through John and Jamie's extracts.

3.4.2. 'Negative event chain reaction': Things that happen in life and how therapy can help

Nearly all participants (excluding Yvonne) explored the effect of events and circumstances in their lives, and how this impacted on their mood and sense of wellbeing. Margarita summarised this as 'outside forces' and the combination of this with feeling 'weak emotionally' as a 'combination of guaranteed depression'.

Employment, and demands and stress related to it were a key feature of participants' accounts. Seven of them were in either full-time or part-time employment at the time of the interview (excluding Jamie and Faiz). Participants frequently described escalating demands and stress at work that then spread to other areas of their life:

> *And that work itself became overwhelming and even going into work became overwhelming. And that started to spread. (Tom, 78-80)*

Clear links were formed between stress at work, and mood, described here by Tom and Margarita:

> *It was always choose, in my work it was always like in my mind, I couldn't you know, after my shift or anything, I couldn't feel like I'm relaxing. (Margarita, 71-73)*

> *I would have a particularly frustrating day at work, where you felt like you couldn't progress certain things because of the culture, or the way I was feeling, and then you would leave in quite a low mood. (Tom, 160-164).*

Work was described as shaping identity:

> *So I was, all it was is work work work work work. That's all I live for, you know, what I do now. (John, 173-174)*

And not working was linked into fear of distress:

> *Because I think I'm going go back how I am gonna go back indoors, doing nothing, being in four walls, start getting depressed, and the anxiety and depression's going to start come. (John, 382-384)*

The idea not working simultaneously was associated with being 'worthless' (for Jamie) and 'useless' (for John). Jamie's concerns about money was a core part of his experience of distress:

> *my money just stopped, that was when I just laid in bed and didn't do anything um. I didn't get out of bed for about two weeks, so for three days straight at one point (Jamie, 572-573)*

> *It's all linked to the, generally linked to money so (Jamie, 610)*

Fear of unemployment was a concern for Ravi too. The 'horrible balance' he describes conveys the tension he felt at having to continue to work hard despite being bullied by several of his bosses:

at the back of my - our minds, it er – obviously if you're out of work you don't have income, and so there was this horrible balance between um, in my case, continue to be fearful, but – but [pause] just try your damnedest to be strong and show that you're a good worker (Ravi, 122-125)

Escalating demands in other areas of life led to a sense of being 'overwhelmed' (Tom, 771), 'trapped' (Claudia, 476) and many described a sense of responsibility in multiple spheres of life:

So basically I had to take care of my job, my health, and him (Margarita, 22-23)

So work environment, emotional environment, I felt alone as well, and I didn't know anybody in that town, you know (Claudia, 227-228)

Participants used metaphor to make sense of their experiences, for example Ravi's comparison of himself to a 'computer':

So on top of that, on top of the fear, and on top of the bullying, I was doing my work, and which is a very overloaded work as it is, and but on top of this burden, it – it's just like, er, I don't know – what's the word, I'm trying to – a computer would just shut down you know (Ravi, 127-131)

The sense of a crescendo in stress is emphasised by his repetition of 'on top of', indicating the ever-increasing 'burden' he felt under, and the inevitability of him 'shutting down' under the pressure. This is linked into his later exploration of the way that he felt he wanted to be in a 'coma' (line 29) or a 'cocoon' (line 239) such was the extent that he wanted the pressure to stop.

Margarita too in her exploration of the effect of multiple demands combined with the after effects of surgery describes a sense of being 'broken only'

> *Yeah like after the surgery, when I had. When I wasn't strong, um. [Pause.] I was in pain. That actually was like the like straw in the classic, you know like you say, to actually being very, very emotional. And like. Broken only. (Margarita, 245-248)*

Escalating demands, and responsibility, therefore reached a certain point where participants felt that they needed further support, which resulted in their eventual referral for psychological therapy.

Participants' sense of control within this was mixed – Jamie's admission that

> *if something does happen it does hit me quite hard still (Jamie, 53-54)*

implies that he had a limited sense that he could control what 'happens' and that the effect on him was serious.

Ravi described feeling 'hopeless and helpless' prior to therapy in relation to the bullying and escalating demands that he experienced at work, invoking a sense of lack of control and power of what was happening around him.

Participants had different ideas about what they wanted therapy to be for in relation to life events. For some, it seemed that therapy was important in helping them to better 'cope', or 'manage' the difficulties:

> *I mean I know I've still got the same issues, just dealing with it better really, so I dunno it's not really – just gonna go away, but um, I know I'm more aware of them and what's going on, if you know what I mean, being able to cope with it. (Jamie, 932-935)*

> *the therapy helps you manage the condition and understand what levers you have to employ throughout the rest of your life (Tom, 783-785)*

Whereas for others, it seemed that therapy empowered them to make changes to life. Claudia described feeling more able to 'take risks' following therapy (line 1041) which permitted her to request to work part-time, allowing her to pursue activities and studies that she enjoys. Tom described how therapy had enabled him to take 'time out' of his busy schedule, to allay stress he associated with being too busy:

> *this whole idea of taking time out, and consciously taking time out, is something that I employ now a lot more readily than I would have done before (Tom, 775-778)*

Ravi described being able to apply CBT to his everyday experiences at work, where he had previously been bullied, enabling him to feel 'empowered and protected' (line 436):

> *So and er when the phone rings, you know, even now, I still think – remember your bill of rights, don't let – you know, don't let anybody put you down. (Ravi, 715-717)*

Debbie, Jamie and Margarita explored the scope of therapy, and how far they felt it had gone, or could go, in ameliorating their distress. Jamie described his sense that it was 'disheartening' that his depression was not going to go away:

> *it's a bit um, disheartening knowing that it's not going to go away really, but knowing I can cope with it does give me a bit more strength to deal with it (Jamie, 939-941).*

Margarita too in her analysis of expectations of therapy compared with what her experience was described hoping for something with a different reach.

> *I was accept – expecting something more, a bit more, effective? (Margarita, 401-402)*

Debbie explored the 'depth' of different parts of therapy and how this fitted with what she needed. Her extended analogy of her 'system of thought' as a living, organic, thing allowed her to conceptualise her beliefs as being 'deep-rooted' (line 443) and therapy therefore needing to 'dig' deep enough:

I felt like I'd lopped off the top of the plant, but the roots were still there and it was going to grow back, so I felt like I really needed to dig then and get everything out, pull it all out, otherwise it was just going to come back (Debbie, 752-756)

Her experience of computerised CBT when first accessing the service was deemed to be

So surface, that it didn't have really relevance at all (Debbie, 366-367)

Contrasting her own formulation of her difficulties as being 'deep' with her perception that therapy tackled some of the more 'surface' parts permits an interpretation that she sensed therapy needed to go further for her.

Many of those interviewed spoke of the value of CBT techniques in helping them to explore and challenge their own thoughts, suggesting that the 'scope' of therapy fitted for them and helped them to make positive changes:

So every single, every single [pause] negative thought I had to tackle it, you know write it down on a piece of paper and I had to challenge it. You know. So this helped me a lot as well. Yeah. And er through that it's like er restoring my self-esteem (Claudia, 613-617)

Just the general rationalisation really, with like a negative thought, to question it, not um, [pause.] Um. Just to – yeah just to instead of like thinking in negative ways, trying to think in a more rational way about it. (Jamie, 832-834)

Understanding the influence of outside forces therefore had implications both for participants' conceptualisations of distress, and for their experience and expectations of therapy.

3.4.3. The meeting of cultural understandings and personal understandings

Debbie, Yvonne, John and Tom all referred to other people with mental health issues, seemingly as a way of understanding their own distress. For Debbie, comparing herself to others seemed to be simultaneously a way of distancing (through the use of the words 'those people') herself from people with what she perhaps perceived to have more serious mental health issues:

I'm not one of those people, like dribbling and wearing one shoe (235-236)

And a way of understanding the level of her own distress

I just thought you're a lightweight, that doesn't sound like anything bad to me. Like my life is much worse than that. Why are you moaning? (312-315).

John, similarly, classified himself as a 'mild mental' (line 1139) against a description of what he believed to be a wider public (mis)understanding of mental health:

mental illness could be different things, different levels. And they say what do you mean, I say well you know they think you just going to get a knife out, out the cupboard and start going round stabbing everybody, got this thing of a mental person, or going mental in the streets start shouting at people being abusive, and start kicking people and hitting people, and I thought people got the wrong idea what different levels of so say you could have schizophrenics you get this but there are all different levels of mental – mental side. And er I class myself as a mild mental I suppose, that's how I look at it like (John, 1139-1149)

For Tom, considering that there were other people with a 'greater need' (line 512) was perhaps a way of questioning his own need for psychological therapy, given his status as a 'sort of middle class white male with some minor issues um coming to talk through my problems' (line 509-511), and exploring the 'guilt' he felt around this. Given the way that the 'serious stigma' (line 228) he felt surrounded depression might have meant that he denied his own for years. Perhaps considering there were other people with more serious issues was helpful in allaying some of the stigma he felt when thinking about his own experience.

Depictions of distress in wider popular culture, including books (Yvonne), radio programmes (Debbie), films (Debbie and John) and celebrity culture (Debbie, Tom, Yvonne) were deemed to be useful in understanding own distress, appearing to have the effect of normalising it an increasing personal and public understanding. Debbie described her experience of hearing a radio programme featuring Ruby Wax talking about postnatal depression

> *What I'm just seeing as a weakness, or like some sort of evil inside me, people are just talking about as if it's like a thing in the world, do you know what I mean, it exists in the world in discourse among people on radio four. And I think that was a real sort of revelation (Debbie, 319-323)*

A key feature of therapy for Debbie was making her own distress tangible and bringing a new level of understanding; through describing hearing about distress as 'a thing' that 'exists' it seems that hearing this programme started this process for her. Similarly for Tom:

> *I think certainly in the recent press in this country there's people like Stephen Fry are talking a little bit more openly about it. And I think it's getting a bit of a different public perception. (214-217)*

Hearing others speaking about distress and mental health, particularly well known public figures, therefore can perhaps be understood as a way of

normalising own experience, and starting the process of making it more 'open' and tangible.

4. DISCUSSION AND CRITICAL REVIEW

4.1. Discussion

In this chapter I discuss the findings of the study in relation to the research questions. IPA can lead to the discovery of new, or unexpected themes during interview and analysis. Some of the literature contained below has not been discussed in the Introduction chapter (Smith et al. 2009). I will then discuss the implications for clinical practice and for further research. Finally, I turn to a critical evaluation of the study, and discuss the methodological limitations.

4.1.1. Addressing the Research Questions

4.1.1.1. Research Question 1 – How do people using psychological therapy at an IAPT service make sense of their own distress? To what extent do they draw on contextual factors?

The analysis suggests that people attending therapy at an IAPT service make sense of their distress in varying and complex ways. Participants drew on different areas of experience, including their emotional world and identity, their relationships with other people, and the wider context. These areas were all inter-related and influenced by each other. This supports previous research that has suggested that people draw upon different areas of experience when conceptualising their own distress (e.g. Williams & Healy, 2001; Karasz et al. 2009).

Research suggests that biological explanations tend to be dominant in public understandings of distress (e.g. Time to Change, 2012), whereas people who have themselves experienced distress may prefer a more 'social' model, drawing upon wider contextual factors (e.g. Beresford et al., 2010). The current study adds to Beresford et al.'s (2010) findings through asking open questions about conceptualisations of distress, rather than questions focussed around the appropriateness of a social model for mental health. The results of the analysis suggest that participants in this study explored experiences of their relational and

social contexts during the process of understanding distress, but in addition also looked to their internal world, identity and emotions. I will now turn to each super-ordinate theme and how it responds to the above questions.

The super-ordinate theme 'Looking to myself' explores the way that participants referred to their emotional world and identity during the process of making sense of distress. The range of emotions felt, and sudden, inexplicable nature of distress were explored in the interviews in different ways. Firstly, by using a wide range of metaphors and comparisons. Rhodes and Smith (2012) state that metaphors: 'express, constitute and amplify the very experience of the person' (p.407) – they inform us about how it is that distress is experienced. Metaphors were used in different ways by participants – to indicate the severity of distress (for example, comparing it to death, torture, or wanting to be in a coma); to describe a point of extremity where things became 'too much' (such as likening the self to an overloaded computer); or to provide shape to the distress in a way that helps joint understanding between therapist and client in therapy. For example, Debbie's comparison of her 'system of thought' to a beautiful tree, and a parasite, might imply that therapy needed to go 'deep enough' to get to the 'roots'. Paying attention to this metaphor might aid a therapist in understanding Debbie's distress as she sees it. Secondly, many participants drew upon their experiences of diagnostic labels when talking about understanding their own distress, with different attitudes towards the value of these labels. Some participants seemed to feel initial hesitation towards receiving the label, but described adjusting to acknowledge the label's benefits in terms of accessing services and support. Others remained unsure about the use of medical terminology, for example Debbie's assertion that 'they call it OCD – I don't'. Alternative understandings were arrived at through participants learning psychological theory behind why they were feeling the way that they were, and through collaborative formulation jointly with therapists.

The sub-theme 'It usually has to do with the people that you interact' illustrates the relational nature of distress, and the way that participants considered their relationships with other people when seeking to understand their experience of distress. This resonates with Granek's (2006) research into depression, which

suggested that depression is a relational phenomenon, conceptualised and understood in the context of relationships with other people. Much research exists to suggest the role of other people in close social networks in contributing to, and ameliorating distress. In a recent review of the literature, Pilgrim, Rogers and Bentall (2009) highlight the central role of a lack of group belonging in the emergence and maintenance of mental health problems, and the opportunity that group membership provides for close intimate relationships that provide security as advocated for by Bowlby (e.g. 1988) and other attachment theorists. The results of the analysis extend previous research by expanding on the subjective experience of 'others' during the process of making sense of distress. The interviews suggest that people attending therapy at an IAPT service include in their personal formulations of distress:

- An appreciation of the importance of their early social environments, and the link between 'toxic[ity]' of these environments and later likelihood of distress;
- A conceptualisation of how the actions of 'others' in the present can directly cause, or contribute to feelings of distress
- An exploration of the link between the absence, as well as presence, of others and distress
- An understanding of the role of others in close social networks (including family, friends and professionals) in providing support for distress

The above findings all suggest that the experience of relationships is at the forefront of people's minds when thinking about their own distress. In addition, participants explored the ways in which they thought different therapeutic approaches allowed for the exploration of past and present relationships, and how this fitted with their needs at the time. For example, this was suggested by Claudia's rationalisation of how psychotherapy was helpful in the past, but the more 'pragmatic' approach offered by CBT was what she seemed to feel best fit her needs during her current therapy. This suggests that IAPT service users are aware of the way in which different therapeutic approaches may account more or less for different types of difficulty, and the need for flexibility in approach.

The super-ordinate theme ''Outside forces': Contextual influences on the experience of distress' looks at the way that people explore wider contextual factors in the process of making sense of how they feel. This includes the role of life events; the pressures felt from a range of social role people feel expectation to perform in; and influences from the wider cultural context. I consider each of these in turn below.

Nearly all participants drew upon the influence of a wide range of life events when making sense of their distress, replicating previous research (e.g. Brown and Harris 1978; Sisley et al 2011; Williams and Healy, 2001). The current study adds to this research by exploring the process by which participants link what is happening in their life to their sense of wellbeing and distress. Participants explored the effect of ever-increasing demands and burden, and the responsibility that they felt in different spheres of their lives. Demands built up and sometimes led to a point at which things 'shut down' and they felt 'broken'; or led to them experiencing a lack of control, causing them to feel 'hopeless and helpless'.

The analysis also gives a novel insight into the experience of the link between difficulties with employment and the experience of distress. For instance, Ravi discussed the dilemma of feeling pressure to perform at work in the face of potential unemployment, as well as experiencing bullying at work. Margarita and Tom discussed the build-up of stress and the difficulty of leaving this stress at work. Jamie also explored the pressures of unemployment, and feelings of not 'contributing' or 'providing'. A key financial argument behind IAPT services means that people are supported to return to work in order to reduce reliance on benefits. The findings above suggest that, as Pilgrim and Carey (2012) suggest, a lack of decent working conditions can be a potential source of distress, rather than returning to work being an indicator of recovery.

Participants had different opinions of how therapy could help them with difficulties at work. Some described that therapy empowered them to take action and do things differently, such as requesting to go part-time (Claudia) or defending themselves against managers who are bullying (Ravi). For others, learning ways

to manage stress and regain a sense of control was felt to be most effective. This suggests that finding a space in therapy to talk about employment, whether this is its presence or absence, may be helpful.

Participants explored the expectations that they felt were placed upon them in their various social roles, alongside the influence of these expectations on their sense of wellbeing and distress. Distinctions were drawn between 'feeling' better and 'functioning' better, with 'functioning' appearing to be considered the priority by a number of participants. The analysis suggests a process by which societal expectations (such as what it means to be a mother) are internalised, and conceptualised as something that people feel they *should* be achieving. Distress arises through failing to meet the internalised expectation. The idea of providing a space within therapy to explore these issues was discussed, with a range of views expressed. Some described what seemed to be an acceptance that issues such as these will not change; for others it seemed to be more of a disappointment. Future research could further explore these questions, perhaps considering a range of therapeutic approaches, and how they take social issues into account.

Previous research has shown a link between media and understandings of distress. Participants in this study also cited multiple media sources – books, films, radio programs, for helping them to learn about distress, that seemed to shape their understanding. Previous research suggesting that media only delivers a negative, biomedical depiction of distress (e.g. Coverdale et al., 2002) was not supported. Rather participants described how seeing celebrities 'come out' about their mental health issues was a helpful way of making sense of their own experience. Many compared their own personal experience of mental health to a wider, more serious cultural depiction. This is perhaps reflective of the relative infancy of the provision of psychological therapy for 'common mental health problems' on the NHS. Future research could explore if, and how, this changes as provision of psychological therapy by IAPT services continues to increase.

4.1.1.2. Research question 2 – How do people experience the 'fit' between their personal explanations of distress and the explanations they encounter in therapy?

The theme ''Connection' in therapy' captures participants' experiences of feeling understood, 'connect[ed]' and disconnected during the therapy process. The essence of this 'connection' as explored in this theme is the experience of a collaborative, tailored therapy using an approach and techniques that 'fit' with the person and their preferred way of understanding distress. Different aspects of participants' IAPT experience appeared to increase, and decrease, this sense of 'connection'.

Many participants valued therapy as a joint and collaborative process, highlighted by their frequent use of 'we' to refer to the partnership between them and their therapist. This view of therapy ties in with previous research that highlighted the positive influence of collaboration on both the experience of therapy (Gostas et al., 2013) and it's outcome (Westra et al., 2010). Some used the metaphor of therapy being like a 'journey', with the therapist either showing the participant which path to take, or taking him or her by the hand and walking down the path together – the value of therapy appeared not to arise solely from the explanation offered by the therapist, but more so from the therapist being *with* the person during their journey through therapy. This finding supports previous literature that has implied the importance of the therapeutic relationship (e.g. Blow et al., 2007; Horvath & Simonds, 1991) and indicates the possibilities for warm, supportive therapeutic relationships within IAPT should be prioritised.

This stood in contrast to times when participants described a lack of support and collaboration from their therapist, or from the IAPT service itself. This included times when therapists appeared to be not paying attention, or during phone calls from administrative staff when assessing for the need for follow up therapy. A relative disconnection seemed to be experienced at these times. This has implications for the way that IAPT services are run, particularly at low-intensity level, where delivering therapy by telephone is more common (e.g. Hammond et al., 2011). Future research could explore the idea of 'connection' (to therapists,

and the service itself) and how this is experienced by people who receive IAPT therapy by telephone.

Participants also spoke about a 'connection', or lack of connection to the therapeutic approach, or specific techniques used. This was frequently explored in the context of the therapeutic relationship, meaning that it was difficult to separate 'connection' to the therapist, and 'connection' to the approach. Questions were raised about the process by which a therapeutic approach is chosen – Tom, for example, felt that the phone triage assessment was not broad enough to take his wider needs into account. This supports previous research that suggests that further thought be given to the way that a therapeutic approach is selected (e.g. Hall & Marzillier, 2009). Other participants considered the utility of different therapeutic approaches for different types of difficulty, comparing past experience of alternative approaches to the approach taken in the current therapy and rationalising the benefits and drawbacks offered by each. Claudia, for example, describes appreciating the methodical and measured approach offered by CBT at the IAPT service, contrasted with her appreciation of previous psychodynamic therapy.

A key question for IAPT services is therefore the range of approaches that are offered, and how an approach is selected for any one person – whether this is a collaborative decision between client and therapist, or one that is made by the therapist. Previous research has suggested that therapy offered through IAPT is most effective when there is a choice in approach (Mind, 2013), however in practice the range of approaches offered, and how an approach is decided on, varies from service to service. The data presented in the current study suggest that services consider to explore the process by which an approach is decided on, and the best way to proceed with this to ensure that service users feel 'connection' to the approach they use, accepting that that this may be largely shaped by the relationship with the therapist offering that approach.

Within any given approach, participants explored their experience of particular techniques, and the sense they had of how the approach was tailored to meet their needs. For example, the sub-theme 'This is me' explores the way that

participants made sense of their identity in relation to distress, and how this changed throughout the therapy process. Therapists taking account of the profound influence that distress has on identity was spoken about as being important, for example by pacing talk, and by paying attention to participants own understandings.

In contrast, moments where participants felt a lack of tailoring, or 'fit' were also explored. This included therapists' attempts to re-label participants own understanding of their experiences; not paying attention to the rich and complex ways that they had come to describe them in; or rushing work without paying necessary attention to how participants were experiencing it. Several described their sense of receiving 'textbook' or 'script[ed]' therapy, from past therapists. This approach influenced both their connection with the therapist, and their overall experience of therapy – for instance, it was described as not feeling 'natural'. For some, this went further, and they described feeling negatively about the particular techniques used by the therapist, or the way in which they were used. Yvonne's experience of feeling 'forc[ed]' into behavioural experiments by her therapist, and Margarita's experience of feeling pushed into using schemas in therapy were examples of this. This links into a wider question around the respective role of therapists and service users in structuring therapy and deciding on which particular techniques are followed, and how important collaboration and agreement on this is. Agreement on therapy tasks, or techniques is included in measures of therapeutic alliance (e.g. the Working Alliance Inventory, Horvath, 1994) and collaborative resolution of disagreements about therapy tasks can help to maintain or restore alliance, therefore improving experience, and potentially outcome of therapy (Kuyken, Padesky & Dudley, 2009). In a summary of research which looks at the link between the structure of therapy and the therapeutic relationship, Kuyken, et al. state that the 'optimal balance of structure and relationship factors is probably the most structure possible that does not damage the therapy alliance' (2009, p. 67). Therapists deciding on which tasks/techniques to adopt is therefore suggested to be beneficial. However, for Margarita and Yvonne, the techniques adopted were aversive to the point the they considered discontinuing therapy. A potential way forward could be for

therapists to check with services users their thoughts about particular techniques, and explore how they are being experienced.

In summary, the data presented in the analysis suggest that people experience the 'fit' between their own conceptualisation of distress and that they encounter in therapy in different ways. The data also implies that 'fit' can be experienced with the approach adopted, and within structures in place within the service itself. This has implications for the way that IAPT services, and therapists who work within them, practice, which will be discussed in the next section.

4.1.2. Summary and Implications for Practice

4.1.2.1. Service User Experiences of IAPT

This study has provided a novel insight into how people using IAPT services experience the therapy that they receive. As discussed in Section 1.3.3, qualitative research exploring service user views of IAPT has been limited, despite service user evaluations demonstrating that there is an 'appetite' from service users to be more involved in planning and feedback (e.g. Hamilton et al., 2011). Many of the participants I interviewed valued the opportunity to speak about their experience of therapy, and to give feedback on the service they received. More people than I was able to interview wanted to take part in the research. A number of participants reported that flexibility around timing (e.g. meeting outside working hours), as well as the opportunity to meet individually, were beneficial. This suggests there is a need for IAPT services to explore accessible mechanisms for service user feedback. Different options could include holding meetings outside working hours, and considering flexible options for ways to give feedback (e.g. interviews, groups, telephone conversations in addition to questionnaires).

4.1.2.2. Tailoring Therapy

Participants explored different parts of their IAPT experience, including the therapy itself, their relationship with the therapist, and aspects of the way that the

service related to them. They drew on rich, unique and varied conceptualisations of their own distress, and had clear ideas about how therapy could best support them. Use of metaphor appeared to be a key way of making sense of distress, and sharing this sense-making with therapists. This suggests the importance of supporting people in using their own language and metaphors for understanding distress. Therapy was experienced less positively when it was felt to be 'scripted' or 'textbook', illustrating the importance of flexibility and responsiveness to need in therapy. This is in keeping with previous research, which suggests that satisfaction with IAPT services decreases when people feel they are receiving a 'textbook' therapy (e.g. Hamilton et al., 2011). The analysis suggests different areas of service delivery which contribute to person feeling that therapy has been tailored to them:

- Paying attention to personal conceptualisations of distress and how a person understands it;

- Paying attention to the language that they use to describe someone's distress (e.g. giving it a diagnostic label);

- Adapting the pace of talk, which was spoken about as being particularly important in the context of the profound change in identity that people spoke about experiencing during the course of therapy. This may be particularly important to consider in the context of the time-limited nature of IAPT therapy (e.g. Hamilton et al., 2011, suggest that the majority of IAPT users are offered up to twelve sessions of therapy).

4.1.2.3. Therapeutic Approaches in IAPT Services

Participants discussed their experience of a range of therapies (e.g. CBT, psychodynamic therapy, DIT) contrasting their use for particular difficulties at particular times. In addition, they explored ideas around the process by which a therapeutic approach is selected, and their experience of particular therapeutic techniques. This has the following implications:

- That IAPT services consider the process by which a therapeutic approach is selected, and an assessment procedure that is broad enough to take in the full range of people's needs is used;

- That IAPT services offer a range of different therapeutic approaches;

- That therapists find ways of checking service users' experience of particular therapeutic techniques, and adapting therapy as necessary.

4.1.2.4. Including Context?

The results of this study add to the debate around how social issues are drawn on in the process of making sense of distress. Participants linked a range of relational and contextual factors into their descriptions of their experience. This resonates with Beresford et al.'s (2010) finding that people who have experienced distress prefer, to some extent, a social model drawing on social and environmental factors. How ideas around context are included, or excluded, from therapy in IAPT services could be a focus for future research. Burton & Kagan (2009, p. 65) emphasise the need for psychologists to understand how ' social phenomena that exist at a level of analysis beyond the interpersonal nevertheless enter into the construction and functioning of human actors, their ideas, desires, prejudices, feelings, preferences, habits, customs and culture'. The results of the analysis go some way in elucidating the process by which this happens, through exploring the way in which perceived expectations from others (for example, feeling as though you have to 'contribute' and 'do' as Jamie describes) are internalised, and feeling as though you are not meeting expectations can lead to distress.

Therapeutic approaches, and therapists themselves, differ in the extent to which they consider contextual issues as a part of therapy. As stated in the response to Research Question 1 (Section 4.1.1.1.), future research could explore how IAPT service users experience different therapeutic approaches in relation to the extent to which they take context into account.

4.1.2.5. Therapeutic Relationships and 'Connection' in IAPT Services

In line with previous research, participants highly valued the therapeutic relationship, suggesting that it is important that IAPT services continue to seek ways to prioritise developing high quality relationships with clients. In addition, it may be important to consider how clients are experiencing their connection with the service, in addition to the therapist. Several people I interviewed explored their experience of phone contact with the service as a moment of relative dis-'connection' with the service. Research exploring the effectiveness of phone therapy in IAPT services is starting to emerge (e.g. Hammond et al., 2012). An interesting avenue for future research could be to explore the experience of phone therapy in relation to 'connection' and the therapeutic relationship.

4.1.3. Implications for Further Research

- For research exploring similar research questions to be carried out with people who finished therapy early, who may have different experiences of the ways in which personal conceptualisations fit with service conceptualisations.

- For research exploring similar research questions to be carried out with people from different cultural groups, for whom research suggests distress is conceptualised differently.

- For research to explore how telephone therapy in IAPT services is experienced in relation to therapeutic relationships and 'connection'.

- For research to explore in further detail how people experience the different therapeutic approaches offered in IAPT, particularly in relation to the extent which they explore context.

4.2. Critical Review

4.2.1. Quality in Qualitative Research

Quality is important in all research, but can be harder to assess in qualitative studies. Different frameworks have been developed for assessing quality, including Yardley's (2000) criteria. Here I discuss the principles for quality set out by Yardley (2000) and how I have tried to address them in this research.

1) *Sensitivity to context*

Yardley (2000) states that good qualitative research should show sensitivity to: the context of the relevant literature and theory; the socio-cultural setting of the study; and to the relationship between the researcher and participant. I showed sensitivity to the relevant literature and theory through carrying out my literature search (see Appendix A for details) that drew on IPA and non-IPA studies, and through grounding the discussion of my analysis in theory.

To orient myself to the socio-cultural setting of the study, I met with both IAPT therapists (attending whole service meetings, presenting an early proposal of the research at an away day to gather feedback, and team meetings) and service users (attending a 'Service User Forum' meeting) to speak about the research and gather their feedback on my ideas for research focus and recruitment process.

Smith et al. (2009) state that sensitivity to context can also be shown in good interactional interviews, where the researcher shows empathy, recognizes the power imbalance and helps the participant feel at ease. I found ways to do this in each interview I conducted – for example, Debbie described feeling nervous prior to the interview, and had brought a closing therapy letter her therapist had written that she said articulated her experience better than she could. We spent time talking about how she was feeling and I reassured her that I was most interested in hearing her

words and that she was the 'expert by experience', to help her to feel at ease before the interview started.

2) *Commitment, rigour, transparency, coherence*

Yardley (2000) states that commitment 'encompasses prolonged engagement with the topic […] the development of competence and skill in the methods used, and immersion in the relevant data' (p. 221). I demonstrate commitment to the topic through my engagement with the IAPT service that was the site of the research, and my knowledge of IAPT through having worked in an IAPT service previously. I demonstrate commitment to IPA and the data collected through my extensive reading about IPA, and reflective conversations about IPA with a peer-researcher. Commitment to the data included the way that I ensured an in-depth reading and understanding of each case before moving onto the next. This felt particularly important given the diverse range of experiences that participants brought to the interviews. Including this in each theme by exploring incidences of both convergence and divergence ensured that all participants' views were represented.

Rigour is defined as referring to the completeness of the data collection and sample (e.g. its ability to provide all the information needed to address the research questions and provide a comprehensive analysis**)**. I selected the sample carefully to be able to answer research questions, and also be sufficiently homogenous**.** I also showed rigour in the interview process by practicing the interview schedule beforehand – unfortunately not with a service user (due to initial difficulties with recruitment, discussed in Section 4.2.2.1) but in supervision and with an acquaintance who had received psychological therapy.

In order to attempt to be transparent, I include in my appendices a detailed demonstration of the process of analysis of one case. Following analysis, I discussed my themes and super-ordinate themes with a fellow researcher

carrying out IPA, in addition to receiving feedback in supervision. This also allowed me to check coherence and transparency of the themes.

3) *Impact and importance*

Yardley (2000) state that research should be judged for its impact and utility. This study offers a novel insight into the experience of service users of IAPT. The study will be presented at the IAPT service where the participants were recruited from, and it is planned that it will be written up as a journal article in order to disseminate its findings more widely.

4.2.2. Methodological limitations

4.2.2.1. Focus of the Research

As set out in 'Summary and Implications for Practice' (Section 4.1.3.), the study offers a novel contribution to the literature in the way that it explores different parts of service users' IAPT experience, and relates this to their understanding of distress. In seeking to explore people's experience of IAPT, in the interviews I often found myself hearing the 'story' of the experience of therapy, in addition to the responses to questions I asked with relation to the research questions. Ensuring that I paid enough attention to people's stories and experiences, in addition to eliciting their personal understandings of distress, meant that the focus of the interviews was fairly broad, and choosing where to narrow down, and ask more specific questions presented a challenge. This may have meant that there was less focus in the analysis (and the super-ordinate themes generated) than there could have been. Future research could improve on the current study by focussing separately on understandings of distress, and experience of IAPT services. Ideas for further research exploring experience of IAPT services are included in Section 4.1.4 ('Implications for Further Research'). Ideas for further research focussing on understandings of distress are included in Section 4.2.2.2. ('Timing of Interviews').

4.2.2.2.Timing of Interviews

I chose to interview participants after they had finished therapy. It could be argued that through interviewing a group of people who have already experienced psychological therapy, social, relational and psychological influences may be more likely to surface, particularly given that research has shown that understandings are often shaped by interaction with health professionals (e.g. Sisley et al., 2011). Participants may have been reporting understandings that they had arrived at in therapy, rather than their own personal understanding of distress prior to attending therapy. Future research could explore personal understandings in further depth by recruiting people to interview who have yet to start therapy. Concerns around the ethics of interviewing individuals who are possibly experiencing high levels of distress could be allayed by recruiting participants once they reach the top of the waiting list, and are about to start therapy.

4.2.2.3. Recruitment

Initial recruitment for the study was problematic as participants were slow to show interest. Initially information about the study was included in the closing questionnaires given out at the end of therapy. Several people then expressed an interest, and in consultation with senior management from the IAPT service, I decided to make an amendment to the recruitment method so that therapists asked service users in their final session if they had seen the information about the study and if they had any questions about taking part. Using this method, the remainder of the participants were recruited (with the exception of two who were recruited from the 'Service User Forum'). After I had carried out 9 interviews, I decided I had rich enough data to be able to stop interviewing. Regrettably I had to inform several participants who had expressed an interest in taking part that I was not able to carry out interviews with them as I had sufficient data.

4.2.2.4. Payment

I wanted to pay participants to acknowledge their contribution to the study, and to recompense them for the time it took to take part in the interview. As Head (2009) states, paying participants in research can be a way to overcome part of the power imbalance between the researcher and the researched, as it means that the researcher is not the only one to benefit. Service users are routinely paid a £10 fee for events where they give feedback about the service (such as the 'Service User Forum' meetings I attended).

However it is possible that paying participants might have affected the responses they gave, in several ways. Participants were aware that the money was funded by the service. This may have might have meant that participants felt obliged to give more positive feedback than they otherwise might have done. McKeganey states that paying interviewees could mean they 'tell us what he or she feels we want to know' (2001, p. 1237) – in this case it is possible that participants felt influenced to be positive. Two participants (Ravi and Tom) stated that they did not want to accept the payment, as they wanted to express their gratitude to the service for the treatment they had received. On reflection they, and all other participants seemed to give balanced accounts, drawing on strengths and challenges of the service they received. I was therefore not overly concerned about the effect of payment influencing the results.

4.2.2.5. Location

All interviews took place in a room at one of the IAPT service sites. Many of the participants had taken part in their therapy sessions at a local GP surgery, so the site was different. However conducting the interview at a base that was part of the IAPT service may have framed it as a continuation of their previous therapy experience, or influenced participants to give a different account of their experiences than they might in a more 'neutral' location.

In an attempt to separate the interview from therapy, I explained carefully my role as someone who was separate from the service, stated that feedback would be

given but anonymised, and encouraged participants to be open in their responses. Future research could consider where the interviews might take place – for example, in a neutral venue such as a community centre in order to increase the chance that it is fully separate in the minds of the participants from therapy.

4.2.2.6. The Sample

An additional factor I was aware might influence the results was recruiting only people who had finished therapy. This decision was made in order to try to assess the effects of a 'complete' course of therapy. It might have meant that I interviewed people who were more likely to have had a therapy experience that 'fitted' with their own understandings, as they had stayed till the end of the number of recommended sessions. Therapy not fitting with personal explanations of distress could well be a reason for people to finish their sessions, so it might have made for a more varied set of data. However in addition, asking people who had dropped out of therapy about their experiences of it may have brought up a range of issues, meaning that it could have been hard to carry out interviews that stay focused on the research questions.

4.2.2.7. Excluding non-English speakers

Excluding non-English speakers is a particular limitation of this study, and one that was potentially a key influence on results. The research questions focussed on personal understandings of distress. This together with the wide range of literature highlighting that individuals from different cultural backgrounds have different ways of conceptualising distress suggests that interesting and useful results could have been potentially achieved by including interviews with non-English speakers. Future research should explore this area further, possibly using a different research methodology given the challenges that using interpreters presents when carrying out IPA.

4.2.2.8. Checking the Results of the Analysis with Participants

I agreed at interview with participants that I would send them a summary of the results, which they would be free to comment on if they so wished. Unfortunately, due to time constraints this has not been possible before this thesis was completed. I still plan to send out the summary, and include any responses from participants in future write-up and/or feedback of this research to the service. In IPA, meaning is arrived at through the researchers interpretations – this may mean that participants have different interpretations of the results.

4.3. Personal reflections & Summary

4.3.1. Reflexivity

Brocki and Wearden (2006) state that interpretations are bound by the researcher's ability to reflect. It is therefore crucial to remain reflexive throughout the research process. I attempted to do this in several ways. Through conversations in supervision, and with peer-researchers also interested in IPA, I reflected on the assumptions that I brought to the research, and how they might influence the interpretative process. Writing a reflective diary following each interview helped me to record the thoughts and feelings that came up during the interview. Reading the relevant diary extract for each participant prior to analysing their interview helped me to remember what my initial impressions were, and to be aware of how these might influence the analysis.

One particular potential influence I was aware of was my own preference for working systemically, and the orientation this leads me to have to relationships and context. I held this in mind throughout the analysis to try to ensure that I remained open to other interpretations too. One of the strengths of IPA is the way that it acknowledges the influence researcher's assumptions and values and how these may influence the process; I accept that there can be many interpretations and mine is just one of them.

4.3.2. Personal Reflections

I have appreciated the opportunity taking part in this research has given to explore service users' views of therapy, and to consider how they experience IAPT services. I was grateful to each participant for sharing their story with me, often in very open and honest ways. I was moved by their accounts of distress, both during the interviews and at analysis and write-up stage. I noticed that the boundary between clinical work and research felt less distinct, particularly for participants who described more challenging experiences of distress, and of therapy. I used research supervision and discussions with peer researchers to reflect on the interviews and manage my own emotional reaction to their content.

4.3.3. Being a novice researcher

Trying to balance asking questions and probing to ensure that the interview covered material in a way that would help me to answer my research questions, and yet also be led by participants, exploring their experience and hearing their story presented a challenge. I had to strike a balance between 'hearing' their story enough to understand their experience, while also staying on task with focusing on their understanding of distress and experience of therapy. I did this by starting the interviews relatively broadly, asking participants to tell me about how things were before they started therapy, and then becoming increasingly focused on conceptualising distress and experience of therapy in relation to this. I noticed that I became more skilled at this as I carried out more interviews, finding particular questions that were helpful in eliciting useful responses. Transcribing the interviews soon after they were completed was useful in helping me to reflect on the way that I was asking questions, and I was able to consider this in supervision following the second interview. However it inevitably means that the first few interviews may have been carried out in a less skilled way than the last ones. For example, listening to the transcripts enabled reflection on the many potential avenues that were opened up during participants' responses that I did not follow. During later interviews, being more aware of this helped to ensure I followed up on particular answers participants gave more fully.

I was aware of the fact that the way I asked questions was likely to influence answers. Willig (2013) cautions that the labels researchers use in their questions will shape their findings. In asking questions about how a particular experience made someone 'feel', for example, the category 'emotion' is evoked, and will probably be oriented to by the respondent (Willig, 2013, p.10). Where word count has allowed, I have included my questions in the quotes included in the analysis to attempt to be transparent about this.

4.3.4. Experience of IPA

This research was my first experience of using IPA. I enjoyed developing my skills in it throughout the research process, and appreciated the close, rich reading of the data it permitted, alongside the importance it placed on my understandings and assumptions as a researcher. A question I had in mind throughout the analysis was how much to interpret – initially I struggled to find a balance between descriptive and interpretative. Reading Jonathan Smith's comments about interpretation being a 'gentle, local process', and his assertion that IPA means 'wanting to be able to get close to the person' yet also being 'able to stand outside and say something about them as well' (2012, p. 209) helped me to reflect on the process. Alongside discussion in supervision, and with peer-researchers, it helped me to find a middle ground where I felt more comfortable that I was staying close enough to participants' words and meanings, but also add an additional, interesting, interpretative layer.

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Appendix A – Literature search strategy

I searched Psycinfo (accessed via EBSCOHOST), Cinahl-PLUS (accessed via EBSCOHOST), and Google Scholar, using a combination of different synonyms for 'understandings' (for example "subjective experience", "explanations", "personal accounts", "client attitudes", "comprehension") with different synonyms for distress (for example, "depression", "anxiety", "psychological distress", "mental health").

I also carried out a search using a combination of different synonyms for 'understandings' with different types of therapy (for example, "CBT", "psychotherapy", "systemic therapy").

Given the large number of search results, studies that researched the terms with an adult population, in the UK, using a qualitative methodology, were prioritised. Articles not written in English were excluded.

I followed up on relevant references. Some papers were recommended by colleagues interested in the area.

Appendix B: Interview Schedule

Before therapy

Can you tell me about how things were for you before you came to therapy?

Possible prompts: *What was happening in your life?*
What effect did that have?
What kinds of thoughts were going through your head?

How were you understanding what was happening to you?

Possible prompts: *Tell me more about that*
What helped you to understand?
What explanations did you have for how you were feeling?

What led to you making the decision to come for therapy?

Expectations for therapy

What did you expect, or want from therapy?

Experience of therapy

What was your experience of therapy?

Possible prompts: *Going back to the things that you wanted to talk about in therapy…*
Were you able to? How was that?

How did your therapist understand what was happening for you/your problems?

Possible prompts: *What did your therapist want to talk about? Was it the same thing*
as you wanted to talk about?
How did you understand what was happening in therapy?
Were there times when you understood things in the same way?
Were there times when you understood things in a different way?
Were there things that weren't talked about in therapy that you
would have liked to have talked about?

Thinking about how things were before you came to therapy – are there any differences with how things are now?

Possible prompts: *What helped these changes?*
How important was therapy in this?
Were there other things that were important too?

Closing

Is there anything that we haven't talked about that you think is important?

Appendix C: Recruitment Letter

<u>**INVITATION LETTER:**</u>
<u>**Did psychological therapy take your needs into account?**</u>

I am writing to let you know about some research that is currently taking place at … Talking Therapies. This letter will provide you with the information that you need to consider in deciding whether to take part. I am carrying out the research as part of my Doctorate in Clinical Psychology at the University of East London.

What does taking part involve?
If you choose to take part in the project, this will involve a one-off interview with the researcher once therapy has finished at … Talking Therapies. During this interview you will be asked questions about the reasons that you initially came for therapy. This will include questions about whether your decision was related to your life situation, or whether other factors were involved, and how your experience of therapy fitted with this – was it what you wanted?

The interview will take approximately 1 hour. Taking part is voluntary. Whether you take part or not will not affect your treatment.

What will I get out of taking part?
By taking part, you will be contributing to our understanding of the different factors that can lead to mental health difficulties, and increasing our knowledge of how therapy can account for these. The results of the study will be written up as a report, and fed back to … Talking Therapies and used to ensure that people's experience of therapy is as useful as it can be. It is also intended that the study will be written up written up for a journal to share the findings with other mental health services.

You will also get the chance to reflect on your experience of therapy, and whether it met your needs. You will be given £10 for your participation in the study.

If you are interested in taking part in the study, please complete the response slip contained with this letter. Please hand it to your therapist, or place it in one of the boxes at reception.

Please feel free to contact me to ask me any questions, either by email (u1138153@uel.ac.uk) or telephone (07971390701).

Thank you in anticipation.

Yours sincerely,

Amy Baddeley
Trainee Clinical Psychologist, University of East London
Contact details: Email: u1138153@uel.ac.uk, Telephone number: 07971390701

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor [Sim Roy-Chowdhury] **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)

Response Slip – Please complete and pass back to your therapist, or place in the Response Box at reception

☐   **I agree to be contacted by the researcher, to see if I want to take part in the research.**

My preferred contact details are:

Name:……………………………………………….
Address:……………………………………………
        …………………………………………..
        …………………………………………
Email address:……………………………………….
Telephone number:…………………………………….

Amy Baddeley/Address: … Psychological Therapies Service/Email address: u1138153@uel.ac.uk

Appendix D: UEL Ethical Approval Confirmation

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Kenneth Gannon   **ASSESSOR:** David Kaposi

STUDENT: Amy Baddeley   **DATE (sent to assessor):** 28/05/2013

Proposed research topic: Do People Accessing Psychological Therapy Want it to Take Their Social Context into Account?

Course: Professional Doctorate in Clinical 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? ambiguous (see below)

5. Will participants be adequately debriefed?   YES

6. If this study involves observation does it respect participants' privacy?   NA

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?   / NA

9. If there are inducements to take part in the project is this ethical?   YES / NO / NA

10. If there are any other ethical issues involved, are they a problem?   NA

APPROVED

	YES, PENDING MINOR CONDITIONS	

MINOR CONDITIONS:

As for right of withdrawal, the proposal (as well as the appendix to it) contains two positions on right of withdrawal which are in my opinion contradictory:

"If participants choose to withdraw from the study, their data up until the point of withdrawal will remain in the study."

"My participation is completely voluntary and I am free to withdraw from the study at any point, taking any information I have provided with me"

There are arguments to be made for each but consistency would be desirable.

REASONS FOR NON APPROVAL:

Assessor initials: dk   Date: 13/6/2013

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Kenneth Gannon   **ASSESSOR:** David Kaposi

STUDENT: Amy Baddeley   **DATE (sent to assessor):** 28/05/2013

Proposed research topic: Do People Accessing Psychological Therapy Want it to Take Their Social Context into Account?

Course: Professional Doctorate in Clinical 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:

APPROVED

YES		

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **dk**   Date: 13/6/2013

For the attention of the assessor: Please return the completed checklists by e-mail to
ethics.applications@uel.ac.uk within 1 week.

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.
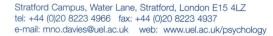
The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward 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

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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

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Appendix E: NHS REC Ethical Approval:

NHS
Health Research Authority
NRES Committee London - Queen Square
HRA Head Office
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2584
Facsimile: 020 7972 2592

30 July 2013

Ms Amy Baddeley
Professional Doctorate in Clinical Psychology - University of East London
Water Lane
London
E15 4LZ

Dear Ms Baddeley

Study title:	**Should psychological therapy take social context into account? Views from users of an IAPT service.**
REC reference:	13/LO/1025
Protocol number:	n/a
IRAS project ID:	129543

The Research Ethics Committee reviewed the above application at the meeting held on 18 July 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Audrey Adams, NRESCommitte.London-QueenSquare@nhs.net

Ethical opinion

The Committee reviewed the above study.

In discussion, the Committee noted the following ethical issues:

- The Committee noted this is a student project for a PhD qualification. The Committee also noted this is a qualitative study using semi structured interviews; questionnaires will be given to be completed at the beginning and end of a therapy session. The applicant aims to recruit via letters, 8 – 10 participants from a clinical setting.

- The Committee noted the interviews will be recorded and will last for 45 – 60 minutes.

- The Committee noted that non English speakers will be excluded from the study.

- The Committee noted there will be a small payment of £10.00 to participants.

- The Committee noted there may be some distress to participants, but also noted that participants will be offered a debriefing session after the interview and that other information will be given for further support.

- The Committee noted the applicant says that information may be stored on a home computer.

- The Committee commented that this is a low risk study that has been well presented.

The Chief Investigator did not attend the review of the application, but was represented by Ms Amy Baddeley, Student on the project.

The Chair introduced the Observers and advised the Researcher of the procedure regarding the Observer's responsibility to maintain the confidentiality of the meeting. The Chair also advised the Researcher that the Observers would leave the meeting if they wished. The Researcher agreed for the Observers to remain in the meeting.

Discussion took place as follows:

- The Researcher gave an overview of the study and informed the Committee that she was training as a Psychologist and had experience of working this this client group.

- The Committee discussed with the Researcher the procedure should a participant become distressed. The Researcher informed the Committee that she has experience of dealing with this situation as she is training to be a clinical Psychologist, but said if a participant was very distress she would refer them on to someone who would be in a position to support the person further.

- The Committee discussed the Information Sheet with the Researcher and recommended some minor changes to the document.

- The Committee advised the Researcher that there was no need for participants to sign a slip stating they do not wish to be part of the study.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee discussed the Researcher's responses further and felt that a Favourable Opinion with Conditions should be given to the study on receipt of the following information been received by the Committee:

    i.   The Committee asks the Researcher to advise them where the interviews will take place.

    ii.   The Committee notes the Researcher will ask participants to sign a slip stating they do not wish to be part of the study and asks that this is removed as they feel this step is unnecessary.

    iii.   The Committee informed the Researcher that the in future she should ensure that the Information Sheet is written in lay terms and should follow the standard Health Research Authority's (HRA) format.   Guidance can be obtained from www.hra.nhs.uk

    iv.   The Committee asks the Researcher to confirm that all information stored on computers comply with the data protection act.

Decision: Favourable Opinion with Conditions

The Committee concluded that a Favourable Opinion with Conditions be given to the study, subject to receipt of further information/clarification set out above.

The REC nominated the Co-ordinator to be the point of contact should further clarification be sought from the application upon receipt of the decision letter.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought

from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Advertisement	1	24 May 2013
Evidence of insurance or indemnity		
Interview Schedules/Topic Guides	1	24 May 2013
Investigator CV	Amy Baddeley	
Letter of invitation to participant	1	24 May 2013
Other: CV: Dr Sim Roy-Chowdhury		
Participant Consent Form	1	24 May 2013
Participant Information Sheet	1	24 May 2013
Protocol	2	25 February 2013
REC application	129543/465874/1/999	13 June 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1025	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Pp
Dr Yogi Amin
Chair

Email: NRESCommitte.London-QueenSquare@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" [SL-AR2]

Copy to: Professor Neville   Punchard

19 August 2013

Ms Amy Baddeley
Professional Doctorate in Clinical Psychology - University of East London
Water Lane
London
E15 4LZ

Dear Ms Baddeley

Study title:	**Should psychological therapy take social context into account? Views from users of an IAPT service.**
REC reference:	**13/LO/1025**
Protocol number:	**n/a**
IRAS project ID:	**129543**

Thank you for your email of 30 July 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 30 July 2013

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		30 July 2013
Letter of invitation to participant	2	02 August 2013
Participant Information Sheet	2	02 August 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Advertisement	1	24 May 2013
Covering Letter		30 July 2013
Evidence of insurance or indemnity		

Interview Schedules/Topic Guides	1	24 May 2013
Investigator CV	Amy Baddeley	
Letter of invitation to participant	2	02 August 2013
Other: CV: Dr Sim Roy-Chowdhury		
Participant Consent Form	1	24 May 2013
Participant Information Sheet	2	02 August 2013
Protocol	2	25 February 2013
REC application	129543/4658 74/1/999	13 June 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/LO/1025	Please quote this number on all correspondence

Yours sincerely

Audrey Adams
Committee Co-ordinator
(pp. Thomas McQuillan)

E-mail: nrescommittee.london-queensquare@nhs.net

Copy to: *Professor Neville Punchard,*

Appendix F: Local Research and Development NHS Ethical Approval

NHS

FINAL R&D APPROVAL

16 September 2013

Dr ██████████████
██████████
█████████████████████
██████████
███████████

Tel: ████████████
Fax: ████████████
Email: Sponsorsrep████████████

Dear Dr. ██████████

Protocol: Should psychological therapy take social context into account? Views from users of an IAPT service.

ReDA Ref: KO1309/1
REC Ref: 13/LO/1025

I am pleased to inform you that the Joint Research Management Office for ████████████████████ and ████████████████████ has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project, on behalf of ████████████████████. Approved study documents are as follows:

Type	Version	Date
REC approval		30.07.2013
Protocol	v.2	25.02.2013
Participant Information Sheet	v.2	02.08.2013
Participant Consent Form	v.1	24.05.2013
Letter of Invitation to Participant	v.2	02.08.2013
Interview Schedule/Topic Guide	v.1	24.05.2013
Advertisement	v.1	24.05.2013

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, or the BH and QMUL policies that reinforce them, you can obtain details from the Joint Research Management Office or go to:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

You must stay in touch with the Joint Research Management Office during the course of the research project, in particular:
* If there is a change of Principal Investigator
* When the project finishes
* If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any Serious Adverse Events (SAEs) or untoward events occur it is **essential** that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the Risk Management Unit on 020 7480 4718.

We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Yours sincerely

Gerry Leonard, Head of Research Resources

Copy to: Sponsor – UEL

Appendix G: Consent form

Consent form

Did psychological therapy take your needs into account?

If I decide to take part in this study, all of the information I provide will be treated in strict confidence. My participation is completely voluntary and I am free to withdraw from the study at any point, taking any information I have provided with me. Please sign below to confirm you understand and consent to the following:

I have the read the information sheet relating to the above research study and ☐

have been given a copy to keep ☐

The research has been explained to me, and I have had the opportunity to ask questions

I understand that my involvement in this study, and the information from my interview, will remain strictly confidential. Only the researcher involved in the study will have access to any data that identifies me (this consent form, my contact details & the demographic information I provide) ☐

I understand that I can leave the study at any time. If I choose to withdraw, the information that I have given up until this point will remain in the study ☐

I give permission for my interview to be audio-recorded and typed up afterwards. I understand that my name will be deleted from the typed up version. ☐

I understand that anonymised quotes from my interview may be used in the ☐

write-up of the research. ☐

I consent for the researcher to contact me with the initial results from the research, so I can comment on the themes generated if I wish to

I hereby freely and fully consent to participate in the study. ☐

Participant's Name (BLOCK CAPITALS)   Participant's Signature

……………………………………………   …………………………………………….

Researcher's Name (BLOCK CAPITALS)   Researcher's Signature

……………………………………………   …………………………………………….

Date: ……………………..…….

Appendix H: Participant Information Sheet

<u>**PARTICIPANT INFORMATION SHEET:**</u>
<u>**Did psychological therapy take your needs into account?**</u>

The above research project is currently taking place in … Talking Therapies. This sheet will provide you with the information that you need to consider in deciding whether to take part. I am carrying out the research as part of my Doctorate in Clinical Psychology at the University of East London.

Purpose of the Study
We aim to look at the reasons that people seek talking therapies and how they explain these reasons to themselves. We also aim to look at how your experience of therapy fitted with these reasons, and whether there were other issues that you would have like to have talked about too.

Why have I been invited?
You have been invited because you have recently taken part in talking therapies at … Talking Therapies. We are inviting all individuals who have received either Cognitive Behavioural Therapy (CBT), Dynamic Interpersonal Therapy (DIT), Interpersonal Therapy (IPT), or Multi-Modal Therapy at High Intensity level. We are hoping that between 8-10 people will take part in this study.

Do I have to take part?
It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Whether you take part or not will not affect your treatment.

What does taking part involve?
If you choose to take part in the project, this will involve a one-off interview with me once therapy has finished at … Talking Therapies. At the beginning of this interview, I will ask you for some brief information about your therapy (what type of therapy you received, how long it was for, when it finished) and will ask for some brief details about you (for example, your age, ethnicity). During the interview itself you will be asked questions about the reasons that you initially came for therapy. You will also be asked about your experience of therapy in meeting your needs.

The interview will take approximately 1 hour, and will be voice recorded.

What are the benefits of taking part?
You will be contributing to our understanding of the different reasons people experience mental health difficulties, and increasing our knowledge of how therapy can help.
The results of the study will be written up as a report, and fed back to … Talking Therapies and used to ensure that people's experience of therapy is as useful as it can

be. It is also planned that the study will be written up written up for a journal to share the findings with other mental health services.

You will also get the chance to reflect on your experience of therapy, and whether it met your needs.

You will be given £10 for your participation in the study.

Are there any disadvantages of taking part?
It is possible that talking about these issues may bring up different emotions in different people. If you do find that difficult issues are brought up for you, time will be given after the interview to talk about things, and organisations that are able to support you will be discussed.

What happens after I take part?
I will analyse the data and produce a set of themes. You will be invited to comment on these themes. If you are willing to do this, I will send a short document to you (1-2 sides of A4) outlining the themes and ask for any comments that you might have on them. The information that is generated from this research will be written up in a report, which will be submitted as a Doctoral Thesis. It will also be presented to … Talking Therapies. Any information you give will be anonymised. This means that any information that could identify you (such as names, or places) will be taken out.

What happens if I want to stop taking part?
If at any point before, during or after the interview you wish to stop taking part from the study for any reason, then you are allowed to do so, without having to give a reason. The information that you have given up until this point will remain in the study.

Confidentiality
All the information that you provide in the interview will be kept strictly confidential. Upon entering the study, you will be given a code. This code will be kept in a locked cabinet with your consent form and contact details. Only the researcher will have access to this cabinet. Your confidentiality would only be broken if the researcher had significant concern about your safety, or the safety of other people. They would try to speak to you about this first.

What will happen to the information I give?
Recordings of your interview will be kept on a voice recorder and transferred to a password-protected computer the same day as the interview. I will then transcribe (write out) the interviews. You will be given a different name in the written out version. Any information that could identify you (such as names or places) will be anonymised. Only myself, the study supervisor, and study examiners will have access to the transcripts. After the study has finished, all audio files will be erased. Your anonymised transcript may be kept for further research.

Do I need to tell my GP/Doctor that I am taking part?
It is up to you whether or not you tell your GP that you are taking part.

Contact information
If you wish to get in contact with me at any point, please use the following contact details:

Name: Amy Baddeley
Telephone: 07971390701
Email Address – u1138153@uel.ac.uk

What should I do if I have a concern about the way the study is being conducted?
If you have a concern about any aspect of this study, I will do my best to answer your questions. Alternatively, please contact the study's supervisor [Sim Roy-Chowdhury] **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)

Appendix I: Extract from reflective diary

My first impressions were of Debbie being very composed, and smiley. She made jokes on the way up to the interview room, seeming confident. I noticed she was reading a letter from her therapist in reception before we went in to the interview. As soon as we started talking, she said she could read it out to me. I said that was one option, but I'd be really keen to hear how things were in her words, and I had some questions in mind. As we started talking about the interview, and how it would work, Debbie said she was concerned she wouldn't be answering the questions 'right'. I reassured her that I was interested in her understandings and experiences, and there was no right or wrong.

Debbie seemed to be tentative around going further into describing how she had been 'struggling' – I needed to check I had her permission to ask her about that. I wondered how she found it to share those times with me. I was struck by the depth of the system of thought she had created, and wondered whether talking about it with others was a challenge - Debbie often giggled while talking about what sounded like extremely distressing experiences, such as when talking about her fears about her children dying. It felt as though there was a temperature change part way through the interview, and her story felt more detached - perhaps coinciding with when we started talking about her second set of therapy sessions? I wondered if this reflected her relationship with her second therapist.

I felt the need to reassure Debbie at several points during the interview – around her worry she was slipping in to metaphor, and after the interview that her conversations would be useful for my research.

I was particularly aware of the power imbalance in our researcher-interviewee partnership following this interview – Debbie commented that she felt 'goofy' for telling me so much about herself. I thought about how much she had shared, when we had only met for an hour and a half – and considered how this might feel different in clinical work, when you meet more than once, and form a therapeutic relationship. I noticed the difference between research and clinical work particularly during Debbie's interview.

Appendix J: Transcription Key

[pause]   Denotes pause in speech of longer than 2 seconds

[non-verbal]   Denotes non-verbal utterances/actions such as laughter/clearing throat

[inaudible]   Inaudible section of transcript

<speech>   Brief interjection by other speaker

[…]   Denotes words that have been cut out to ensure that excerpts are concise and clear. Care has been taken not to alter participants' intended meaning in any way.

Appendix K: Extract of Analysed Transcript (Debbie)

EMERGING THEMES	TRANSCRIPT	EXPLORATORY NOTES

1. Amy: So to begin with, would you mind just telling me a bit
2. about what was happening for you before you came to
3. talking therapies?
4.
5. Debbie: Yeah. Um first of all, I think that I'd had mental
6. health problems since probably the age of seven, eight. And
7. um *[pause]* I didn't recognise them as that all of that time. I
8. knew that I was like really struggling and er had various
9. different sort of episodes in my life, um of kind of like total
10. sort of mental and physical collapse. Um. I had managed to
11. get myself into a really nice situation, so I had um two young
12. children, and a lovely partner, and a lovely house, and um I
13. was really where I wanted to be. But um um I think having
14. my children had set off a really bad um episode for me. So I
15. was really really struggling. <Amy: OK.> I had a GP um and
16. really luckily, what happened is I changed GPs, and my old
17. GP, I think I kept trying to tell her um you know but she just
18. wasn't willing to hear the message at all. And she wasn't
19. really willing to sort of like um she was quite sort of
20. combative and er defensive. You know so one thing she said
21. was um, I'm not here to make you feel better. <Amy: Right.>
22. *[Laughs]* OK, I see. But then I got a new GP and um *[clears*
23. *throat]* what I would do was like present all the time with lots
24. of different worries and lots of ailments and that kind of thing
25. and then eventually one day I just said I'm really struggling,
26. I'm really miserable. Um, and that was just amazing,
27. because after twenty years, she just took it seriously which
28. was just um incredible. And really shocking, because um I
29. grew up in a sort of family culture of just sort of you know,
30. chin in chest out. <Amy: Right.> Um you know, just pull your
31. socks up. So er just for somebody to even call it something,
32. and name it and take it seriously, and think that it was
33. something that they should take time exploring, was just that
34. was really the beginning. Yeah. Um.
35.
36. Amy: And would you mind telling me a bit more about what
37. was happen –

Emerging themes (left margin, handwritten):
- understanding comes later
- contrast of situation with how felt – inner turmoil; outer world?
- having children a trigger
- other people don't want to hear about my children
- power of someone listening
- lack of understanding in family
- importance of struggle being named

Exploratory notes (right margin, handwritten):
- How defined? Would someone else have had to tell her? Bias at onset age?
- understanding comes late
- sense that Debbie is properly happening to something that – what it is is serious – is this hard for her to speak about?
- contrast of 'lovely' picture of life with internal world – is it 'ok' for Debbie to feel like this – does she feel she deserves it?
- understanding of children as trigger?
- difficulty being heard by GP – how do others understand Debbie's distress?
- GP role – what are they there for?
- is laughter a defence / show it's something she doesn't believe in?
- how was Debbie understanding what was happening at the time? Others felt physically
- gravity of being understood after so long
- Shock / surprise at self then seriously taken and very metaphorical 'British stiff upper lip'
- naming, taking time mattering??
- mattering??

1

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38
39 Debbie: How I was struggling
40
41 Amy: Would that be OK, if you feel OK to do that
42
43 Debbie: Yeah no that's fine. It's um, it's really – actually it's
44 quite difficult, it's not fine, it's quite difficult to talk about
45 because I was really shocked, now I've sort of come out of it
46 a bit, I was shocked at how ill I was. Um. So I had um
47 [pause] they call it OCD, I don't - I'm still a little weerrr
48 uncomfortable with the label [laughs]. But um er I had this
49 sort of system of thought which had grown up to explain my
50 circumstances when I was a child. And um it had, I was just,
51 it had just got the point where it was so all-consuming that I
52 was just feeding it, and I was really losing touch with um
53 reality and what was happening in the world. Um and I was
54 spending more and more time in my own head, trying to
55 keep everything together. Um. I felt like it was my
56 responsibility to keep everything um together. And um but –
57 strangely kind of at the same time, really sort of um [pause]
58 you know it had really beautiful architecture this system of
59 thought because um, it just could hegemonise anything into
60 it, so any counter-example, <Amy: Right.> would just be
61 drawn in. So at the same time as having to protect
62 everybody, I was actually a threat to them as well, because I
63 felt like I was rotten and I was exuding this sort of rot and
64 decay and um. So I just you know so it's like the Freudian
65 thing of the pain being inside you and you're just building a
66 bigger and bigger shell but actually you're just trapping it
67 inside so um. So it was just it was like an arms race really,
68 and how it was working out with my children was um, um
69 [pause] I whenever I closed my eyes I could see them
70 [pause] like saw my son all the time, dead under the water in
71 the bath. And um. So I couldn't bathe him for like the first
72 year of his life, I couldn't his dad had to bathe him. And
73 whenever they weren't physically right next to me um I could
74 hear them screaming. And um so I couldn't be in another

2

Handwritten margin notes (left):
- conflict in talking
- their label vs my label
- pervasiveness of "system of thought"
- my world vs. the real world
- (surprise?) beauty / appeal of system of thought
- power of that system of thought
- self as rotten / needing to be enclosed
- theory-based understanding
- visceral experience of distress - seeing children dead
- effects on the people around me

Handwritten margin notes (right):
- Debbie's choice of word - jumps in with it - pre-empty me noting?
- complicated feelings about talking
- shock at earlier "illness"
- their name for it isn't the same as mine
- Debbie's personal explanation: a "system of thought" - been a part of her life for some time
- sounds pervasive, also "living" - needing to "feed it"
- separation from reality
- was Debbie thinking about theme today too?
- beauty of this system - yet also painful - complicated feelings about it?
- "strange" that it could be beautiful; others' expectations?
- responsibility - complicated self - protecting / a threat
- rot & decay vs. "beautiful" system of thought
- system = seductive, Debbie = decay
- psychoanalytic understanding
- brittle imagery
- "um" & pauses - this is very hard for Debbie to say
- effects of system of thought
- sounds incredibly difficult/distressing...

Appendix L: Picture to show one cluster of emerging themes for one participant

Saying good bye (to the "system of thought") is terrifying

Finding a community to support the "obsessive behaviour"

Own (changing) identity

"System of thought" as a part of me

Pervasiveness of behaviour ~ became a part...

Therapy as exposing – left without "edifice"

Starting again after therapy "like a newborn"

"Obsessive behaviour" like a biological necessity – dropping down like dieting

Re-learning the basics after therapy

"System of thought" shaped my identify

Losing the "system of thought" leads to existential crisis

Therapy changed my identity (changes in identity post-therapy?)

Being "found out" is terrifying – clutching onto internal world

Therapy as a process of "coming out of the mental health closet"

Self as different form the problem

Reactions of others to the new me

Change in identity

Appendix M: Mind-map of all emerging themes for one participant

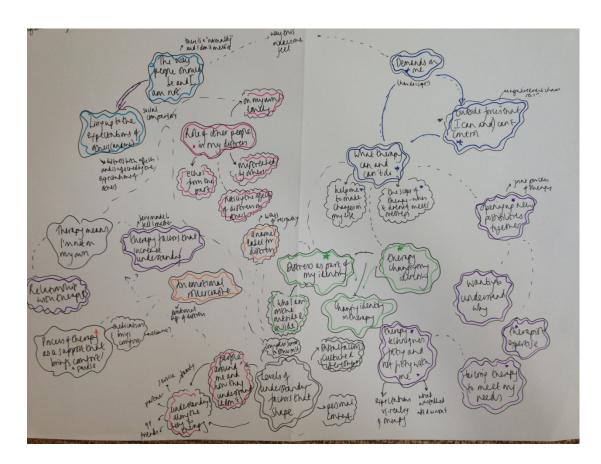**Appendix N: Extract from table of emerging themes for one participant**

| Cluster	Theme	Line	Quote
Own (Changing) Identity	"System of thought" as a part of me	624-627	I really felt like that, I really felt like, if you take this out of me, what's left of me. I was worried how much of my personality was based on it. How much of my likes and dislikes. How much of everything
	Pervasiveness of behaviour	466-468	all the behaviours had morphed a lot over time, and they'd attached themselves, as they would, to different situations in my life
	"System of thought" shaped my identify	630-634	a group of friends, and I think probably from my twenties really, um were always quite sort of exhiliarated by how negatively I saw things and how kind of like, they thought it was kind of like I was kind of like some sort of urban existential warrior
	Therapy as changing identity	641-643	Because you don't go into this big spiel about you know, sleeps the cousin of death and we're all just er living till we die and all that
		647-649	I think all of, I mean all of it in terms of sort of like [clears throat] if you take this away, what will be left?
	Therapy as a process of "coming out of the mental health closet"	1182-1183	because if you've, sort of come out of the mental health closet
	Reactions of others to the new me	639-641	then they'd sort of ring up, after I'd sort of like started therapy, they'd ring up you know how are you, oh you know I'm happy, they'd be disappointed.
	Exposing nature of therapy	899-902	And um. I feel as well, really kind of naked and exposed at the moment, because I haven't, I've torn down this massive edifice, um.
	Starting again after therapy	649-650	And I did feel, in that period of therapy in particular, like a newborn
		650-654	Like I had to decide whether I liked tea or coffee in the morning, and I had to decide how I liked my eggs, and I had to decide what music I liked, I kind of just had to re – just go right back to the beginning and kind of re-think everything.
	Losing the "system of thought" leads to existential crisis	574-578	Are we all just little combinations of atoms, just trying to get through. Like where's the system here? And it was just you know really terrifying, like some sort of existential werrrrr, so I was just like who's in charge, who's in charge?
	Being "found out" is terrifying – clutching	176-177	So I actually lived in terror of being found out.
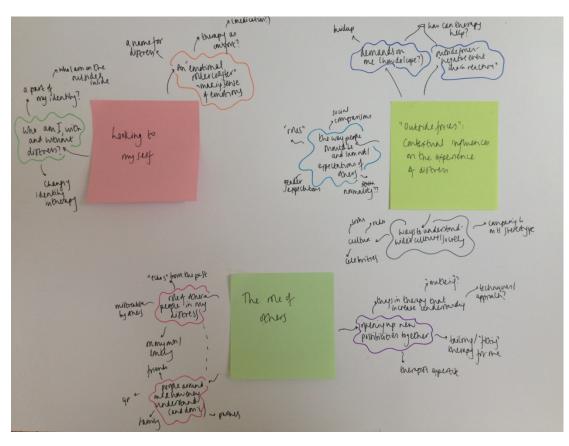
	onto internal world		
	Self as different form the problem	903-915	And just sort of like, again, just knowing what's you and what's it, and er we did the big I little I
	Change in identity from pre-therapy	955-958	I had a horror of that. I just thought that would be just ridiculous, and so uncool, and not stylish, and not clever, and like being miserable was so clever.
	Change in identity	971-973	Yeah, I think it's a matter of changing your aesthetic as well, isn't it. And sort of like the aesthetic of the broken and the ugly, and the, you know.
Identity of distress	OCD is one of many identities	712-715	Yeah but also you can pick any number of labels, and I think that a lot of people pick one label and then they're just like OK, I am an attachment parent, or I home-school, or I'm a vegetarian, or I'm a vegan, or I'm a runner, or I'm a cyclist, or I've got OCD
	Rejection of the "OCD" label	666-669	No I mean I totally rejected the OCD thing, I think for a long time. Because I don't have any, I was just like why is my house not tidy. [Laughs.] Why is my house not beautifully clean.
	Uncomfortable with their label	47-48	I'm still a little weerrr uncomfortable with the label [laughs]
	Their label vs. My label	47	[pause] they call it OCD, I don't
	"OCD" label vs own experiences	670-674	like I think that the popular perception of OCD is to do with the tidying and the cleaning and the checking the cats and that kind of thing, so because I didn't fit into that, um I had a really sort of baroque version
	I don't want to pick a label	716-717	You don't have to, I don't feel comfortable picking one.
	Labels don't have to be pathologising in themselves	721-723	Yeah exactly everybody belongs to all of them, but some people just go right down the road of one. And um, I'm not comfortable with that
	Visceral experience of distress	69-70	[pause] like saw my son all the time, dead under the water in the bath

Appendix O: Picture showing an example of clustered emerging themes across all participants

Appendix P: Initial mindmap of clustered emerging themes across all participants

Appendix Q: Final mindmap of super-ordinate themes and sub-themes

Appendix R: Letter to show confirmation of title change

UEL
University of
East London

Amy Baddeley
108 Choumert Road
London
SE15 4AA

14 March 2014

Student number: 1138153

Dear Amy

<u>Notification of a Change of Thesis Title:</u>

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Both the old and new thesis titles are set out below:

Old thesis title: Do people accessing psychological therapy want it to take their social context into account?

New thesis title: Experience of distress and use of psychological therapy: Perspectives from users of an IAPT service.

Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

James J. Walsh.

Dr James J Walsh