

**Service Users' Conceptualisations of
Compassionate Care in an Improving Access to
Psychological Therapies Service: A Grounded
Theory Study**

Claudia Alonso Soriano

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ABSTRACT

Background

The clinical relevance of compassionate care is now widely accepted and is currently one of the most cited requirements for best practice in guidelines and policies. The latest Improving Access to Psychological (IAPT) Services manual states that effective and efficient approaches should be balanced with compassionate care (NHS England, 2019). However, despite its current centrality, the concept lacks a consensual definition and a framework for practice in this context.

Aim

Knowledge of relational aspects, such as compassion, is best elicited by exploring individual experiences and perceptions (Robert et al., 2011). Therefore, an empirical understanding of compassionate care in IAPT based on the perspective of service users, the recipients of compassionate care, is essential. To the day, there is limited research investigating service users' conceptualisations of compassionate care, and studies have generally been based in physical healthcare settings, arising questions regarding the generalisability of the findings to an IAPT service.

To address the identified gap in the literature, this study will investigate service users' understandings and experiences of compassionate care in an IAPT service.

Method

This grounded theory (GT) study used semi-structured interviews to investigate how service users understand and experience compassionate care in an IAPT service. Thirteen people who used or had used an IAPT service were interviewed. Drawing from the constructivist GT guidelines of Charmaz (2014), the analysis process was iterative in nature, occurring simultaneously with data collection, using methods of transcription, systematic coding, memo writing and diagramming.

Findings

The analysis yielded five categories, each containing specific themes. Together, they constitute the grounded theory model 'Humanising Responses to Distress'. This is the first empirically based model of compassionate care in a psychological therapies service in the

UK. The model defines compassion as a humanising response to distress. This response involves striving to understand the individual experience, acting to meet the person's needs, empowering the person and creating a secure relationship with them.

Conclusions

The components of the compassion model provide insight into how service users understand and experience compassionate care in IAPT. The model highlights the importance of prioritising individualised, relational and empowering approaches over rigid and prescriptive interventions that are not tailored to service users' needs and preferences. Therefore, the current emphasis on standardised approaches and outcome measures may have a negative impact on compassionate care in IAPT as defined by service users.

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1. INTRODUCTION

1.1. Overview

Compassionate care is currently one of the most referenced requirements in service guidelines and policies. The latest Improving Access to Psychological Therapies (IAPT) manual states that effective service delivery should be balanced with compassionate care (NHS England, 2019). However, despite its centrality, an empirical understanding of this concept from the perspective of service users of IAPT services is lacking.

This chapter will review relevant literature in order to contextualise the use of the concept of compassionate care in services and policies. Studies on the topic will be critically reviewed and evaluated, with a particular focus on research investigating clinicians and service users' experiences and perceptions. The relevance of this topic in the context of IAPT services will also be illustrated. Finally, the rationale and aims of the study will be presented.

1.2. Literature Review Method

A thorough review of the literature was conducted by using a number of search strategies, in line with Booth, Sutton, and Papaioannou's (2016) recommendations. An initial review of the literature using the search terms "compassion" or "compassionate care" and "Improving Access to Psychological Therapies" or "IAPT" yielded no relevant articles. In order to identify relevant papers, a systematic database search was then conducted reviewing research within related contexts (i.e. health and mental health services). The search was conducted using PsycINFO, Academic Search Complete, CINAHL Plus and Scopus. The combinations of search terms used, and a flow diagram of the literature process are presented in Appendix A. Further searches of the grey literature were carried out using Google Scholar. All databases were searched for the period 2009-2019. References cited within relevant articles were also reviewed to locate pertinent publications not brought up by the searches. This allowed the identification of significant historical literature while also ensuring that current literature formed the focus of the search. The latter was considered important as the compassionate care agenda has become particularly

prominent in the last decade (Department of Health [DoH], 2015; Perry, Palmer, Thompson, Worrall, & Chaplin, 2017). Due to resource limitations, the search was restricted to those publications written in English.

1.3. Compassionate Care in the NHS and Policy Context

The emphasis on compassionate care appears to have been precipitated by an increase in healthcare scandals involving cases of below-standard care and breaches of safety (Duffield et al., 2011; UNISON, 2013). Here the Mid-Staffordshire case is particularly relevant due to its resulting in highly influential public inquiries that evidenced and condemned appalling incidents of suffering by large numbers of patients (Francis, 2010, 2013). A detrimental culture of fear, which had triggered many institutional failures, was also exposed. In particular, healthcare leaders' preoccupation with narrow organisational targets and their use of pace-setting styles were roundly criticised (NHS England, 2014).

The notion of 'McDonaldisation' was coined by Ritzer (1996) to describe an increasingly widespread form of rationalising organisations characterised by a focus on predictability and calculability. These principles were considered to enter the NHS in the form of new public management (NPM). The NPM approach promoted a series of reforms to the public sector involving the application of market mechanisms and an increase emphasis on efficacy and efficiency (Hood, 1995). Compassion scholars suggest that these reforms have led to caring interactions being compromised in favour of performance targets, economy and measurement (Fotaki, 2015; Mannion, 2014). These arguments are now supported by research showing that an over emphasis on productivity can undermine compassionate care in healthcare (Sinclair et al., 2016). Consequently, the 'compassion agenda' appears to be a response to an accumulated dissatisfaction with the increasingly dominant target culture, and a desire for more value-based approaches (Pollitt & Bouckaert, 2017).

Within the NHS, the need for compassionate care has now become somewhat of a catchphrase (De Zulueta, 2013). Numerous policies and training schemes promoting compassionate care have been developed (DoH, 2012). Compassion has also been identified as one of the six values in the NHS Constitution (DoH, 2015b) and, as such, it is considered a behaviour to be demonstrated by all staff (Willis, 2015). This

constitutional value is reiterated in the government response to the Mid-Staffordshire Inquiry: “Compassion. We respond with humanity and kindness to each person’s pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering” (DoH, 2013, p.9). This statement, based on the perspectives of patients, public and staff, suggests the need to identify suffering and take action to alleviate it. However, it fails to specifically expound what compassion involves.

Despite its current centrality, the concept of compassionate care lacks a clear and consensual definition and framework for teaching and implementation (Dewar, Adamson, Smith, Surfleet, & King, 2014). Instead, it has been defined in several ways to address specific problems. In the ‘Compassion in Practice’ strategy, for example, it includes everything from communication to courage (DoH, 2012). In other policies, it has been described as distinct values or personality characteristics that healthcare staff must possess (DoH, 2014).

The lack of coherence raises challenges for clinicians who have manifested anger and resistance towards policies and strategies, identifying them as top-down initiatives which do not sufficiently articulate a clear vision of the practices and behaviours they should be aiming towards (O’Driscoll, Allan, Liu, Corbett, & Serrant, 2018). Moreover, policy documents presenting compassionate care as a solution have been criticised as simplistic and misleading for failing to recognise the resources and energy required for its delivery (O’Driscoll et al., 2018). Although initially intended for nurses and care staff, the compassion agenda is now directed at all NHS staff regardless of their role (DoH, 2012). However, Pedersen & Obling (2019) argue that the call for compassion as a meta-virtue across services and roles introduces abstract notions that are not tailored to the specific skills, relationships and tasks.

1.4. Conceptualisations of Compassion

Understanding compassion is complex due to its subjective and unique nature (Harrison, 2009). Attempts to conceptualise the term have come from a range of disciplines and often integrate knowledge from religion, biology, neuroscience, psychology and evolutionary research (Gilbert, 2005). While there are some recurring elements present across definitions, the exact meaning of compassion is

invariably shaped and influenced by the context in which it is situated (Davison & Williams, 2009).

1.4.1. Etymology of Compassion

The Latin root of compassion ('pati') is one that is common with the term 'patient' and means 'to suffer'. The prefix, com-, means 'with', creating the meaning of compassion 'to suffer together with' (Simpson & Wiener, 1989).

From an evolutionary perspective, researchers believe that being compassionate became desirable and advantageous as it promoted care taking towards those that need it, such as children or those who are ill. This contributed to the survival of the human species (Ekman, 2010; Goetz, Keltner, & Simon-Thomas, 2010). Historical data indicate that the construct of compassion has been deliberated on throughout history and can be traced back to the contemplations of Aristotle (van der Cingel, 2014). Early work was mostly conducted in a religious context. Compassion is seen as a fundamental aspect of Buddhism, Christianity and Islam (Welford, 2012). Across religions, compassion seems to involve openness and empathy for one's own or others' suffering, combined with a commitment to relieve that suffering (Welford, 2012).

1.4.2. Compassion in Healthcare

Originally, caring for those in poor health resulted from religiously driven motivations in a time where the provision of care was dominated by the Church (Shelly & Miller, 2009). As medicine progressed, the emerging emphasis on technical skills started to challenge traditional theological ideas of compassion (Aita, 2000; Cornwell & Goodrich, 2009).

1.4.3. Theoretical Conceptualisations of Compassion

More recently, compassion has been studied from a range of perspectives including health, psychology, education, and policy. A summary of the most recurrent conceptualisations in the literature is presented below.

1.4.3.1. *Compassion as an emotional and behavioural response to suffering*

While there is not a consensus regarding the definition of compassion, two elements, a recognition of another's suffering and the motivation to alleviate it, are common threads (Chochinov, 2007; Gilbert, 2009). While empathy is regarded as a component

of compassion, allowing the connection to others' experience of suffering, empathy does not involve the motivation and action to relieve that suffering (Von Dietze & Orb, 2000).

The motivational aspect of compassion is highlighted by Gilbert (2014), who refers to compassion as “sensitivity to suffering in self and others with a motivation and commitment to relieve it” (p.19). Within Gilbert’s definition compassion is conceptualised as ‘flowing’ in three directions: towards the self, towards others and from others (Gilbert, 2005). Gilbert (2009) highlights that humans require the care and protection of others in order to survive and thrive. Simplifying research in neuroscience, he developed a theory of compassion involving the interaction of three emotion regulation systems (Figure 1).

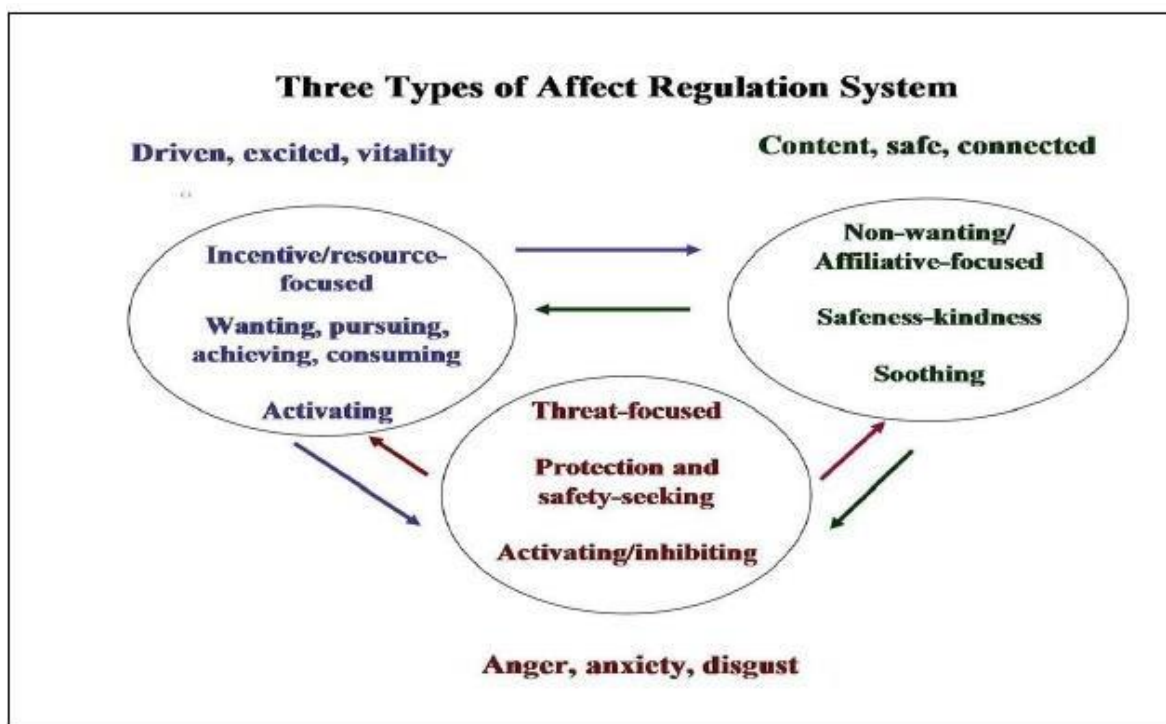


Figure 1. From Gilbert, *Compassion: Conceptualisations, research and use in psychotherapy* (2005). Source: <http://compassionatemind.co.uk/>

The threat system facilitates self-protection by creating defensive emotions, such as fear, anger and shame as well as defending behavioural responses (e.g. fight, flight freeze). The drive system creates feelings of excitement and pleasure which motivate people to seek out goals and resources (e.g. money, friendship). Finally, the soothing system relates to feelings of attachment and safeness. It allows

individuals to connect socially and also has a role in soothing distress. Compassion is considered to be encapsulated in the soothing system as it provides nurturance and protection and creates feelings of acceptance and belonging (Gilbert, 2010).

Jull (2001) also highlighted the existential nature of compassion, considering it to be founded on the identified condition of human connectedness by which suffering is ready to be perceived and alleviated by others. He suggested that this process requires full attentiveness to the other and a readiness to connect with their feelings.

All these definitions convey the sense that compassion involves recognition of suffering and emotional resonance as well as motivation or action to try to alleviate that suffering.

1.4.3.2. *Compassion as a moral virtue*

For some authors compassion is not just spontaneous sentiment and action, but involves a rational and moral dimension (Gelhaus, 2012; Von Dietze & Orb, 2000). Von Dietze and Orb (2000) posit that at the core of compassion is the notion of deliberate altruistic participation in another's suffering. Intrinsically, then, compassion requires understanding and making decisions (Von Dietze & Orb, 2000). While clinicians may struggle to create emotional responses at will, Gelhaus (2012) emphasises there can be a duty to cultivate certain moral attitudes which can then guide clinicians' decision-making process. Bradshaw (2009) related this perspective by considering care as a practice so that compassion is not merely an event of subjective emotion, it is a whole praxis, "a virtue to be cultivated" (p. 466). Therefore, the volitional dimension to compassion is emphasised, locating it above behaviours out of mere duty, in 'a moral order' of choice (Van Der Cingel, 2009). Compassion is, therefore, considered to be a virtue based on a universal regard for, and solidarity with, all human beings (Burnell, 2009; Gelhaus, 2012).

1.4.3.3. *Compassionate care as relationship and person-centred care*

Compassion relies on the idea that all human beings are sentient and possibly suffering beings (Neff, 2003; Strauss et al., 2016). Such suffering needs to be supported through interactions that promote a sense of safety, belonging and significance (Nolan, Davies, Brown, Keady, & Nolan, 2004). In line with this,

some authors describe compassion in healthcare as the process whereby meaningful relationships are formed between clinicians and patients (McCormack & McCance, 2011; Nolan et al., 2004). Within these relationships, clinicians recognise and respect the person and their individuality, positioning them at the centre of care (Cornwell & Goodrich, 2009).

1.4.3.4. *Compassionate care as a systemic concept*

While the majority of literature focuses on individual clinicians, propose a transactional model (Figure 2) which sees compassion as being influenced by the complex interplay between clinician, physician, patient and family, and environmental and institutional factors. Thus, to ensure that physicians can provide compassionate care, the focus should not be only on their personality attributes, knowledge or skills, but also on the environmental and organisational processes.

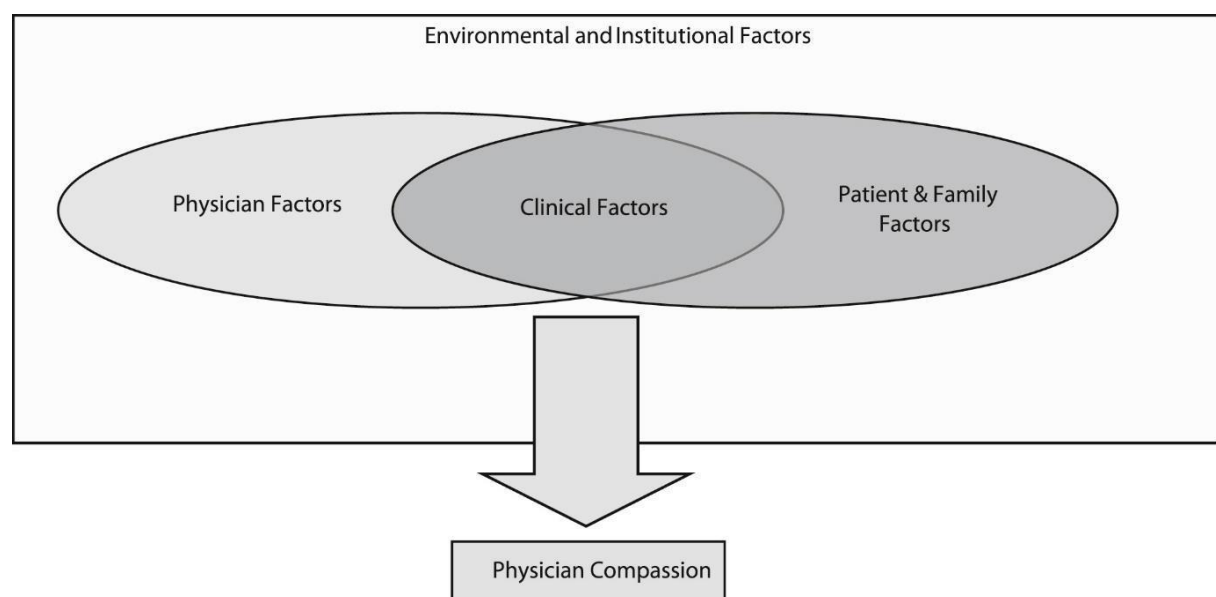


Figure 2. The transactional model of physician compassion (Fernando & Consedine, 2014).

1.5. Empirical Research

A variety of empirical research has been conducted to explore both clinicians' and service users' perceptions of compassion. According to systematic reviews (e.g. Durkin, Usher, & Jackson, 2019; Sinclair et al., 2016), most empirical studies have been published in the last 10 years, coinciding with the increased emphasis on compassion in policy developments.

1.5.1. Clinicians' Conceptualisations of Compassionate Care

In an early study investigating psychiatric nurses' understandings of ethics (Armstrong, Parsons, & Barker, 2000), researchers found sixteen different meanings in nurses' conceptualisations of compassion. This research pointed out at the phenomenological complexity of the concept, anticipating some of the emergent dilemmas in more current literature.

Clinicians in Bray, O'Brien, Kirton, Zubairu, & Christiansen's (2014) and Day's (2015) studies identified compassion to be dependent on certain qualities, such as warmth, empathy and kindness. Respect for patients' individuality (Bray et al., 2014; Kvangarsnes, Torheim, Hole, & Crawford, 2013) and effective and trusting relationships (Christiansen, O'Brien, Kirton, Zubairu, & Bray, 2015; Kvangarsnes et al., 2013) were also identified as key aspects in clinicians' definitions of compassion. An integration of these features was found in a Canadian grounded theory study where healthcare providers conceptualised compassion as a virtuous response to know someone, to discern their needs and alleviate their suffering "through relational understanding and action" (Sinclair, Hack, et al., 2018, p.195). This conceptualisation was illustrated in the 'Healthcare Provider Compassion Model' which was found to be congruent with a 'Patient Compassion Model' developed previously (Sinclair, McClement, et al., 2016). Follow-up research also confirmed the credibility and transferability of the model within palliative care (Sinclair, Jaggi, et al., 2018).

Attending to the 'small actions' that could help patients feel cared for is also included in Christiansen et al.'s (2015) conceptualisation of compassion based on understandings of a range of health professionals. The idea of compassion as involving attending to 'the little things' also emerged as a theme in a study exploring conversations in Schwartz Rounds in a range of health settings (Goodrich, 2016). In contrast, clinicians in some studies described compassionate care as occurring at a systemic and organisational level. For example, in Horsburgh and Ross (2013), nurses indicated a tension between 'agency' and physical, social, managerial and cultural 'structure'. Consistent with this, a study involving clinicians working with diabetic patients (Tierney, Seers, Tutton, & Reeve, 2017), revealed a model of compassionate care based on the notion of flow. The compassionate care flow

could be boosted by defenders (e.g. supportive leadership) or depleted by drainers (e.g. high or excessive workloads).

In the mental health sector, there are also differences in staff's conceptualisations, with some describing compassion as something intensely practical (Brown, Crawford, Gilbert, Gilbert, & Gale, 2014) and others as an emotional response or a driving force underpinning a relationship (Barron, Deery, & Sloan, 2017). The role of systemic and organisational processes in the provision of compassion in mental health care has also been highlighted in empirical studies. When asked explicitly about the meaning of compassion in mental health care, practitioners in acute mental health units talked about concerns related to targets and managerial processes. Crawford et al. (2013) concluded that a 'production-line mentality' was interrupting or blocking compassionate care. While findings from these studies have implications for the conceptualisation of compassion in mental health care, the sample sizes were small, and participant self-selection biases may have affected the research.

Only one study, conducted in a private practice in the USA, explored psychotherapists' perspectives (Vivino, Thompson, Hill, & Ladany, 2009). In this study, compassion in psychotherapy was described by therapists, nominated by colleagues as compassionate, as relating to the client's suffering and fostering change through action. They considered that compassion helped clients feel understood, and relieved symptoms. However, these findings were limited to the sample of nominated therapists who were mostly female, European-American and psychodynamic and humanistic in orientation. Therefore, the findings may have been skewed, as other groups may have different understandings. Moreover, while compassion was only examined in long-term therapy, it may be perceived differently in brief or more focused therapy.

1.5.2. Collective Conceptualisations

Some of the empirical studies simultaneously explored professional and patient perspectives of compassionate care, leading to collective definitions which blend all the perceptions into one single representation. Highlighting the complexity of this notion, these conceptualisations often resulted in multi-dimensional and dynamic composites including a range of virtues, skills, and behaviours (Dewar & Nolan,

2013; Kneafsey, Brown, Sein, Chamley, & Parsons, 2016). A desire to understand the person's individuality was a common theme across studies (Dewar & Mackay, 2010; Smith-Macdonald et al., 2019) as well as the importance of relational communication (Dewar & Nolan, 2013; Tehranineshat, 2018). This was seen to be achieved through an emotional connection and by using certain interpersonal skills (e.g. listening, using humour) (Dewar & Mackay, 2010; Kneafsey et al., 2016).

The Leadership in Compassionate Care Programme (LCCP; Edinburgh Napier University & NHS Lothian, 2012), a three-year programme seeking to integrate compassionate care across practice and education following the increase in incidents involving lack of adequate care, utilised appreciative inquiry to elicit from staff, patients and families in different clinical settings how they experienced and understood compassionate care. A range of methods including observation, interviews, storytelling and group discussions were used. Overall, six themes emerged: caring conversations; person-centred risk taking; giving and receiving feedback; 'knowing me, knowing you'; openness and adaptability (Adamson, 2013). In one of the LLCP studies taking place in acute hospitals (Dewar & Nolan, 2013), the definition provided generated a framework based on the 7Cs of 'appreciative caring conversations': connection, curiosity, collaboration, compromise, consideration of others' perspectives, courage and celebration of effective practices. Caring conversations involve gaining person and relational knowledge which enables partnership work.

Although these studies make some headway in improving understanding of compassion in healthcare, they provide a collective representation that is generated from clinicians, patients and their families; therefore, it is not possible to determine from whose perceptions the main themes originated.

1.5.3. Patients and Service Users' Conceptualisations

A range of research has exclusively explored patients and service users' perceptions of compassion. While these conceptualisations differ from clinicians' in some ways, they also include attributes, (Bramley & Matiti, 2014; Kret, 2011) and relational skills (Badger & Royse, 2012; Lloyd & Carson, 2011). Being treated as a person by being valued and heard was also incorporated in patients' conceptualisations (Adamson et al., 2017; Badger & Royse, 2012).

The first empirical model of compassion, emerging from a grounded theory study exploring the perceptions of patients in palliative units in Canada (Sinclair, McClement, et al., 2016) appears to integrate these descriptions, including seven key themes: virtues, relational space, virtuous responses, seeking to understand, relational communicating, attending to needs and ensuing outcomes. This definition was found to be congruent with the professionals' model of compassion previously described (Sinclair, Hack, et al., 2018). A study located in the USA investigating compassionate care from the perspective of burn survivors (Badger & Royse, 2012) found three primary themes: respect, communication and provision of competent care. While providing valuable insight into patients' views of compassion, these studies were conducted in North America. Therefore, the relevance of the findings in the UK needs to be considered as people's definitions of compassion seem to be impacted by their country's culture and socio-political structures (Papadopoulos et al., 2016).

In the UK, Bramley & Matiti (2014) interviewed ten inpatients from respiratory wards. A thematic analysis of the data yielded three key themes which related to knowing the person, seeing their perspective and ensuring effective and respectful communication. The research recognised that compassion requires time and commitment but, as studies investigating clinicians' conceptualisations (Goodrich, 2016; Perry, 2009), also highlighted the importance of small acts. However, participants were still inpatients and data were collected within the clinical area, which may have influenced their responses. In a study exploring the meaning of compassionate care for people attending day hospitals (Adamson et al., 2017), four themes were identified: relationships, feeling valued, expectations and perceived benefits. The patients also appreciated knowing the clinicians working with them and being known as a person, which coincides with the 'knowing you, knowing me' theme found in LCCP studies (Edinburgh Napier University & NHS Lothian, 2012).

The model for compassionate practice developed by Brown et al. (2016) based on the experiences of patients with intellectual disabilities, family and carers evokes an effective and relationally skilful clinician who understands the system, gets to know the patient and improves their experience. Straughair et al.'s (2019) model representing patients' views of compassion in nursing, also proposes compassion is

enacted when nurses manifest character, competence, motivation, relating and action. These definitions suggest compassionate care necessitates practitioners to invoke their personhood alongside their clinical proficiencies.

In the only study located investigating service users' perspectives in a mental health context (Lloyd & Carson, 2011), presence, collaboration and persistence were identified as indicators of compassion. Presence involves considering the diversity of actions required to help someone. Collaboration means clinicians giving equal recognition to service users and creating a dialogical relationship. Finally, persistence, offering continued hope and optimism, was a theme exclusively found in the mental health sector definition. While this study advances the research on compassionate care in mental health, service users were recruited from 'consumer-run' charities which may limit the generality of the findings to mental health services in the NHS.

The empirical evidence reviewed supports the idea that certain elements of compassion are universally understood, while identifying variations in their expression and experience between settings and populations. Moreover, while these findings, reflect a strong affinity between the expression of compassion by clinicians and how compassion is experienced by patients, some dissonance between the two was also noted (Durkin et al., 2019). Further research on the receipt of compassion by service users has been recommended to advance understanding of compassionate care (Durkin et al., 2019; Sinclair, Norris, et al., 2016).

While the literature discussed provides an insight into perceptions and definitions of compassion in healthcare, most studies are located in the physical care context. There is, therefore, a clear and significant gap in relation to service users' perceptions of compassion in mental health services which is worthy of further investigation. In particular, a comprehensive and exclusive understanding of what users of psychological services perceive compassionate care to involve is missing.

1.6. The Benefits of Compassionate Care

The significance of compassionate care to patients is repeatedly demonstrated in surveys where they consistently rank compassion among their greatest healthcare needs (Attree, 2001). While many were already aware intuitively of the power of

compassion, this is now also being confirmed by empirical research. Studies demonstrate that the provision of compassionate care has wide-ranging benefits, including improving patients' emotional wellbeing (Blomberg, Griffiths, Wengström, May, & Bridges, 2016), health outcomes (van der Cingel, 2014) and adherence to treatment (Hamilton, 2010). Other positive consequences of compassionate care suggested by the evidence include improved self-care (Arman & Hök, 2016) and increased sense of health-related responsibility and control (Tehranireshat, 2018). Research in the mental health field underscores the relationship between being treated compassionately and recovery from mental health problems (Spandler & Stickley, 2011). Proxy reports from psychotherapists highlighted multiple patient-reported outcomes that were enhanced with compassionate practice, including compliance and disclosure (Burack, Irby, Carline, Root, & Larson, 1999).

1.7. Factors Influencing Compassionate Care

Overall, there seems to be a general consensus that the capacity for compassionate care is determined by both individual and environmental conditions, which can facilitate or impede its provision. A summary of the most cited factors influencing compassionate care is presented below.

1.7.1. Individual Factors Influencing Compassionate Care

Individual factors hypothesised to influence the provision of compassionate care include the therapist's personality traits and life history, emotional wellbeing, training, clinical experience and ability for reflection.

1.7.1.1. *Personality Traits and Life History*

In empirical studies, both clinicians and patients have described compassion as being motivated by inherited qualities or virtues, such as empathy, fairness and kindness, possessed by clinicians prior to their training (Badger & Royse, 2012; Bramley & Matiti, 2014). These views are supported by evidence showing that people are often driven to healthcare professions as a result of an intrinsic eagerness to care for other people determined by pro-social traits such as empathetic concern and social responsibility (Baldacchino & Galea, 2012; Penprase, Oakley, Ternes, & Driscoll, 2013). Childhood experiences appear to be key in promoting the development of the ability to recognise the needs of others and

respond to these (Layous, Nelson, Oberle, Schonert-Reichl, & Lyubomirsky, 2012; Peterson, 2016). Nonetheless, Roberts & Mroczek (2008) found that personality factors associated with compassion are highly predisposed to change. Clinicians themselves have identified their capacity for compassion to be influenced by significant life events, such as experiencing a serious illness or encountering compassionate role-models (Roberts, Warner, Moutier, Geppert, & Green Hammond, 2011; Sanghavi, 2006).

Current NHS policies and ethical codes often refer to clinicians' personality and attitudes (Gelhaus, 2013), with the underlying assumption being that to deliver compassionate care, one must be compassionate. In line with this, The Francis Inquiry recommended the introduction of aptitude and performance appraisals to identify such character traits (Francis, 2013). Subsequently, the DoH published a document focused on "developing the right people with the right skills and the right values" (2014, p.1) which was followed by the introduction of a value-based recruitment (VBR) strategy (Health Education England, 2014).

1.7.1.2. *Emotional Wellbeing*

The Dalai Lama (2003) argues that "caring for others requires caring for oneself" (p. 125). Comprehensive studies have linked clinicians' wellbeing and self-compassion with increased and more sustained compassionate care (Heffernan, Quinn Griffin, McNulty, & Fitzpatrick, 2010; Neff & Pommier, 2013). Mental health nurses indicated they needed to be mindful of their own needs and adequately care for themselves in order to care for others and sustain compassionate practice (Barron et al., 2017).

Professional caring involves 'emotional labour' (i.e. inducing or suppressing feelings in order to make others feel cared and comforted; Hochschild, 1983). Emotional labour can become overwhelming if staff feel stressed and less able to induce or suppress feelings, leading to 'compassion fatigue'. Compassion fatigue has been described as a natural consequence of helping others in distress, involving feelings of frustration, impatience and anxiety which, if not recognised and addressed, can lead to unpleasant, avoidant or neglectful behaviours (De Figueiredo, Yetwin, Sherer, Radzik, & Iverson, 2014; Menzies, 1960).

1.7.1.3. *Ability for Reflection and Mindfulness*

Cole-King & Gilbert (2011) propose that, to provide compassionate care, clinicians

need to 'stand back, think and reflect' in order to be present and attuned to others and selves' experiences (Hunt, Dewar, Cultivating, & Dewar, 2015). Noticing emotions in the moment facilitates the identification of appropriate responses (Barratt, 2017). Accordingly, reflective practice and self-awareness have been identified as crucial elements for compassionate care training (Sinclair, Norris, et al., 2016). Mindfulness meditation, in particular, has increased in popularity as a means of boosting clinicians' confidence and ability to provide compassionate care (Hunter, 2016; Olson & Kemper, 2014).

1.7.1.4. *Training*

The evidence suggests effective training can be instrumental in teaching, or at least 'awaking', relevant abilities to care with compassion (Herbst, Swengros, & Kinney, 2010; Wear & Zarconi, 2008). In Bray et al.'s study (2014), clinicians considered that, while learning compassion-based qualities could be challenging, teaching interpersonal and communication skills could improve students' ability to elicit and understand patients' situations and views. The use of feedback to help students recognise what they do well and what could be enhanced was also proposed as a means to teach compassionate care (Dewar et al., 2014). In addition to these, training methods suggested by patients include self-reflection exercises and role modelling (Sinclair, Norris, et al., 2016). Specific strategies to enhance compassionate care within the NHS have been developed, such as the Scottish Valuing Feedback programme, focused on feedback processes and appreciative listening techniques (Smith, Gentleman, Conway, & Sloan, 2017) and a Compassion in Practice e-Learning programme which teaches clinicians the core attributes and skills to practice compassionately (Health Education England, 2020).

1.7.1.5. *Clinical Experience*

Professional socialisation in the clinical context is considered a vital process in learning and internalising the required values, norms and behaviours for compassionate practice (Curtis, 2014; Gelhaus, 2012). Socialisation is mainly influenced by more senior staff who are responsible for guiding, role-modelling, assessing and supervising novice clinicians (Drumm & Chase, 2010; Wear & Zarconi, 2008). However, socialisation can also ensue in the assimilation and

perpetuation of observed negative behaviours (Dimitriadou, Pizirtidou, & Lavdaniti, 2013; Goodare, 2015). Certain initiatives within the compassion agenda have been based on the idea that compassion can be fostered through clinician experience. To this purpose, the Francis report (2013) recommended that, prior to training, nurses complete a period of work as healthcare assistants to help develop caring and compassionate attitudes. However, there has been little evidence to support these propositions (Snowden et al., 2015).

1.7.2. Organisational and Systemic Factors Influencing Compassionate Care

Many authors have pointed out that, whilst clinicians' capacity to act compassionately could be a manifestation of individual propensity, capacity and motivation, this is, undeniably conditioned by a range of institutional, contextual and systemic factors.

1.7.2.1. *Workplace Culture*

The literature highlights that workplace culture plays a key role in influencing caring practices (Cochrane et al., 2019; Powell, Rushmer, & Davies, 2009). Compassionate care requires clinicians themselves to be supported, respected and empowered, so they can do the same for patients (Nyatanga, 2013). Formal support mechanisms (e.g. supervision, reflective practice) appear to be effective in preventing clinicians' stress and compassion fatigue by providing a space to process experiences and associated feelings (Straughair, 2012).

In terms of the compassionate mind approach (Gilbert, 2009), an environment where staff work together through emotional engagement and support enables the activation of staff's soothing system. In contrast, target-driven systems or a 'blame and shame' culture are likely to trigger a sense of threat which leads to withdrawal, defensiveness and avoidance, hindering other-directed and altruistic responses (Crawford et al., 2013). Therefore, as recommended in the Francis Report (2013) clinicians need a "positive, safety culture" (p.1357) in order to provide compassionate care.⁴

1.7.2.2. *Leadership*

Francis (2013) also maintained that sustainable culture change was only possible if compassionate styles of leadership were adopted. Following from this, a compassionate leadership programme was introduced (NHS England, 2014) which

highlights the importance of NHS leaders adopting behaviours, attributes and characteristics that embody compassion. By setting standards for team performance, addressing any lapses in care and striving to ensure that staff feel cared about, leaders can help institutionalising compassion (Lilius, Worline, Dutton, Kanov, & Maitlis, 2011). As role-models, leaders can embody compassion themselves by actively attending, feeling and responding to distress, and expressing emotions themselves (Straughair, 2012; Youngson, 2011). Where clinicians identified supportive leadership, they described more success in being themselves compassionate with colleagues and patients (Curtis, Gallagher, Ramage, & Wrigley, 2016). In contrast, the flame of compassion can become extinguished by oppressive or unsupportive leadership (de Zulueta, 2015), sometimes precipitated by managers themselves lacking appropriate support (George, 2017).

1.7.2.3. *Workload, Staffing Levels and Time Pressures*

Some evidence proposes that compassion only requires minimal resources of time or effort, as it can be enacted through small acts of kindness (Perry, 2009; Scammell, 2015). However, clinicians in a range of studies have described how low staffing levels and increased workloads result in less time interacting with patients, care left undone or errors occurring, all of which impact on the provision of compassionate care (Brown et al., 2014; Curtis, Horton, & Smith, 2012). Moreover, clinicians often tend to prioritise technical and administrative activities as they believe they would be judged more vehemently on these than on the actual care they deliver (Straughair et al., 2019). Cole-King & Gilbert (2011) suggest that lack of resources and occupational targets also activate staff's threat system (Hoyle & Grant, 2015) which can result in clinicians' burnout and compassion fatigue (Dewar & Christley, 2013).

1.7.2.4. *Socio-political Factors*

Compassion operates in and through social relationships shaped by cultural value systems which may (or may not) be conducive to compassion. Illouz (2008) describes how cultures become concerned with particular emotions and develop certain scientific, linguistic or ritual strategies that capture them. In Western societies compassionate styles of service delivery, leadership and governance have become the solution to enhance the quality of everything, from banking to higher education (Pedersen & Obling, 2019). So, while "advice of the 'stiff upper

lip', 'pull yourself together' variety" were highlighted as distinctive emotional responses in the 1950s (Menzies, 1960, p.54), behavioural standards have now changed towards more sensitive ways of interacting (Obling, 2013).

Simultaneously, neoliberalism values have resulted in highly structured practices focused on achieving efficiency and control (Ritzer, 2011). Austin (2011) considers these ideas have resulted in the 'commodification' of attitudes, which can be observed in the scripted customer service interactions. While such scripts may guarantee civility, faked and superficial responses can compromise genuine care and blind clinicians to patients' individuality. Evidence-based policy also offers a contradictory context (Spandler & Stickley, 2011). While the impact of compassionate care is now evidenced (van der Cingel, 2014), the evidence-based paradigm focuses on identifying the 'best' interventions independently of context or relational factors (Warner & Spandler, 2012). Yet, as previously reviewed, it is precisely these factors which are seen to constitute compassionate care.

1.8. Compassionate Care in Mental Health Services

Whilst references to compassionate care were missing in previous mental health policy, in recent years the term has been incorporated (NHS England, 2016). Nonetheless, since their inception, service user groups have been demanding more 'humane care' in mental health (Hervey, 1986), with some of the campaigns referring to the lack of compassion provided to particular manifestations of distress. The Hearing Voices Movement, for example, was created as a response to the psychiatric conceptualisation of voices as merely symptoms of a 'mental disorder' to be eliminated instead of accepted and understood (Romme, Escher, Dillon, Corstens, & Morris, 2009). The Self-harm Movement, meanwhile, condemns how those who self-harm are frequently described as 'manipulators' or 'attention seekers' (Pembroke, 1994). These initiatives make it clear that service users value the recognition and appreciation of their uniqueness, and want their distress, however expressed, to be understood and accepted (Spandler & Stickley, 2011).

1.9. Improving Access to Psychological Therapies Services

Improving Access to Psychological Therapies (IAPT) is a UK government-funded initiative aiming to widen the availability of psychological interventions within the NHS (Marzillier & Hall, 2009). It was a response to a report by the London School of

Economics (2006) which highlighted the high prevalence of ‘common mental health difficulties’ (i.e. mild to moderate anxiety and depression) in the context of a lack of therapists trained to provide evidence-based psychological interventions. The report argued that psychological therapies could achieve health, social and economic benefits by supporting people return to work and consequently reduce absenteeism and reliance on incapacity benefits.

Since its implementation in 2008, the IAPT programme has had a profound change in mental health provision in the UK, with a new range of staff being trained and employed to deliver therapeutic interventions (Rizq, 2012). While the programme was initially trialled with working-age adults experiencing common mental health problems, the range of ages and type of problems the service responds to has significantly expanded (Pickersgill, 2019). Clark (2011) emphasised that “a large number of people who would not otherwise have had the opportunity to receive evidence-based psychological treatment have accessed, and benefited from, the IAPT services” (p. 375). IAPT services are currently being accessed by around one million people each year (NHS Digital, 2019). This number is expected to increase further and by 2024 it is expected that 1.9 million people per year will be seen (Clark, 2019).

Before the implementation of IAPT, psychological therapy could only be accessed in secondary care services, hindered by long waiting times, or by accessing counselling services in primary care, perceived as brief and inconsistent (Binnie, 2015). The IAPT initiative, therefore, appears to have improved access to psychological treatment. However, since its inception, it has received critiques with regards to its ideology and implementation (Binnie, 2015; Watts, 2016). Concerns have related to the widespread use of Cognitive Behavioural Therapy (CBT) and the emphasis on economic rationales, leading to a rigorous monitoring of treatment outcomes (including service users’ ‘workability’; Watts, 2016) which has been described to pose threats to therapeutic quality (Pickersgill, 2019).

1.9.1. IAPT structure and service delivery

People can self-refer to IAPT or be referred by social/health care professionals. The service follows a ‘stepped-care model’ of delivery (Bower & Gilbody, 2005). People who are considered to require less input are provided with ‘low-intensity’ CBT-

based interventions (i.e. guided self-help or psychoeducational groups) by Psychological Wellbeing Practitioners (PWP), usually psychology graduates trained for a year. Those perceived as needing more input, or who do not benefit from low-intensity CBT, are offered 'high-intensity' interventions (i.e. a longer course of face-to-face CBT or counselling) by either CBT therapists, clinical/counselling psychologists, or counsellors.

CBT is the main therapeutic modality in IAPT (Clark et al., 2009), in line with National Institute for Clinical Excellence (NICE) recommendations for both depression and anxiety (NICE, 2009). NICE guidelines privilege randomised control trials and data related to 'symptoms' of 'mental health disorders' (Mcpherson, 2018). Consequently, the IAPT system has been described as a medical model of psychological therapy (Binnie, 2015) as it operationalises distress in diagnostic categories and uses associated diagnosed-specific 'manualised' interventions (Marzillier & Hall, 2009). Moreover, outcomes are assessed on the basis of achieving recovery-medicalised targets (NHS Digital, 2019), which seems to ignore the contextual determinants and the complexity of mental health problems (Binnie, 2015; Marzillier & Hall, 2009).

1.9.2. IAPT and Compassionate Care

IAPT has been described as an example of the 'McDonaldization' process discussed previously (Ritzer, 1996), as the economic rationalities appear to inform and justify many of its practices and accountability methods (Pickersgill, 2019). In order to evidence clinical need and efficacy, everything is manualised and measured (Strawbridge & Woolfe, 2010). Many researchers, clinicians, and patients have praised IAPT for being accountable to scientific evidence (Pickersgill, 2019). Moreover, quantification represents a means to ensuring funding. Like many NHS services, IAPT services are subject to the tendering process. This competition encourages providers to prioritise quantity over quality in order to hit targets (Binnie, 2015). Some IAPT services, for example, have been reported to reduce session limits to process more referrals. This is likely to affect service users' experience as they may have to go back for more support because the treatment initially provided was insufficient (Binnie, 2015).

The focus on efficacy and productivity also appears to influence IAPT working environments which are described as 'intense' and stressful due to high volume

caseloads and the emphasis on targets manifested in the close monitoring of therapists' workload and therapy outcomes (Walklet & Percy, 2014). The evidence indicates there are high levels of burnout and low mood within IAPT workforce (Walklet & Percy, 2014; Westwood, Morison, Allt, & Holmes, 2017). While therapists strive to provide good quality care, reporting that their main concern is to help people, high caseloads can lead to lack of reflection and impulsivity when making decisions and can prevent real encounters between therapists and service users (Binnie, 2015; Watts, 2016).

While service user satisfaction with IAPT services has been found to be generally high (Hamilton et al., 2011), the programme reports significant levels of attrition and dropout (Griffiths & Steen, 2013; Richards & Borglin, 2011). In a study investigating service users' experiences of low-intensity therapy (Amos, Morris, Mansell, & Edge, 2019), personalised therapeutic approaches and the promotion of idiosyncratic processes of psychological change were seen as the most beneficial aspects of therapy (Amos et al., 2019). These aspects coincide with many of the definitions of compassion involving individualised care that positions patients' views at the centre. Understanding the person's perspective and creating a strong therapeutic alliance are key components of cognitive therapy (Beck, 1979). However, in practice, low-intensity CBT in IAPT is highly prescriptive, emphasising 'technical' aspects and attending less to service user choice and individuality, and the therapeutic relationship (Samuels & Veale, 2009; Williams, 2015).

Nonetheless, the IAPT programme is currently, amongst other priorities, looking towards improving "quality and people's experience of services" (NHS England, 2019, p.6). Moreover, the latest IAPT manual states that effective and efficient service delivery should be balanced with compassionate and person-centred care (NHS England, 2019). This shows a tension in evidencing qualities such as 'compassion', which are not explicitly defined, within a market-based policy framework which monitors specific targets and indicators (Rizq, 2012).

1.10. Justification

While compassionate care has gained a prominent position within IAPT policies and practice guidelines, the concept lacks a comprehensive definition or framework for teaching and practice in this context. If accepted that knowledge of relational aspects

is best elicited through exploration of individual experiences and perceptions (Robert et al., 2011), a conceptualisation of compassion in clinical practice needs to incorporate service users' perspective (Sinclair, McClement, et al., 2016). Yet, research on compassion investigating service users' perspectives is limited and emanates mostly from studies based in healthcare settings (e.g. Bramley & Matiti, 2014; Sinclair, McClement, et al., 2016). This raises questions regarding the generality of the findings to psychological therapies services, as perceptions and expressions of compassionate care appear to vary across contexts (Roze Des Ordons, Maclsaac, Everson, Hui, & Ellaway, 2019).

Moreover, the empirical models of compassion developed to date (e.g. Sinclair et al., 2018; Sinclair, McClement, et al., 2016) mostly focus on individual clinical factors while, as evidenced by the research reviewed, the provision of compassionate care appears to be influenced by elements at multiple levels which need to be considered.

1.11. Aims of the Study and Research Questions

This research aims to address the identified gap in the literature by trying to understand and define compassionate care in IAPT from the perspective of individuals who have personal experience of using services. Having greater awareness of service users' conceptualisations of compassionate care can have implications for how to design services and deliver interventions in ways that individuals identify as supportive and helpful. Specific organisational, environmental and process changes may be identified, which could be used to shape training, research and policy frameworks.

As these aims are exploratory in nature, a qualitative approach appeared most suited and was used to explore the following research questions:

Research Question 1. What do users of an IAPT service perceive compassionate care to involve?

Research Question 2. What are the perceived facilitators and inhibitors of compassionate care in an IAPT service?

Research Question 3. What is the perceived impact of providing compassionate care?

2. METHODOLOGY

This chapter will outline the epistemological and ontological position adopted by the research. An overview of Grounded Theory (GT) and a rationale for its selection as the method of data collection and analysis will then be provided. Procedures of participant recruitment and methods of data collection will also be described before considering the process of analysis. Finally, the approach taken to evaluating the quality of the study will be delineated.

2.1. Epistemological and Ontological Position

Epistemological positions concern both epistemology and ontology and can be viewed along a continuum between realism and constructivism (Willig, 2012). The epistemological position within which the qualitative researcher works carries certain implications for the evaluation of the research and therefore needs to be made explicit (Madill, Jordan & Shirley, 2000).

This study is approached within a critical realist epistemological position, being ontologically realist and epistemologically relativist (Willig, 2012). Critical realism argues an existence of independent external reality, while also acknowledging the subjectivity in making sense of this reality (Gorski, 2013). This position emphasises the generalising task of scientific activity by looking to identify 'generative mechanisms' (interacting and transforming forces that generate empirical phenomena) (Bygstad, Munkvold & Volkoff, 2015). The outcome of a mechanism is contextual, so that data cannot exist independently outside of historical, cultural and social circumstances (Jaeger & Rosnow, 1988; Madill et al., 2000).

This ability to engage in explanation, together with its consideration of context, make critical realism particularly useful for examining social issues (Fletcher, 2017). This makes it suitable for this research given the social nature of 'compassion'. This position also fitted well with my understanding that, rather than being static, unchanging and located within an individual, expressions of compassionate care are changeable, subjective and negotiated within a context.

In line with a critical realist position, this research aimed to investigate 'compassionate care' within a material reality that, it was believed, exists independently of personal experience and across time. However, it was also

recognised that the concept under investigation was socially constructed, rather than a 'real' physical entity, with perceptions of its nature and determinants changing across time and across contexts, as illustrated in the Introduction. Therefore, compassionate care was seen as meaning different things to different people in different situations. Consequently, it was acknowledged that the construction of this experience, and any interpretations, were going to be shaped by the participants and any contextual processes as well as by the researchers, recognising that multiple interpretations of the data were possible.

2.2. Grounded Theory

2.2.1. Grounded Theory Outline

This research used the constructivist GT of Charmaz (2014) to facilitate the generation of a theory that represents compassionate care in IAPT services as perceived by the participants. GT was originally developed by two sociologists, Glaser and Strauss (1967), who wanted to investigate social processes and asserted that the traditional emphasis on quantitative hypothesis-testing restricted theory generation and relevance (Willig, 2008). They proposed that systematic qualitative analysis had its own logic and could generate theory. This led them to develop a method which 'grounded' the research in the data itself, rather than relying on analytic constructs or categories from pre-existing theories (Willig, 2008). In particular, Glaser and Strauss (1967) intended to construct abstract theoretical explanations of social processes by asking about what happens and how people interact in the social context. GT is therefore particularly useful for studying topics of a social nature, such as compassion (Charmaz, 2014; Goulding, 2002).

While Glaser and Strauss eventually parted company, they both advanced their work in a positive way, emphasising objectivist assumptions (e.g. Glaser, 1998, 2002; Strauss & Corbin, 1990). These versions of GT assume phenomena create their own representations that are directly perceived by observers, so that categories and theories simply 'emerge' from the data and are entirely separate from researchers' categories of meaning (Glaser & Strauss, 1967). Charmaz (1990) introduced a constructionist version of GT that argues instead that the data are constructed by the researcher who actively creates a particular understanding, organisation and presentation of the phenomenon based on their ideas (Charmaz, 2014). The

constructionist position also asserts that all findings are context specific so that all knowledge is provisional, local and situation dependent (Madill et al., 2000).

While GT has evolved into a number of versions, the method used in GT has remained fairly consistent, providing a set of strategies to construct theoretical frameworks from data through processes of induction (Oliver, 2011; Willig, 2013). Charmaz (2014) proposes these strategies, rather than being prescriptive rules, should be applied flexibly, adapting them according to the researchers' needs. In this study, carrying out data collection and analysis simultaneously, as recommended by GT guidelines (Charmaz, 2014), was not always possible due to time constraints. Nonetheless, some initial analysis was undertaken between interviews, whenever possible, to look for emerging categories to help direct further interviews more effectively.

2.2.2. Rationale for Using Constructivist Grounded Theory

GT is a methodology that uses method which is not pre-bound within disciplinary pre-conceptions, allowing for patterns in the data to explain the research question rather than verifying existing understandings (Wuest, 2012). As GT enables a rich level of data analysis without relying on pre-existing theoretical categories or constructs, it is often used in areas of research that are under-defined (Tweed & Charmaz, 2012). In this way GT was well aligned to the research's aim to develop an empirically informed theory that provides a richer naturalistic understanding about service users' definitions of compassionate care in psychological services, which as yet, lacks a strong theoretical framework.

GT's focus on social processes also seemed particularly relevant to how service users talk about their experiences and views of compassionate care. In this way, GT is well placed to support the ethical intention of this research, specifically to rebalance the terrain of knowledge regarding service users, whose perspectives have classically been neglected from the production of knowledge regarding them (Pilgrim & Waldron, 2009). Strauss and Corbin (1998) suggest that grounded theories not only enhance understanding but can also feed meaningfully into action. This was important as it was hoped the research would provide feedback to the service from which participants were recruited in order to promote ways of delivering care that meets the needs of users.

The epistemological flexibility of GT also accords with the critical realist position of this research. Critical realism sees all understanding as partial and tentative and therefore requires a method that allows for conceptualisation and reconceptualisation (Pratt, 1995). This is achieved through GT methods, such as open coding, the constant comparative analysis and theoretical sampling (Charmaz, 2014). In particular, it was considered that a constructivist approach to GT would fit best with the critical realist epistemology, which sees the production of knowledge to be impacted by the context and inevitably involving the subjective interpretation of meaning (Charmaz, 2014).

2.3. Participants

2.3.1. Inclusion Criteria

All participants were recruited from an NHS IAPT service in London. Participants were adults aged eighteen and over, who had used the IAPT service within the past three months, so they could easily recall their experience. Participants were only required to have completed the initial IAPT assessment, either by telephone or face-to-face. There were no restrictions on number of sessions attended, mode of delivery of the sessions, or level of support received (i.e. step 2 or 3). These broad inclusion criteria were intended to maximise the variety of experience captured.

2.3.2. Exclusion criteria

Unfortunately, non-English speakers listed in the IAPT database as needing an interpreter were excluded due to lack of funding to recruit interpreters for the research. People unable to understand the information sheet (with support) or who lacked capacity to consent to participation were also excluded.

2.3.3. Recruitment

There were three different approaches to recruiting potential participants. Firstly, posters and leaflets containing information about the study and my contact details were put up in the waiting areas of four teams within the IAPT service (Appendix B). Secondly, I attended the IAPT Service User Advisory Group meeting and presented the study to the attendees, providing leaflets and my contact details to the interested members and encouraging them to contact me should they wish to participate. The Advisory Group is a forum where people who have been discharged from IAPT can

give feedback on their experience of the service and suggest changes. Lastly, an assistant psychologist in the service shared a database with contact details of those service users who had agreed to participate in research at their initial assessment. Those who fitted the eligibility criteria were sent a letter of invitation containing full information about the study (Appendix C) by email.

All the participants were recruited via the last method described. Approximate records were kept as to who declined to take part. Some people were clear from the outset that they did not want to take part as they had other commitments. Two potential participants reported that they were not interested in taking part as they did not want to be reminded of their negative experiences with the IAPT service (further reflections on the methodological limitations with regards to this are included in the Discussion). Approximately two thirds of individuals contacted (n=28) expressed interest in participating. Consequently, they were asked to email me with a convenient time and place. Thirteen individuals replied to the second email and a mutually convenient time and place was then arranged to conduct the interviews.

2.3.4. Participant Characteristics

Thirteen people, seven females and six males, who used or had used an IAPT service were interviewed. The demographics and profile of participants is provided in the table below.

At the time of data collection, nine participants had completed their therapy sessions and were no longer using the service (69%); three participants were halfway through their therapy (23%) and one participant had completed her therapy sessions but was planning to use the service further (8%).

Participants had attended an average of eleven sessions in the IAPT service (range 1-21). The majority had done face-to-face individual therapy (n=11, 85%), while two participants (15%) had experienced individual, telephone and computer- based therapy and two (15%) had attended group therapy sessions.

Table 1: Profile of participants

Interview Number	Name¹	Age²	Gender	Ethnicity	Religion	Type of therapy (Number of sessions)
1	Filipa	36-45	F	White-Other	Christian	Individual, face-to-face (16)
2	Theresa	Under 25	F	White-British	No religion	Individual, face-to-face (11)
3	Marta	Over 65	F	White-British	Jewish	Individual, face-to-face (21)
4	Gerard	26-35	M	White-British	No religion	Group and Individual, face-to-face (15)
5	Iris	56-65	F	White-Other	No religion	Individual, telephone and computer-based (13)
6	Karen	26-35	F	Black-Caribbean	Christian	Individual, face-to-face (17)
7	Anita	56-65	F	White-Other	Christian	Group and Individual, face-to-face (4)
8	John	Under 25	M	White-British	No response	Individual, face-to-face (11)
9	Roberto	26-35	M	White-Other	No religion	Individual, face-to-face (12)

¹ Names have been changed to preserve anonymity

² Age ranges have been presented to preserve anonymity

10	Mary	Over 65	F	White-Other	Christian	Individual, face-to-face (18)
11	George	26-35	M	White-Other	No religion	Individual, face-to-face (1)
12	Kabir	36-45	M	Mixed- White and Asian	No religion	Individual, face-to-face (6)
13	Morgan	36-45	M	White-Other	No religion	Individual, telephone and computer-based (3)

2.4. Method

2.4.1. Interviews

Grounded theories may be constructed from different forms of data (e.g. information from reports, focus groups, interviews). The kind of data pursued depends on the topic to be studied (Charmaz, 2014). Using interviews was deemed most suitable for investigating service users' conceptualisations of compassionate care as it enabled more direct control over the construction of data while also facilitated in-depth explorations of participants' experiences, offering an open and flexible approach to what they wanted to communicate (Charmaz, 2014).

Interviews also fitted with the epistemology and ontology of the study by considering that, to gain the most accurate possible insight into a reality, it must be elicited directly from the individual who has lived it. Kvale (1996) argues that interviews are particularly appropriate for exploring people's understandings of the meanings in their lived world by allowing them to describe their experiences and to clarify and elaborate on their perspectives. As I wanted to allow the conversations to unfold in a fairly natural way, trying to limit the imposition of previous framings, I determined that semi-structured interviews were the most appropriate method for data collection (Charmaz & Belgrave, 2012). Semi-structured interviews are inductive and flexible; while they provide a general shape and direction of the conversation, they do not

dictate the parameters or content (Morse, 2012).

2.4.2. Interview schedule

I developed a loose interview schedule (Appendix D), with just a few potential open-ended questions designed to enable an in-depth discussion about compassionate care which was based on the literature review and feedback from the service user forum on an initial draft. Glaser (1998) argues that using an interview schedule can preconceive the data by forcing it into categories before your start. However, Charmaz (2014) states that using an open-ended interview schedule does not equal to imposing received codes on collected data. In fact, she argues that thinking about the questions can help novice researchers to avoid blurting out loaded questions. (Charmaz, 2014).

The schedule was used to shape the format of the interviews so that service users' conceptualisations and experiences of compassionate care were explored, elucidating participants' personal beliefs and views on the topic. A flexible approach was taken in order to enhance the validity of the data gathered. Thus, there were only a few key questions and prompts. Follow-up questions were decided in response of participants' answers, following particular areas of interest and significance which arose (Charmaz & Belgrave, 2012), so that each interview was tailored to each individual participant.

2.4.3. Process of Interviewing

An invitation to participate in the study was sent via email to potential participants, including an introductory covering letter and the participant information sheet (Appendix C). The information sheet was also discussed with participants before the interviews, reminding them of the aims of the research, confidentiality clauses and their right to withdraw. The process of recording was also discussed before the interview. Participants were then given the opportunity to ask any questions before being asked to sign the consent form (Appendix E) and to complete a short demographic questionnaire (Appendix F), which included questions regarding their engagement with IAPT services.

Data were collected using face-to-face semi-structured interviews. Interviews were held within a private and confidential space either in the IAPT service (n=11) or via

Skype videocall (n=2). Interviews were audio-recorded on a digital recording device and lasted between 35 and 60 minutes. The interview schedule broadly guided the interview and participant were asked to speak from their own experience.

2.4.4. Transcription

Each interview was transcribed verbatim within three weeks of taking place and, in most cases, before conducting the next interview. A simple approach to transcription was used, adapting Banister, Burman, Parker, Taylor and Tindall's (1994) transcription conventions (Appendix G). During this process any identifying information was removed. I performed all the transcription in order to further consolidate the bond between participants' views and resulting analysis (Langdrige and Hagger-Johnson, 2009), as transcribing enabled me to be familiar with the ideas communicated, therefore influencing the questions asked in following interviews.

2.4.5. Interaction between data generation and analysis

Drawing from the constructivist GT guidelines of Charmaz (2014), the analysis process was iterative in nature, occurring simultaneously with data collection, using methods of transcription, systematic coding, memo writing and diagramming.

2.4.5.1. *Initial Coding*

Systematic coding involves breaking data down into smaller components that share central features and labelling those components. The analysis began with initial coding which involved 'opening up the data' by assigning each line of the transcript with a descriptive label that remained as close as possible to the words of the participant (Charmaz, 2014). In order to ensure coding was orientated toward the actions and processes in the data, gerunds or verb forms acting as a noun (e.g. being accepted) were used, as recommended by Charmaz (2014) (see Appendix H for example). These initial codes were regarded as provisional and highlighted gaps in the data which were sometimes explored through further data generation.

I continuously questioned why I had developed certain codes in an attempt to become more aware of my own assumptions as well as those of the participants (Charmaz, 2014). To assist in this process, part of interview two was coded by another trainee clinical psychologist and the resulting codes were discussed. Initial and focused coding for the first two interviews was also discussed in detail in

supervision.

2.4.5.2. *Focused Coding*

This phase of coding progressed from a descriptive to a more interpretative and analytical level as meaningful codes that explained and synthesized larger amounts of data were developed (see Appendix H for example). This involved selecting initial codes based on their frequency, salience and significance and examining them to consider their appropriateness and whether they made the most analytic sense to form categories within the data, by comparing them to the data and other codes (Charmaz, 2014). Constructed focused codes 'cut across' individual descriptions and interviews (Charmaz, 2001). These were the codes deemed most relevant to the study topic and research questions after a process of constant comparison.

2.4.5.3. *Codes to Categories*

Focused codes that accounted for themes running throughout the data were selected and refined for conceptual reach. These categories were again compared back to the data, codes and other categories to evaluate their salience and significance. Five categories and nineteen subcategories were developed.

2.4.5.4. *Diagramming*

In order to develop coherence between and within categories, Clarke's diagrams (2003) were used alongside data collection and coding which facilitated reassembling the disintegration of data from initial coding. This involved creating visual representations of the categories and their relationships, specifying the properties and dimensions that linked each category. Drawing diagrams was helpful in seeing the data as a process, for example, by drawing my attention to the fact that most participants had identified their experience of distress as an antecedent to compassionate care.

2.4.5.5. *Memo Writing*

Detailed analytic notes were written throughout the process of data generation and analysis to document links across the data and any arising impressions, interpretations and decision-making. Memo-writing aided the process of constant

comparative analysis and allowed me to remain reflexive, alerting me to my own preconceived ideas (Charmaz, 2014) (Appendix I).

2.4.5.6. *Constant comparative analysis*

Constant comparative analysis was used to refine constructed categories by identifying similarities and differences between them so that they captured all instances of variation (Charmaz, 2014). This took place at each level of analysis.

2.4.5.7. *Theoretical sampling*

Theoretical sampling involves systematically selecting sources of data (people, events, information) according to the emerging categories in order to challenge or refine them. Theoretical sampling was used in order to follow some of the leads and concepts as they were identified within the data (Bryant and Charmaz, 2007; Charmaz, 2014). This resulted in the recruitment of service users who, in addition to meeting the initial inclusion criteria, fulfilled one of the following:

- Had only accessed Step 2 therapy (and were therefore offered a more limited number of sessions)
- Had disengaged before the completion of the intervention
- Had to wait to access high-intensity therapy following the completion of a low-intensity intervention
- Were male

The interview schedule was also adapted in order to fill gaps in the data, clarify uncertainties, and test my interpretations. In line with Charmaz's (2001) suggestion, this was delayed until the later stages of the study so as not to force analytic directions. For example, the theme of 'effective relationships' arose despite not having asked participants directly about this. Consequently, a question about this was included in the interview schedule so that this idea could be further explored and developed. However, the process was inherently less thorough than in Charmaz guidelines (2014) as, due to time constraints, theoretical sampling was not possible for all the interviews. I therefore went back through the transcripts and memos looking for exceptions to, and instances of, categories through constant comparative analysis.

2.4.5.8. *Category saturation*

According to the original GT texts, theoretical sampling should continue until gathering new data does not reveal new discoveries and 'theoretical saturation' is achieved (Glaser & Strauss, 1967). Nonetheless, new revisions of this process have considered how data collection is rarely an exhaustive process. Therefore, research must be assessed instead on how well the data are able to produce a sufficient theoretical account (Dey, 1999). To reach 'theoretical sufficiency' is not to achieve an ultimate limit, beyond which it is impossible to find new insights, but it is to achieve an adequate depth of understanding that can allow the development of a theory. This is the position I took, although it is acknowledged that a larger sample size may have yielded more saturated theoretical concepts. However, it was not possible to pursue new data outside the dataset due to time constraints. Wiener (2007) states that saturation is a judgement that also takes into account the situation of research, including lack of time. The theoretical account developed was nonetheless considered to be robust and consistent with adequate explanatory power and depth as all the categories were explained and relationships between them defined (Charmaz, 2014).

2.5. Consultation with the Service User Forum

Collaboration with representatives from the study population is recommended in research development (Lee & Renzetti, 1993; Patel, 2003). In order to ensure the research process was as appropriate and sensitive as possible, I attended a meeting of the IAPT Advisory Group to consult with a group of former service users. Members of the group were asked to share their general observations about the study as well as specific feedback on the drafts of the participant information sheet, the interview schedule and the participant debriefing form (see Appendix J for a summary of the consultation). Their suggestions were used to shape and adapt these documents.

For example, the final interview schedule included less questions as various members of the IAPT Advisory Group considered the original document too lengthy. The content of the schedule was also revised, and some questions were rephrased as suggested, making them more open and clearer. The Advisory Group members were also concerned that some study participants may need a few days to reflect

after the interview before coming up with any questions or concerns. As a result, some suggested the debrief should take place at a later date. While I considered it was still important to provide an immediate debrief following the interview, I acknowledged the feedback suggested by providing contact details of me and my supervisor to participants who were encouraged to make contact at any point during the research if they had any questions or concerns.

I also inquired the members of the Advisory Group about suggestions for involving service users in the interpretation of the research findings. Both service users and practitioners in the meeting proposed that I could return to the group to discuss the results and recommendations prior to completing the write-up. Unfortunately, due to COVID-19 Social Distancing Guidance, the IAPT Advisory Group meetings were temporarily suspended.

2.6. Ethical Considerations

Ethical considerations were guided by professional codes of ethics (British Psychological Society, 2018) and guidance on research (British Psychological Society, 2014).

2.6.1. Ethics Approval

As participants were drawn from the NHS, ethical approval was sought and granted from the North West – Liverpool Central Research Ethics Committee (Appendix K). Relevant local NHS research and development approvals were also obtained. The project also received ethical approval from the University of East London (Appendix L).

2.6.2. Informed Consent

In order to ensure that prospective participants were fully informed about the purpose and plan of the research, letters of invitation to participate included a detailed research information sheet (Appendix B). Those who agreed to participate in the study were asked to sign a consent form (Appendix E) which outlined their right to withdraw from the research without any negative impact on their care. Participants were also informed that confidentiality may have to be broken, in consultation with supervisors, if there were any concerns about their safety. This situation did not present during the research process.

2.6.3. Confidentiality, Anonymity and Data Security

Participants' involvement and all data collected remained confidential. I transcribed all the interviews and only my supervisors and examiners had access to the transcripts which were stored in a password protected drive on the university server.

Personal data was pseudonymised immediately during transcription and all identifiable data had been altered in the thesis extracts or resulting publications, to protect anonymity.

2.6.4. Managing Potential Distress

Participants were asked about their experiences of compassionate care, which could be from positive or negative perspectives. People may find it helpful to discuss their experiences, but I was also mindful that there was a small risk that individuals could find participating distressing as the interview had the potential to bring to awareness unpleasant memories which could trigger difficult emotions. I used my clinical judgement and skills to complete the interviews in a sensitive and considerate manner. Interviews were carefully designed so that participants felt as comfortable as possible to share their experiences. Before commencing the interview, participants were informed that they could interrupt the interview at any point, take breaks or reschedule. In addition, there was a debrief at the end of the interview (Appendix M) where participants were given time to reflect on any issues or unexpected emotional responses that may have been arisen during the interview and were provided with details of relevant support agencies.

2.7. Evaluating the quality of the research

Yardley's (2000) evaluative guidelines for qualitative research were used as a framework to assess the validity of this study. These guidelines regard sensitivity to context; commitment, rigour and coherence; and transparency as required methodological processes.

2.7.1. Sensitivity to Context

Sensitivity to context involves being aware of the relevant literature as well as of one's own perspectives on the topic (Harding & Gantley, 1998). Yardley (2000) proposes that evaluating sensitivity to context involves a consideration of both sensitivity to theory and sensitivity to the social cultural context. In GT, this can be

accomplished by using memos to present the evidence of the theoretical dimensions developed (Appendix I).

2.7.2. Commitment and Rigour

Commitment involves evidencing prolonged engagement in the research subject as well as skill in the adopted methodology (Yardley, 2000). This principle is regarded as especially significant in demonstrating validity in qualitative research (Yardley, 2008). This was accomplished through a detailed process of coding, memo writing and reflexive journals. The idea of rigour considers how complete the data collected are and whether the sample can provide all the necessary details for a comprehensive analysis (Yardley, 2000). This was achieved through the recruitment of people who had diverse experiences with the services and whose demographics differed, allowing for a more refined understanding of the topic (Olsen, 2004).

2.7.3. Transparency and Reflexivity

Given that the adopted epistemology emphasises the unavoidable influence of my perspective on the research, it is presumably pertinent to share some information about myself for the sake of transparency. I am a 28-year-old White-Spanish woman training to become a clinical psychologist. Prior to training I worked in an IAPT service. I therefore have an appreciation of the service and some knowledge and experience of the phenomena under consideration. Thus, before starting this research, I had my own assumptions about how services users may define and experience compassionate care in this setting. However, I had never been a service user of an IAPT service myself which gave me limited personal insight into how people who are not trained in psychology and who access IAPT service define this phenomenon.

I saw compassionate care as an essential feature of psychological therapy as well as an ethical duty for healthcare professionals (DoH, 2015). Simultaneously, personally and professionally, I tend to look at contextual and systemic explanations.

Consequently, I acknowledged the relevant social, political, cultural and economic factors that may impede or enable compassionate care. I was also aware of some of the main psychological theories related to compassion (e.g. Gilbert, 2009) and discerned that most understandings of this phenomenon were academic and philosophical rather than the product of knowledge produced or validated by those

who use services. I therefore endeavoured to pursue the experiences of service users in order to oppose these polarised academic perspectives and to work towards the development of nuanced model of compassionate care in IAPT that was able to account for the interaction between individual and system.

Charmaz (2014) states it is important to scrutinise the implications of our theoretical orientations and personal assumptions both before and throughout the research. Interests and sensitising concepts, based on previous research, literature and psychological theories on compassionate care, provided a departure point for developing ideas, guiding rather than commanding my enquiry (Charmaz, 2014). I approached this project from its conception with the consideration that lack of compassionate care in services can be problematic and this research would attempt to locate its solution. I also assumed compassionate care may be a multi-level construct and I endeavoured to explore the complex interaction between social and individual explanations. Nonetheless, I strived to remain open, avoiding forcing preconceived ideas and theories on the data, and pursuing other topics that respondents saw as important. Discussions with my supervisor and with peers and the use of the reflective journal and memos helped me to remain alert to how my privileges, values and preconceptions may have influenced the research process (Charmaz, 2014).

3. ANALYSIS

The grounded theory model constructed from participants' interviews by following the analytic methods described in the previous chapter will be presented first. A more detailed description of categories and subcategories in the model will then be provided which is supported by participants' quotes.

3.1. The Grounded Theory Model: 'Humanising Responses to Distress'

Providing a 'humanising response' to the person experiencing psychological distress was identified as the dominant process described by participants as representing compassionate care within the context of an IAPT service.

Five core categories were constructed from the data gathered which are presented in Table 2.

Table 2: Categories and sub-categories

CATEGORIES	Sub-categories
DISTRESS	
RECEIVING A HUMANISING RESPONSE	Experiencing Genuine Concern Striving to Understand the Individual Experience Acting to Meet Individual Needs Empowering the Person Creating a Secure Relationship
RECEIVING A DEHUMANISING RESPONSE	Lacking Genuine Concern Disregarding the Individual Experience Neglecting Individual Needs Taking Away Choice and Control Developing an Insecure Relationship

CONDITIONS FACILITATING OR INHIBITING THE HUMANISING RESPONSE	Individual Relational Systemic Contextual
RESPONSE DEPENDENT OUTCOMES	Level of Trust Level of Relief Level of Purpose Level of Satisfaction Level of Engagement

The constructed model 'Humanising Responses to Distress' (Figure 3) accounts for these five categories. The categories were noted to have a clear interdependent relationship and data appeared to reflect a process. There were causal conditions (experiencing distress as an antecedent of the IAPT response), mediating conditions (conditions influencing the IAPT response) and outcomes (consequences of the IAPT response). Arrows illustrate routes of feedback between categories.

A 'humanising response' was described as experiencing genuine concern, striving to understand the individual experience, meeting the individual needs, empowering the person and creating a secure relationship. 'Dehumanising responses' involved lacking genuine concern, disregarding the individual experience, neglecting the individual needs, taking away choice and control and developing an insecure relationship. A range of conditions, operating at four interrelated levels (Individual, Relational, Service-related and Contextual), was identified as influencing the type of response given by the service. In circumstances where conditions were mostly facilitating of compassionate care, humanising responses could be enabled. In circumstances where there were conditions failing to ensure compassionate care, 'dehumanising responses' had the potential to emerge. During their interviews, participants often described a constant oscillation between the two types of responses. Finally, 'response dependent outcomes' were contingent on the type of response the person receives and were also seen to impact on the person's distress experience.

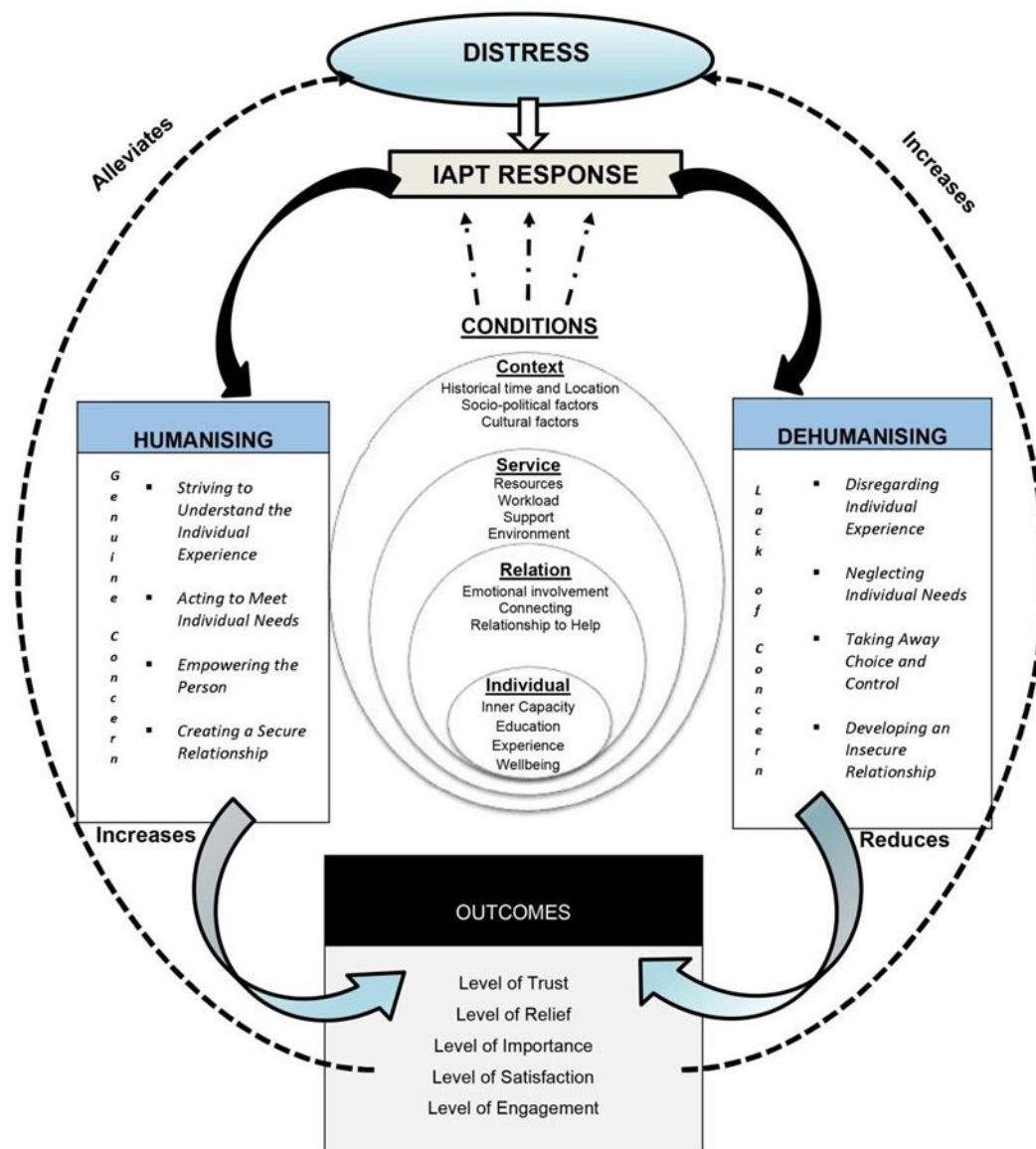


Figure 3: “Humanising Responses to Distress”

The categories and subcategories included in the model will be illustrated and elaborated upon with the support of the quotes from participants’ interviews. This way of presenting the findings gives value to participants’ narratives and reinforces the credibility of the research (Charmaz, 2014). Due to space limitations, only one to three quotes are provided for each concept. The quotes were selected based on their clarity and consistency in illustrating their associated categories and themes.

3.2. Detailed Analysis of the Model

Categories (underlined titles) and subcategories (italicized titles) are summarised

and illustrated below using extracts from participants' interviews.

3.2.1. Category 1: Distress

The "Distress" category includes how service users' experience of psychological distress precedes the provision of compassionate care in an IAPT service. Distress was described as a shared human experience involving a variable level of suffering:

"That's understanding and acknowledging that, everybody has different experiences, but we will all feel some pain...to a different degree." (Sonia).

Experiences of distress were conceptualised by 12 participants as episodes of low mood and/or anxiety which had a negative impact on their wellbeing and, to some extent, on their ability to function and relate to others. For the one participant who did not express distress, their experience involved a behaviour impacting on their relationship with their partner and on their home situation. Experiences of distress were often preceded by a single/series of difficulties, such as bereavement, health difficulties or abuse:

"I lost a lot of members of my family in a very small space of time and (.) my therapist said that she would feel broken, like I was." (Sonia).

"I had like a traumatic experience with a health issue. I went through like procedures that were quite severe and the effects of that problem and procedures still almost linger today in a bad way." (Roberto).

Participants considered that compassionate care takes place in IAPT when the person experiencing distress regards their situation as requiring help from others and, as a result, seeks support from the IAPT service:

"When you're in that state of mind, in that place, it's very hard to see your way through it. And you kind of hope that someone can help you do that. And, I guess, part of that process is feeling that you're being listened to." (Kabir).

"When you sign up for the service, it's probably because you've reached the point where you really need help (.) and you're at a breaking point, and then you might wait, three to six months, to even get information." (Gerard).

3.2.2. Category 2: Receiving a Humanising Response

A humanising response to the person's distress was constructed as a distinct category and an overarching principle of what was defined by participants as compassionate care. Participants described this response as recognising, accepting and prioritising the person's humanity and their uniqueness. Compassionate care was also considered to be humanising by involving interactions and relationships founded on the basis of the shared experience of being human:

"If I had to put it in a very simple expression, compassionate care is to be 'humane', understanding that other humans have feelings and they go through things in life and you can somewhat understand." (Roberto).

The process depicted in the 'Humanising Responses to Distress' model was described as operating, not only in the individual and service user-practitioner relational spheres, but also at systemic levels. Participants also referred to the process as taking place throughout their involvement with the service, from the point of referral till they were discharged.

Filipa's extract below demonstrates how she considered all the interactions she had with the service as important:

"Compassionate care in IAPT is not just the therapist; it is the receptionist, it is the cleaner, it is everything that makes the service work. The lady that calls you to book the appointment, the way she speaks with you, the way she writes the emails. Everything." (Filipa).

3.2.2.1. *Experiencing Genuine Concern*

This subcategory represents participants' perceptions of the service as being concerned and interested in them as a person and in their wellbeing. In describing compassionate care, various participants shared examples of situations when they felt the significance of their concerns was appreciated. That is, their difficulties were acknowledged and taken with a degree of seriousness. John's extract echoes this process:

"Bringing another member of the team, made me feel again, like I was being taken more seriously and receiving a thorough level of attention. And I guess that thoroughness of attention to me implied that they cared." (John).

Within this subcategory, participants also emphasised the need for the practitioner to relate to their emotional experience, often describing this as empathising or ‘walking in the person’s shoes’:

“In terms of the IAPT experience, I would consider compassion starts with empathising with the issues that you are showing that have led you to actually use the product” (Morgan).

“I suppose the only way it is having the ability of putting yourself in other people’s shoes to show compassion. If you cannot do that, I think it’s noticeable.” (Anita).

Martha highlighted it was not a requirement for the professional to have faced similar experiences but emphasised instead that a recognition of the basic human mutuality in the experience of suffering was of utmost importance:

“No one goes through life without some sort of trauma. So, just to recognise that the feeling of that trauma is probably magnified in the person in front of you. I have not experienced the death of a child, but I have friends who have, and you have to relate to them in some way.” (Martha).

Finally, genuine concern was described as involving a motivation to help the person, positioning their needs as the main priority. Motivation was thought to arise primarily from an intrinsic desire to care for others. This is demonstrated in Karen’s extract below in which she highlighted the importance of the intention and motivations behind the actions being performed in an IAPT service:

“I would say that compassionate care has to do with intentions. I would assume that those intentions are guiding principles behind the work. I’d hope however got started it was to address a problem, a need that people were having. People have a great deal of mental distress today and this would be an attempt to alleviate that.” (Karen).

3.2.2.2. *Striving to Understand the Individual Experience*

The subcategory ‘striving to understand the individual experience’ was defined as “paying attention and being present in order to learn about the person and their unique needs and develop an accurate empathetic understanding of their situation”.

For Karen, a real attempt to understand her experience was demonstrated when her words and feelings in the moment were attended to:

“They were never distracted. There were always attentive to exactly what I was saying. And I saw a real interest in making sure that they understood what I was saying and understood it on, you know, a few different levels, both on sort of in an empathic level to an intellectual level.” (Karen).

By remaining curious and avoiding simple assumptions, therapists acknowledge the complexity of service users’ experiences and the limitations of professional and personal perspective. Gerard and Roberto both identified the significance of pursuing a deeper understanding of their individual experience by gaining knowledge about their background and history. This allowed for the contextualisation and individualisation of their situation and emotional experiences. Through this process, the importance of understanding and prioritising the service user as a whole person was highlighted:

“He’ll ask me more questions to make sure that he understood, not just my words, but where I was coming from, and what that related to. He asked for any extra context and extra background. I think that shows a genuine understanding and therefore compassion.” (Gerard).

“It’s not only empathy, it’s trying to understand. If I had to put it in an abstract example, it would be two different people that were in the same dramatic experience, you cannot put them in the same box or bucket, because they’re different. One might have been more affected or have completely different background, culture, beliefs. You have to take all that into consideration.” (Roberto).

Developing an accurate and empathetic understanding of the service user’s experience was also identified as a key aspect of the humanising response. In their extracts, Kabir and Karen stressed how significant it had been for them to feel understood:

“To have someone who then can repeat it back to you in a synthesise way and puts it in a better light, I felt that was very useful. And I guess that was probably why I found him compassionate, because he was able to listen and

when he responded back, he showed he understood.” (Kabir).

“I felt she really understood what I was talking about. And that was just the feedback she would give me in conversations. Her response to whatever I was saying told me that she understood.” (Karen).

3.2.2.3. *Acting to Meet the Individual Needs*

Genuine concern and understanding of the experience were considered essential but insufficient for a response to be considered compassionate. An externalised response aimed at alleviating the person’s distress also had to be performed by the service or the individual therapist. This included the identification of relevant resources and the suggestion of potential ideas or strategies.

Within this subcategory, providing a prompt response to the person’s request for help by facilitating access to the support available was described as compassionate by Kabir and Theresa:

“I think that was a nice thing, how quickly they kind of responded. And I guess that’s possibly a key part of compassion, because you’re craving some kind of relief, the fact that they were quick to respond felt like a massive help at the time.” (Kabir).

“Being compassionate as a service would be like reaching out to people, particularly if it’s people that are feeling low and struggle with speaking out.” (Theresa).

Central to many participants’ accounts was a sense that their physical and emotional comfort and safeness was promoted. This involved displaying certain nurturing behaviours reflecting warmth and calmness:

“I think you make a point of displaying as friendly face as you can. I think you talk in a soft voice; you try to put people at ease. So, trying to make the basis for the interaction as comfortable as possible.” (George).

“For some people, it takes them quite a long time just to feel comfortable. So, I think that in order to create a compassionate environment, you need to have enough time to make the person feel comfortable.” (Theresa).

Adapting the support provided to the unique needs, preferences and characteristics of the individual was also seen as a key aspect of compassionate care:

“Everybody wants to be treated as a unique individual, not as a pack. When it comes to mental health that is a clear priority because each case is very unique, and each person has a very specific issue affecting them.” (Morgan).

“I suppose that kind of personal attention and adjustment to the uniqueness of an individual is something I associate with compassion.” (John).

Filipa noted how a level of flexibility is required in order to adapt to the person’s unique situation and meet them ‘where they are at’:

“I had 16 sessions, but some people will need much more. It depends also in your culture, how depressed you are...some people can literally not understand a simple sentence, so it depends where you are at.” (Filipa).

When describing compassionate care, participants also referred to situations when their views, worries and emotional expressions were enabled and accepted. Filipa expressed how much she valued having a space where she was able to express herself freely:

“If I start to cry, they give me time to cry. That’s very important, to give you time. That’s how they get our trust. To let me speak about whatever I want. I can speak about my parents, maybe I think it is related with the way they raised me, and they will listen to that. All the situations. I can say ‘yesterday I was upset because I broke an egg’ and they will listen to that’.” (Filipa).

3.2.2.4. *Empowering the Person*

This subcategory relates to the service valuing, nurturing and developing service users’ strengths and potentials. Through this process, the service assists the person by increasing their confidence and their ability in managing their distress and achieving their goals. Participants highlighted the importance of being provided with relevant information, skills and resources so that they could do things for themselves.

Morgan described the process of empowerment as respectful of the person's ability and capacity for change:

“It is compassionate because it's respectful of your mind; to empower you to use mechanisms in your head, to give you the power to hold it. It is not patronising. It acknowledges that you have an issue, and that you also have a very powerful tool, which is your own mind, to work on that issue. Compassion is not pettiness, but to feel the pain of the other person and trying to give them the tools to work through that pain.” (Morgan).

Empowering service users also involved working in partnership by 'walking alongside' them instead of leading in the process. This was described as a mutual participatory activity in which professionals work to decrease the power differential. This involved being given choices as well as having their preferences respected. In doing so, the person was able to gain a sense of control over the process and, to an extent, over their life. In her extract, Theresa emphasised how she considered involving and learning from service users by listening and responding to their feedback, to be a crucial aspect of compassionate care. She described a process of collaboration based on mutual respect, shared responsibility, and cooperation:

“Maybe having community engagement events where people could feedback into the service. So, even things like this research; asking people to come back and do things like this. That's really good because it shows that you value the views of people that have used the service and I think that is being compassionate because it's showing that you appreciate people's experiences as valuable.” (Theresa).

Theresa stressed how crucial it was for her to be able to make decisions about the therapeutic intervention:

“What was good about IAPT was that it was focused fully around what I wanted and the goals that I set were my goals and then it was working towards that. I guess that would be compassionate care.” (Theresa).

Participants also felt empowered, and a sense of hope, when they were provided with reassurance. Gerard felt reassured when his distress was 'normalised'. This was done by highlighting that his response was a common human experience and

an understandable reaction to his situation:

“I've had some complications and things in my life, and just from saying ‘it's understandable that this would make you feel this way and it's absolutely normal that you would respond in such a manner’, because when you feel absolutely crazy, there's nothing better than a professional saying the behaviour you are exhibiting is normal.” (Gerard).

3.2.2.5. *Creating a Secure Relationship*

The type and depth of the service user- IAPT relationship was a defining feature of compassionate care for participants. The development of a secure relationship, deemed to be safe and effective by the service user, was a central aspect of the ‘humanising response’. This type of relationship was seen to involve five main dimensions: consistency, certainty, positive regard and acceptance, authenticity and the delineation of certain boundaries.

Anita and Theresa emphasised the importance of experiencing consistency in the relationship with IAPT which involved a certain degree of informational and relational continuity:

“I think continuity is important and if the therapist can't be there in person, to communicate by text or an email. So, you say ‘she's away, but she's thinking about what to do.’” (Anita).

“He would remember, like have notes of what I had said previously, and reference things that I'd said. That is, to me, showing compassion.” (Theresa).

For Filipa, demonstrating perseverance and patience in the relationship was essential, ‘not quitting’ on the person when changes are harder to come by:

“Some people may need more sessions till they understand what is going on. But, in terms of compassion, I feel that IAPT will not quit them. They will always have compassion for them and try their best.” (Filipa).

Participants also valued being provided with a level of certainty. Sonia particularly emphasised the importance of keeping service users informed throughout the

process, especially while they are on the waiting list to access therapy:

“Let’s say people are waiting for a period of time, maybe that can be communicated so that they don’t feel ignored. If you are in the other side and nobody comes back to you in a given time, you might not think they will come back. So, it’s maybe keeping them updated. That might be a good way of showing compassion.” (Sonia).

Authenticity was also identified as a crucial factor in providing compassionate care. Martha and Gerard’s extracts revealed how they value ‘real’ and ‘humane’ interactions in which professionals presented as sincere and reliable:

“I don’t want sort of ‘there, there, everything’s going to be alright’ type of compassion. I prefer it being realistic and practical (...) They are realistic when they don’t make exaggerations and big promises that they don’t know if they can be kept or not. Some people talk very airy-fairy and not practical. For me that’s important, being straightforward.” (Martha).

“I was having serious suicidal thoughts and I nearly acted on them, and at the end of our session he took a moment outside to say ‘I’m so pleased that you didn’t and that I got to see you again.’ And that for me was a genuine moment of compassion. It was a human being saying that they were glad that they got to see me again and that was a really positive display of compassion.” (Gerard).

Maintaining an attitude of non-judgement and acceptance towards the service user was identified by many participants as a necessary condition for a relationship to be compassionate:

“Not being judgmental is the most important thing. People may be uncomfortable or ashamed of their problems. If people feel that, even if you can’t understand, you can withhold judgments, you know, ‘you are not bad, or you have not failed’, they may be able to open up more.” (Anita).

While service users appear to value closeness and developing a meaningful relationship, participants also spoke about the importance of drawing certain boundaries in the relationship for it to feel safe and containing. John spoke about this dichotomy, referring to the importance of both maintaining closeness and distance in

the relationship:

“It’s important for a therapist to be slightly less close to my experience so they can observe it better. So, on the one hand, I want to feel like they are very close, but on the on the other hand, maybe I think it’s better if they’re not (...) It’s about sitting with them but not ‘in them’ or ‘on them’, you’re not exactly feeling their pain.” (John).

3.2.3. Category 3: Receiving a Dehumanising Response

Participants also shared experiences in which they felt compassionate care had been lacking. These experiences portrayed a sense that the person was given an impersonal response to their distress, attributing these encounters to the absence of the necessary conditions for compassionate care to emerge. These experiences were conceptualised as dehumanising responses.

3.2.3.1. *Lacking Genuine Concern*

Some participants recalled situations during their involvement with IAPT in which they had felt there had been an absence of genuine concern for them and their individual experience. George gave an example of an encounter in which he felt his difficulties were not validated:

“My issues might have seemed quite minor to my therapist, and I detected a slight bit of sarcasm. I went quite upset about my current job. Not necessarily the company, but my presence within that industry. And I think she took it as immature slightly. She said something like ‘have a good day, don’t get bothered by your job’.” (George).

3.2.3.2. *Disregarding the Individual Experience*

Participants also considered the service provided a ‘dehumanising response’ when their individual experience was disregarded.

Roberto’s account illustrates how he felt his experience was dismissed when the therapist did not respond to his disclosure and his emotional reaction:

“I was getting emotional talking about one of the most traumatic times and I felt she almost brushed it aside, and asked me something almost unrelated or almost like, ‘okay, let’s move on’. I don’t think you need to be a mental health

specialist to understand that you shouldn't just ignore what the person is saying.” (Roberto).

Adhering rigidly to predetermined understandings, such as personal assumptions or theoretical frameworks, was also described by some participants as being problematic by dismissing the uniqueness of the person's situation. George described how he have felt part of his experience was disregarded in order to fit within the service's therapeutic approach:

“She did talk to me for a bit, but as soon as she found something that could be CBT, we ‘CBTed’ it. I went in with an existential crisis and we worked on social anxiety because that got mentioned and the framework could apply to that, so then we did that, but I still didn't have any help on my essential crisis. So again, I didn't need CBT, I needed talking.” (George).

Karen reported that, for her, failing to show understanding of her experience was related to a lack of compassion:

“If they give me a rote or perfunctory answer where they would just repeat what I say or some sort of ‘pat answer’, you know, ‘that must've been hard for you’ with nothing else, then I would wonder whether they were really getting it.” (Karen).

3.2.3.3. *Neglecting Individual Needs*

A 'dehumanising response' was also considered to emerge when the service did not attend or care for the service user's individual needs. In relation to this, Morgan spoke about the challenges he encountered during the referral process to access the support he needed:

“We are constantly having to call some sort of customer service. If you're going through a mental health issue and you find yourself going through the same thing, it's not very compassionate. It feels rather frustrating and more of a source of stress, rather than a source of relief.” (Morgan).

Kabir considered that the rigidity by which the service's therapeutic approach was implemented meant that his individuality was not taken into consideration. He perceived the intervention was not tailored to his unique experience and need,

describing it instead as a standardised or 'mechanical' approach:

"In terms of the CBT stuff, 'make sure you're doing small tasks and keeping busy'. I didn't think that was my problem. I could get off and do some exercise, do some shopping, keeping myself in some robotic type situation but I didn't feel that was my problem and I felt CBT didn't seem to really address those issues (.) It did feel a little bit uncompassionate in terms of the actual therapy itself." (Kabir).

3.2.3.4. *Taking Away Choice and Control*

When describing compassionate care some participants shared examples of situations where they have not been allowed to input on the intervention. Instead, decisions were made for them and they felt they lacked control over the process:

"She decided we talk about one topic. I've gone there with a few different topics, and she suggested to me to narrow it down. She did a couple of sessions with me on that second thing, but then decided that, despite my experience of it, it was less of a concern than the topic she picked for us." (John).

"I didn't feel that there is a different option. You know, if I went to her and say 'look, this list of tasks is not really working for me', I don't feel there is another option." (Anita).

3.2.3.5. *Developing an Insecure Relationship*

Lack of consistency in the relationship with IAPT presented in different ways for participants. Martha spoke about how she was allocated to multiple therapists and felt she had been "push on" by them:

"Certainly, it was the third therapist who kept me there... the first one was sweet, but she was just too 'push me on'. They seem to work that you see someone, and they then diagnose whether you need more or who you need. That's how I understood it. And then I went to a second one, who I didn't get on that well with, and she was again just there to 'push me on', and I couldn't know what their criteria are because I certainly wasn't sobbing." (Martha).

Participants also considered their relationship with IAPT was 'insecure' if there

were breaks in the communication, leading to a lack of continuity which they considered impacted negatively on the therapeutic process:

“I don't think it's very good to have so many breaks. If they are seeing someone, it needs to be consistent so if they are away on training and it can't be avoided, perhaps they could offer to support the patient via email. Such a complete cut off period is just too long, and I don't get motivated.” (Anita).

Some participants also experienced certain aspects of their engagement with IAPT as ambiguous and imprecise, describing the flow of information as “vague” and “obscure”. Gerard expressed a need for more clarity and certainty in the process:

“Just bridging the gap, making you know that you've not been forgotten, and that help is coming. Because it is quite vague. It'll be like ‘it might be three to six months.’ You've got severe anxiety and low mood, and someone gives you a margin of three months. It's quite an agonising wait.” (Gerard).

Placing personal judgements or ‘conditions’ on accepting the person was also regarded as incompatible with compassionate care. For example, Anita considered her therapist’s acceptance had been determined by her performance, assuming that failure to complete her homework would have led to criticism:

“I do feel that I might be judged. I don't know why, maybe she wouldn't. But I do feel ‘oh no, if you haven't completed it...’ It's like homework, if you have not done homework, you're a fool already.” (Anita).

3.2.4. Category 4: Conditions Facilitating or Inhibiting the Humanising Response

Overall, there appeared to be a consensus that compassionate care was facilitated or impeded by a range of conditions which were individual, relational, service-based and contextual. In circumstances where conditions were mostly facilitating of compassionate care, humanising responses could be enabled. In circumstances where there were conditions failing to ensure compassionate care, dehumanising responses had the potential to emerge.

3.2.4.1. *Individual Conditions*

This subcategory pertains to participants’ perceptions of individual conditions that may influence compassionate care in IAPT, including therapists’ inner capacity for

compassion, learned skills, clinical experience and emotional wellbeing.

Some participants considered IAPT therapists required certain innate personality traits that predispose them, and allow them, to feel and to act compassionately towards others. George maintained therapists' compassionate qualities were likely to be already present before commencing their training:

“Your level of empathy and compassion, I think, come partially genetically in you, partially they are predisposed and partially how you develop as a person. While I believe formal training could influence that, I'm not sure that there's a direct causal relationship. I think it's more down to one's character and how one's character develops than to one's training.” (George).

Participants also made reference to certain extrinsic factors that they saw as influencing the ability to provide compassionate care. For Filipa, for example, early education played a key role in inculcating certain values which will then lead to the person behaving compassionately:

“I know exactly because I was born in a very healthy and nice family, if you get good values from them, you will know what compassion is. You will know how to behave yourself. I think this compassion concept starts from your education and then school and then friends.” (Filipa).

In turn, Roberto spoke about the need for practitioners to acquire specific skills through formal training:

“I suppose that all the training that they go through (.) they necessarily have to be able to pick up signs, certain things that, ‘normal people’ [laughs], just non- practitioners, who might not be able to pick up on certain facial expressions or body language. When you then bring in those things together you have someone who has the capacity to do compassionate care.”
(Roberto).

Morgan believed practitioners increase their understanding and knowledge by gaining clinical experience which, in turn, enables them to provide compassionate care:

“The more practitioners are introduced to these situations, the more they are

able to see what compassion means and how they can actually understand it. Experience is primordial. It is not the same the first time you see somebody who is having a mental health issue than the 20th time.” (Morgan).

However, Gerard offered a conflicting account, suggesting that more experienced clinicians may develop compassion fatigue:

“I would say the biggest barrier for compassion is that it doesn’t become trivial or normalised or boring. Something you can notice in older doctors.” (Gerard).

Referring again to emotional suffering as a shared human experience, participants considered staff’s own wellbeing as a key factor influencing the service’s overall ability to provide compassionate care. Participants stated that if therapists were themselves struggling emotionally, this could lead to them losing motivation, interest and ability to empathise with people’s concerns:

“I think like staff wellbeing is really important for compassionate care. I think if the staff aren’t well themselves or exhausted, then you can’t really have a compassionate service.” (Theresa).

“You got to be very empathetic in that job and I think she was too nervous, too self-worried, but she didn’t do anything wrong, it’s just, she wasn’t calmly, it just didn’t click with me.” (Martha).

3.2.4.2. *Relational Conditions*

Having some sort of connection with the therapist, such as sharing cultural references or a similar sense of humour, was seen as facilitating the development of a relationship that felt compassionate and ‘humanising’:

“I even have a hysterical story about the King of Greece, and she didn’t even think it was funny and I thought, ‘Gosh’ (.) and I feel, if you’re going to get help, you need to be on a similar wavelength. You need to bond with the person.” (Mary).

“Having a British man, he is better able to relate to me and the kind of things that I have experienced growing up here and as my gender, how school might have been, how family might’ve been. When it comes to mental health, there are cultural nuances that people are only going to be fluent in if they’ve

experienced it for a long time.” (Gerard).

Some participants referred to service users’ emotional and interpersonal issues as having the potential to affect their relationship to help which, in turn, may impede or facilitate compassionate care:

“There are some people that their symptoms can manifest in attention seeking ways and that can be quite difficult I think for a professional, and quite trying, to be compassionate”. (Gerard).

John described how experiencing some emotional reaction to service users’ experiences was seen as helpful to understand and navigate what the person is feeling, and to be motivated to produce a compassionate response:

“Being in the place of the observer, noticing their own emotional responses, is a very powerful tool. For example, if I'm volunteering at a helpline, and I'm hearing things that I find distressing, I can just notice what I'm feeling, and I am feeling upset by this and that allows me to keep listening.” (John).

In contrast, George considered that developing intense feelings could be exhausting for therapists, affecting their own wellbeing and, in turn, their ability to be compassionate:

“How are you going to consume yourself feeling for them? I think that would be a very difficult thing for someone. I feel that would be very taxing on one's mental and sentimental energy. So, if I were in that position, I would honestly do my best to not feel compassion”. (George).

3.2.4.3. Service Conditions

A number of factors at the service level were identified as influencing the type of response to people’s distress given by IAPT, including environmental ambience, level of support offered to staff, staff’s workload and service resources.

George explored how the physical characteristics of the therapeutic setting could affect the provision of compassionate care by promoting or hindering comfort and openness:

“The environment feels a bit clinical. I would not put the environment for a source of compassionate care. It feels a bit more like an emergency ward than a place to open-up.” (George).

Karen, among other participants, identified as essential for therapists to be supported by the system:

“When you have happy employees, they do a better job than if they're unhappy. So, the organisation has to support its employees. That is number one.” (Karen).

Staff's workload was also seen as having the potential to challenge their ability to provide compassionate care. Roberto explained how a high workload, which is physically and mentally demanding, may lead to therapists feeling overwhelmed and stressed and can also compromise their ability to provide a 'humanising response' that is flexible and dedicates sufficient time to each person:

“If you have to do, I don't know, six appointments per day, and you are going to hear some very difficult things and very serious things. And just not having the flexibility, not only would that impact the practitioner in ways that I cannot properly understand, it would also like 'oh, I have to hurry it up because I have someone just after you'.” (Roberto).

The level of resource available was recognised as a crucial aspect affecting many of the conditions previously identified and, in turn, the type of response provided by IAPT.

Gerard emphasised how lack of funding could affect other resources, such as time and staffing levels. These, in turn, if insufficient, could impede the provision of key elements of the 'humanising response', such as the ability to tailor the support provided, to give time to the person and to remain present:

“What could really make it easier is resource from funding. I think compassion is always going to come down to feeling like a human being. You can only feel like a human being if there is a personal touch to things. And there can only be a personal touch to things if there is adequate resource available, you can't make someone feel cared about if you can't give them any time.” (Gerard).

3.2.4.4. *Contextual Conditions*

Finally, wider socio-contextual, historical and political factors were also identified as affecting compassionate care in IAPT.

In their extracts, Martha and Roberto described the impact of certain societal discourses and attitudes on compassion:

“I would say in the fifties, no one thought about mental care. No one thought about compassion. The world has changed enormously apart from all the computers and everything else. Just the attitudes and things. I mean, homosexuality was illegal, you know.” (Martha).

“We should have a look at the society as a whole because you can try and just focus on one piece of it, everything is interconnected. So even though you potentially can improve small amounts on these types of services, if you don't address culture, there is only so much we can do.” (Roberto).

3.2.5. Category 5: Response Dependent Outcomes

Participants spoke about the impact of receiving (or not) compassionate care. ‘Response dependent outcomes’ were perceived to be contingent on the type of response given by IAPT (i.e. ‘humanising’ or ‘dehumanising’).

3.2.5.1. *Level of Trust*

Service users appear to be more likely to trust the service and their therapist when they experience care that is compassionate. When asked about the impact of being treated compassionately, Karen described how it had led her to experience a greater sense of trust towards the therapist which, in turn, had facilitated her engagement and openness:

“It allowed me to have quite a bit of trust in her. And it allowed me to be very open. If I felt like there wasn't, you know, true compassion there and understanding, and a desire to help, I would not feel like I trusted the therapist.” (Karen).

3.2.5.2. *Level of Relief*

Service users appear to experience a sense of relief when they are given a

compassionate or 'humanising' response to their distress.

Kabir described how he felt relieved by being understood and reassured after speaking about his difficulties:

"This person, who I finally managed to tell I had a depressive episode, was understanding. He was able to kind of explain to me 'people do go through this, don't worry about it, it's normal and we can find help'. I guess that gave me the sense of relief. It made me feel very, so I guess warm or...grateful because it was a nice sense of relief." (Kabir).

In contrast, Morgan considered that a lack of compassionate care (i.e. the dehumanising response) could lead to the person experiencing increased levels of stress and anxiety:

"If you're going through a mental health issue, and you find yourself going through the same thing that is probably one of your biggest sources of stress to deal with your mental health, it's not very compassionate. It feels frustrating and more of a source of stress, rather than a source of relief." (Morgan).

3.2.5.3. Level of Purpose

Participants considered compassionate care was crucial for service users to be meaningfully engaged with the service.

Theresa and Anita spoke about how it was imperative to feel that they mattered and that their engagement with the service was of some importance, so they could experience a sense of motivation and purpose:

"It feels like it's a compassionate service if it does that because it's like you are like this something, there's an importance to like you being engaged with the service." (Theresa).

"I'm not saying she doesn't care, but it doesn't feel as I am important, to continue. She's gone training and she drops everything, that means I have to do it by myself but now I am not motivated, so I am not doing it." (Anita).

3.2.5.4. *Level of Satisfaction*

The type of response provided by IAPT was considered to impact service users' level of satisfaction with the overall service. Sonia described her experience with IAPT as positive as she had perceived the service to be compassionate:

“Because my experience here has been very compassionate, everywhere I go I always give people the website and I tell them to refer themselves, because my experience was very positive.” (Sonia).

For Theresa, her first experience with the service lacked some of the elements she considered essential for compassionate care. As a result, her initial opinion about the service had been negative. However, she experienced her second engagement with the service as compassionate which increased her level of satisfaction:

“I then had this recent service and my opinion completely changed and I was like, ‘this is completely what I needed and wanted’. Had I not had this experience I probably wouldn't have the best opinion of the service.” (Theresa).

3.2.5.5. *Level of Engagement*

Finally, the type of response given by the service was perceived to affect service users' level of engagement. When asked about the effects of compassionate care, Theresa reported it had made her more engaged and satisfied with the service:

“It made me more engaged with the service. It showed me there was a lot of effort going into it and it was really individualised and not just a service that just provides the same service for everyone.” (Theresa).

In contrast, Kabir considered a 'dehumanising response,' which was delayed in providing help to the person, was likely to prompt service users to disengage from the service, even if they still needed support:

“Because you're not getting that immediate relief, it's very frustrating and with anxiety and stress, frustration is like one of the last things you want to be encountering. It's very easy to go, ‘well forget this, I got no time, this isn't helping me and this voice telling you to step away from it, which one shouldn't be doing.” (Kabir).

4. DISCUSSION

This chapter will consider the findings of the analysis in relation to the research questions and relevant literature. This will involve eliciting links with previous knowledge and highlighting new insights that have emerged from the data to inform compassionate care in the context of IAPT. A critical and reflexive review of the research will be provided, before reflecting on the limitations and implications of the study.

4.1. Discussion of findings

The model 'Humanising Responses to Distress' (Figure 3) was constructed based on the experiences and views participants shared throughout the course of data collection. The qualitative data gathered addressed the following research questions:

4.1.1. What do users of an IAPT service perceive compassionate care to involve?

Participants alluded to the complexity of compassionate care, describing it as a multidimensional and dynamic concept, which is consistent with previous empirical studies where compassionate care was conceptualised as an integration of a range of virtues, skills, attributes and behaviours (Dewar & Nolan, 2013; Smith-Macdonald et al., 2019; Tehranineshat, 2018). Despite some level of diversity in interpretation, a degree of accord among participants was found. The process of providing a 'humanising response' to the person experiencing psychological distress was the core variable constructed from the data.

Humanising responses involved treating the service user as an individual human being, respecting their unique way of thinking and feeling, and facilitating their active participation in the therapeutic relationship.

While humanising approaches have been proposed in the healthcare literature to a significant extent (Todres, Galvin, & Holloway, 2009), compassion was only recently characterised by humanising approaches in Straughair et. al's (2019) study investigating perceptions of compassion in nursing. Here humanising approaches were described as dependent upon the equilibrium of character, competence, motivation, connecting and action.

Participants evaluated their experience with the service in its totality. Consequently, the process described in the model operates, not only in the individual and service user-therapist relational spheres, but also at systemic levels, and throughout their

involvement with the service. In previous empirical studies (Badger & Royse, 2012; Sanghavi, 2006) participants also integrated the totality of their experience with the service in their definitions. This finding highlights the importance of addressing the provision of compassionate care from an organisational, cultural, and team-based perspective, a consideration already highlighted in both theoretical (Cole-king & Gilbert, 2011; Fernando & Consedine, 2014) and empirical studies (Horsburgh & Ross, 2013; Nijboer & Van der Cingel, 2019).

4.1.1.1. *Psychological Distress*

Suffering, the experience of pain or distress, is often cited in theoretical conceptualisations as a preceding factor to the compassionate response (Goetz et al., 2010). Likewise, this research identified psychological distress as an antecedent to the provision of compassionate care. Distress was described as a human response to life adversities, such as bereavement or employment stress. This conceptualisation is in agreement with social and psychological discourses which understand people's distress within their life contexts (Johnstone, 2018).

Nonetheless, study participants also used diagnostic categories (e.g. depression, generalised anxiety) to describe their distress, probably as these labels are given to service users during their initial IAPT assessment (NHS England, 2019)

Distress was considered to have a negative impact on people's wellbeing, thought processes and behaviour. As a result, they feel disconnected and, to a certain extent, 'dehumanised'. As distress was regarded as a shared human experience, it was seen as ready to be recognised and addressed by other human beings (Jull, 2001), in this case, the professionals in IAPT. This is illustrated in Gerard's statement: *"I think compassion comes quite naturally to anyone who's not a sociopath. A human should be able to identify another human who's hurting."* A condition of compassionate care not previously identified in research within medical settings was that, in IAPT, the person had to regard their situation as requiring help from others and be open to receiving that support from the service. This is in line with Rogers (1957) who identifies as one of the conditions for therapy for the client to be motivated to engage.

4.1.1.2. *Compassionate care: A Humanising Response*

Compassionate care in IAPT involved a particular type of response to service users'

distress seen as 'humanising'. 'Humanise' is defined in the dictionary as 'making something more pleasant or suitable for people'; 'showing that someone has the qualities that are typical of a human' and 'making someone or something kinder, gentler, or more agreeable' (humanise, 2020). The five key processes identified as conforming the humanising response in this study encompassed all three definitions, while also adding further aspects. These are: experiencing genuine concern for the person, striving to understand their individual experience, acting to meet their individual needs, empowering the person and creating a secure relationship.

Participants regarded this response to be 'humanising' as it recognised, accepted and prioritised the person's humanity and their uniqueness, identifying and respecting their needs. Compassionate care was also described as humanising by involving interactions and relationships founded on the shared experience of being human which enables a sense of connection. Thus, this response individualises the person, while it is also dependent on the development of effective human relationships. This finding parallels the literature on compassion involving relationship-centred and person-centred approaches (Dewar et al., 2014; Gelhaus, 2012; McCormack & McCance, 2011). It also supports the patient model developed by Sinclair et. al (2016) which sees the relationship between care providers and care receivers as compassionate when they relate to each other "as fellow human beings" (p.196).

- *Experiencing Genuine Concern*

Compassionate care involves the therapist, or the service, experiencing genuine concern and interest in the person and in their wellbeing. This includes acknowledging and validating the seriousness of their difficulties, and their impact. The extent to which therapists actively connect with the person's emotions by positioning themselves 'in their shoes' (emotionally and intellectually) was also seen of vital importance. This connection, also identified by patients in Sinclair, McClement, et al.'s research (2016), is seen as a crucial mechanism to stimulate motivation/action for compassion (Dewar, Pullin, & Tocheris, 2011; Lown et al., 2011). Motivation was considered to arise from an intrinsic eagerness to care for people which led to prioritising their needs over other tasks.

- *Striving to Understand the Individual Experience*

The second element of the humanising response, striving to understand the individual experience, was defined as “paying attention and being present in order to learn about the person and their needs and develop an accurate empathetic understanding”. Therefore, there needs to be a real attempt to know the service user as a whole person (i.e. their background, history and values), trying to understand how they feel and think, and what their needs are. This finding connects with Adamson et al. (2017) who found patients valued being known as an individual, instead of regarded as just a number or diagnosis. As this involves respecting individuality, difference and diversity must be acknowledged while removing prejudices and stigma (Lloyd & Carson, 2011). A certain degree of curiosity is needed to develop a genuine understanding of the person’s experience. In doing so, the therapist acknowledges its complexity and avoids making simple assumptions.

Attentiveness was identified as a key aspect in this process, which translated into a particular kind of verbal and non-verbal communication (e.g. eye-contact, paraphrasing). By being present, the therapist is able to focus upon the diversity of what needs to be done to support the person (Lloyd & Carson, 2011). Along this line, van der Cingel's (2011) study examining older people’s perspectives of compassion in care also found paying attention by engaging in active listening as a key element. When service users’ concerns, reflections and emotions are consequently responded to and interpreted, an accurate and empathetic understanding of their experience develops.

- *Acting to Meet the Individual Needs*

Timely and attuned actions, that actively and tangibly address the person’s needs, are also necessary for the response to be compassionate (e.g. meaningful resources, practical suggestions). This has been previously described as an important demarcation from empathy (Post et al., 2014; Von Dietze & Orb, 2000). When implementing these actions, the person’s physical and emotional comfort must be promoted by displaying nurturing behaviours that reflect warmth, safeness and calmness. This could be understood from Gilbert's (2005) compassionate mind approach which identifies compassion as a process whereby negative affect is soothed through positive social interactions.

Support must also be tailored to the person's preferences and characteristics, including capacity and capability, meeting them 'where they are at'. Therefore, to be compassionate, a personalised and flexible, rather than homogenised or 'one-size-fits-all', approach must be taken (Bramley & Matiti, 2014; Straughair et al., 2019). Within this, supererogatory acts, whereby therapists went 'the extra mile' to meet the person's needs, were identified as meaningful and key turning points. For example, John stated: *"He took me into the garden to do an exercise based on stopping me dissociating and looking at flowers. That to me was the heart of compassion. His adaptability, his responsiveness to what was in front of him."*

In this sense, there seems to be a considerable overlap between compassionate care and person-centred care, a parallelism previously noted in theoretical and empirical research (Adamson et al., 2017; Brown et al., 2016; Cornwell & Goodrich, 2009). In the 'Compassion in Practice: One Year On' report (NHS England, 2013), compassionate care was described as a requirement for person-centred care: "Person-centred planning requires understanding the individual (...) To achieve this, compassionate care through active listening is essential." (p.47). Santana et al. (2018) also consider compassionate care to be an interpersonal phenomenon within person-centred practice, involving an empathetic and reassuring response which allows for sensitivity to emotional and psychological needs. This appears to be congruent with participants' description of 'Genuine Concern' in the model.

Compassionate care was also seen as providing an open space where any communication or emotional expressions are enabled and accepted, without restrictions. In line with this, Nilsson, Svensson, Sandell, and Clinton (2007) found that service users sometimes consider that learning techniques or discussing homework are not helpful as they prefer to talk openly about anything they want.

- *Empowering the Person*

Empowering the person also emerged as a prominent element of compassionate care. Empowerment is a philosophy whereby service users are regarded as competent and of equal value (Rolvsjord, 2004); supporting power from within them, instead of over them. In IAPT, this is enacted through the provision of knowledge and resources which enable the person's independence and agency (Lloyd & Carson, 2011). Partnership working and shared decision making, whereby the service user is included in the articulation of their therapeutic plan, were also

identified as key empowering strategies (Nolan et al., 2004; McCormack & McCance, 2010). Collaboration, which depends upon mutual trust and respect, helps to ensure that compassionate care takes place by preventing oppressive relationships from developing, as narratives of service users and therapists are given equal recognition (Lloyd & Carson, 2011).

Enabling informed choice, so that person feels in control, was also identified as a humanising process. Considering service users' preferences and autonomy shows respect for them as human beings by not taking over their life. This is consistent with findings in a burn survivor sample (Badger & Royse, 2012) where participants highlighted the importance of having choice within their capabilities. There is a growing cognisance that patients must be enabled to have an active role in making decisions about their treatment (Zolkefli, 2017). In mental health this is particularly emphasised by recovery-orientated practice whereby providers offer choice, putting the service user in control so that care plans reflect their voice (CQC, 2020).

Participants also felt empowered and more hopeful, when they were reassured by having their distress described as a 'normal' human experience. Normalisation is meant to be a central process in CBT, which can make the person feel less alone in experiencing certain feelings or thoughts and enhances their self-esteem (Clark, 2013). This has also been found to enable a feeling of connection to, rather than separation from, others (Neff, 2003).

- *Creating a Secure Relationship*

The development of effective therapeutic (and humane) relationships was evident in the findings as a fundamental aspect of compassionate care. This relates to Gilbert's theory (2009) of compassion creating human connection and affiliation. The significance of forming meaningful relationships was also identified by patients in Adamson et al.'s study (2017) as well as in research exploring professional (Lown et al., 2011; Perry, 2009) and collective perceptions (Kneafsey et al., 2016; Sanghavi, 2006). This study further supports these findings by including the perspectives of individuals in a non-physical health environment.

Coping with emotional distress can be testing. Consequently, participants welcomed developing a relationship involving genuine care, continuity, certainty, authenticity

and positive regard. While these aspects have not been explicitly elicited in previous research on compassion, they are often cited in psychology literature examining therapeutic relationships. The idea of the therapist as a secure base is in line with attachment theory (Bowlby, 2005); within the safety of the relationship with their therapist, clients are able to explore their relationship with self and others. A sense of security, or safety, is achieved when the therapist/service is consistent, reliable and trustworthy (Skourteli & Lennie, 2010). Examples whereby continuity and certainty could be attained included having regular contact, remembering previous conversations and keeping people updated. The notion of a boundaried relationship, also informed by attachment literature (Farber, Lippert, & Nevas, 1995), also emerged as an element facilitating security. While recognising the person's emotional states is essential, the therapist's emotions need to remain in balance by maintaining certain distance to prevent avoidance or overidentification (Neff, 2003). The importance of drawing boundaries between the professional and the personal was also identified as an element of compassionate care by patients with intellectual disabilities (Brown et al., 2016).

Positive regard and acceptance, suspending moral judgements and remaining open-minded, and authenticity were also regarded as crucial to compassionate interactions. Unconditional positive regard and 'congruence' (i.e. genuineness) are emphasised in Roger's humanistic psychology (1959). Supporting someone overcoming their distress, which may be very debilitating, requires continued hope and optimism even during periods of increased distress (Firth-Cozens & Cornwell, 2009). It is in the consistent and persistent actions that proof can be found of an ongoing commitment to support the person. Patience and persistency were also found in another study describing compassion in mental health care (Lloyd & Carson, 2011).

While similarities between the model constructed and person-centred care were identified, forming a secure relationship is not emphasised in the latter. Current person-centred care guidelines (e.g. Health Improvement Network South London [HINSL], 2014) highlight the importance of respecting individuality by considering people's preferences, values, and needs. Person-centred care is also seen as enabling by promoting a partnership approach whereby patients are supported to make informed decisions (The Health Foundation, 2016). The emphasis on

respecting and promoting individuality, together with notions of partnership work and empowerment, mirror aspects of the humanising response. However, while early descriptions saw person-centred care as being achieved in the context of relationships (Kitwood, 1997; Rogers, 1959), the current usage of the term highlights aspects related to autonomy and independence and, although there is reference to partnership work, definitions fail to explicitly convey the intricacies of the interdependencies and reciprocities underpinning therapeutic relationships. This has been highlighted by Morhardt & Spira (2013) and Nolan, Brown, Davies, Nolan, & Keady (2006) which call for more attention to be paid to relational aspects. The inclusion of an explicit definition of the relationship dynamics service users wish to encounter when accessing IAPT may complement the current person-centred framework.

4.1.1.3. *Lacking Compassionate Care: A Dehumanising Response*

Participants also shared experiences in which they felt compassionate care had been absent. These included, for example, encountering barriers to accessing the service or being responded to with perfunctory answers that failed to show understanding. Participants also felt their experience was dismissed when therapists appeared unfocused, unresponsive or adhered too rigidly to a predetermined theoretical framework or standardised approach. Bystedt, Rozental, Andersson, Boettcher, & Carlbring (2014) found that when therapists adhere rigidly to the CBT protocol, clients do not feel understood or validated. Moreover, in these situations, clients tend to perceive the therapists as intrusive, disengaged or withdrawn, not providing the support they want or need (Nilsson et al., 2007). When staff are perceived as simply “going through the tasks”, even if the intervention is perceived as appropriate, the ‘human touch’ is missing. This leads to service users feeling objectified, rather than individualised, as their needs and preferences are not considered.

Lack of choice was also related to dehumanisation of the individual. For example, participants who were only offered CBT but had preferred a different approach felt their views and wishes were disregarded. Similarly, Omylinska-Thurston et al. (2019) found some IAPT clients worry that CBT was not suitable for them but they were offered it as a “go to therapy” without consideration of their individual needs. The findings from a cross-sectional survey suggest that people who express a preference

that is not met are less likely to describe their psychological intervention as helpful (Williams et al., 2016). Lack of communication and unclear arrangements also resulted in unsatisfactory care. For example, during transitions (i.e. from referral to initial assessment; from low to high intensity therapy), the service failed to keep participants informed and contact was interrupted. Such instances indicated a failure to acknowledge and respond to service users' needs, as they reported feeling ignored, confused and alone with their difficulties. Although the inevitability of transitions was understood, participants felt more could be done to provide a sense of continuity and certainty. Previous studies have also identified effective and sustained communication as essential for compassionate care (Bramley & Matiti, 2014; Dewar et al., 2011).

These critical points seemed to function as catalysts in exposing the weaknesses in the IAPT system. Labelled as 'dehumanising', these responses make service users feel ignored and disregarded and fail to acknowledge therapist and service user's shared humanity, emphasising instead the relationship's power imbalance.

4.1.2. What are the facilitators and inhibitors of compassionate care in an IAPT service?

A range of biopsychosocial conditions operating at four interrelated levels (Individual, Relational, Service-related and Contextual), were seen to influence compassionate care in IAPT.

- Individual Conditions

At the individual level, an innate capacity or intrinsic disposition for compassion is required (Straughair et al., 2019). This was apparent in therapists who exhibited certain 'prosocial' traits (e.g. patience, kindness, attentiveness) (Ashton & Lee, 2009). Patients in previous empirical studies also identified a range of necessary attributes for compassion (Sinclair, McClement, et al., 2016; van der Cingel, 2011). This research advances understanding of this in the context of IAPT, elucidating that some therapists are perceived as possessing an enhanced dispositional character for compassion. Although it was beyond the scope of this study to discern the causes for this, previous findings suggest it relates to a greater ability to recognise the needs of others (Ashton & Lee, 2009) and increased self-regulation (Hewitt-Taylor, 2015). These attributes, identified as a baseline foundation for compassionate care, were seen to be nurtured and moulded by a

range of factors including parenting, role-modelling and education. Childhood experiences were regarded as particularly vital in fostering compassion, evidenced by participants indicating that this was the reason why they were compassionate themselves.

Although these claims are supported by psychological research (McCrae, 2011), the current findings generate new insights from the perspective of service users.

Clinical training was also considered of utmost importance. Tunney (2015) argues that competence for compassion can be cultivated through formal educational strategies. Some participants suggested training should involve interpersonal and communication skills. In Bray et al.'s study (2014), clinicians reported that formal learning of these skills increased their ability to understand patients. However, in this study, participants emphasised the importance of learning from real life case experiences to develop an insight into the individual perspective (Mead, 1934).

The therapist's emotional state was seen to impact on their capacity to empathise and on their motivation to help. Current research shows therapeutic burnout and compassion fatigue can limit the ability to provide compassionate care (De Figueiredo et al., 2014). Interestingly, while most participants referred to clinical experience as a facilitator of compassionate care, two participants hypothesised the risk of compassion fatigue was likely to increase with years worked which could impact negatively on compassionate care. Previous research has found, conversely, lower experience in job to be associated with increased stress (Cushway & Tyler, 1996). A range of mediating factors may explain this difference.

- *Relational Conditions*

At a relational level, service user-therapist commonalities, such as shared life experiences or background, were perceived to facilitate compassion. This was referred to as “being on a similar wavelength” and “clicking”. Some participants preferred to work with a therapist of the same ethnicity or cultural background which coincides with previous research (Chang & Yoon, 2011). Singh, King-Shier, & Sinclair (2018) found that, while patient-clinician ethnicity concordance was not associated with enhanced compassionate care, cultural sensitivity does influence compassionate care negatively, if showing cultural ignorance, or positively, if demonstrating cultural competence and respect for differing values and practices.

Service users' relationship to help and interpersonal skills were also identified as conditions for compassionate care as they could limit or facilitate the ability to demand/request/accept/use support and to be open in the relationship. This resonates with Fernando & Consedine's (2014) study which suggests patient and family's characteristics are important influences on compassionate care. Expressions of hostility or ungratefulness can generate stress and resentment from clinicians, interfering with feelings of connectedness and compassion. Transference and countertransference were seen as helpful processes to understand the person's emotions. However, they can also be unhelpful if impacting the therapist emotionally and affecting their ability to be compassionate.

- Service Conditions

It was acknowledged that staff operate within specific service-based conditions which influence their capacity and motivation for compassion. IAPT facilities were described as 'clinical' which was not seen as conducive to compassionate care as it made people feel uncomfortable and less likely to open up. High workload and administrative demands were also identified as challenges to staff's efforts to provide holistic and humanising responses. These factors distract staff's attention away from connecting at a human level, in favour of attending to technical activities (Wright & McSherry, 2013). For some participants, this was reflected in a sense of being "passed around", feeling as a task to be completed. The literature suggests 'inattentive blindness' can affect the ability to recognise the needs of others when cognitive resources are invested in other activities, resulting in merely adequate responses (Paley, 2014; Zak, 2011).

Participants also assumed staff required reciprocal appreciation and support from managers and colleagues, claiming that if therapists are not treated with compassion, it is unlikely they would be motivated to treat others compassionately. In terms of Gilbert's (2009) model of emotion regulation, a compassionate environment promotes the activation of the soothing system. Conversely, environments and organisational aspects related to reduced compassion (e.g. high occupational targets, competing demands) can activate the threat system (Cole-King & Gilbert, 2011).

- Socio-contextual conditions

Historical time, location, political context and societal attitudes were all seen as affecting compassionate care in IAPT. The increased focus on individualist values in Western societies at the expense of affiliative and community values (Twenge, 2013), such as compassion, was noted by participants. Societal discourses and discriminatory attitudes, such as homophobia and racism, were also described as changeable over time and influencing negatively on compassionate interactions. This inevitably affects IAPT as a product of society itself. Individualist approaches have contributed to a consumerist effect (Ritzer, 2004), which has impacted psychological practice through the adoption of approaches focusing on quantity and standardisation. This was apparent throughout the findings, as examples of dehumanising responses often involved a rigid adherence to standardised approaches that failed to acknowledge individual needs.

4.1.3. What is the perceived impact of providing compassionate care in an IAPT service?

'Response dependent outcomes' were contingent on the response provided by IAPT. In describing the impact of the humanising response, participants felt it improved their wellbeing and the quality of the relationship with their therapist and with the service, improving their trust, engagement and satisfaction (Flocke, Miller, & Crabtree, 2002; Post, 2011). Following a compassionate interaction, participants felt "relieved" and experienced an increased sense of hope. In the Schwartz Centre for Compassionate Healthcare survey (Lown et al., 2011), both patients and physicians also suggested compassion bolsters patient trust and hope for recovery. Receiving a humanising response also makes the person feel valued, perceiving their engagement as meaningful, leading to increased levels of motivation. In previous studies, compassion was also found to make the person feel respected (Badger & Royse, 2012) and valued (Adamson et al., 2017) which was associated with feelings of self-worth (Woolhead et al., 2006).

Gilbert (2010) argues that human beings, as a social species, rely on the care and support of others to thrive and develop a sense of purpose, meaning, and hope. This research supports this argument from the perspective of service users. Psychological difficulties can overwhelm people, so that they begin to see themselves in terms of their distress and the sense of self can get lost (Lloyd & Carson, 2011). In this study, 'relieved distress' seemed to involve beginning to recognise themselves as a whole person again. These ideas are summarised in

Gerard's claim: *"When you suffer with mental health issues it's quite dehumanising. So compassionate care is humanising, and it is its own kind of therapy., At a time where you don't even feel like a person, you have people treating you like you are a person and that you're not too far gone, or that there's not any way to help you."*

Negative outcomes resulting from a dehumanising response were also noted. These experiences had an equally significant, albeit detrimental, impact on the therapeutic relationship, by resulting in serious breaks in trust with the IAPT system, leaving service users feeling ignored, confused and unsatisfied, and resulting in poor engagement and, even, in formal complaints. Dehumanising responses also impacted negatively on participants' wellbeing, often exacerbating distress in the process. Similarly, Cole-King & Gilbert (2011) suggest that the absence of compassion can result in feelings of confusion and stress. Previous research has found around 5% of people report lasting negative effects from psychological treatment (Crawford et al., 2016). Those not given enough information about the intervention or unaware of the type of therapy they received are more likely to report bad effects (Crawford et al., 2016). This may connect with descriptions of the dehumanising response in this study whereby participants felt they were not being provided with sufficient or consistent information and options which impacted negatively on their level of satisfaction.

4.2. Critical Review and Research Evaluation

There are differing perspectives with regards to the extent to which qualitative studies can be evaluated and the most suitable methods of evaluation (Spencer & Richie, 2012). With the aim of enhancing the quality of the study, Yardley's evaluative criteria were consulted throughout the research process as highlighted in the Methodology, Yardley (2000) proposes four criteria on which qualitative methodology should be assessed:

- Sensitivity to context
- Commitment, rigour and coherence
- Transparency
- Impact and importance

4.2.1. Sensitivity to Context

Sensitivity to context is evaluated by assessing the evidence provided to demonstrate that theoretical discriminations and conflicting observations were considered (Yardley, 2000). The GT methods applied (Appendices H and I) ensured that conflicted observations were accounted for, highlighting, for example, how the core processes of humanising and dehumanising responses were often in constant oscillation during the person's engagement with the service.

A further aspect of sensitivity to context relates to the need to locate the research within the relevant literature. While a comprehensive literature review was delayed until data collection and analysis were completed (Charmaz, 2014), a preliminary review of the literature was conducted to inform the research proposal. This provided a basic orientation to the historical origins of the term, political and professional reaffirmations and theoretical and empirical conceptualisations. This allowed for greater sensitivity to context, making sure that the rationale of the study was reached through consideration of gaps in the literature.

4.2.2. Commitment, Rigour and Coherence

Commitment involves evidencing prolonged engagement in the research subject as well as skill in the adopted methodology (Yardley, 2000). Commitment to the methods of analysis was achieved by engaging in discussion with my supervisor, who is proficient in GT, and by reading about GT methods. The detailed process of coding (Appendix H) allowed the immersion in the data and therefore sensitivity to the constructed codes and categories. Practicing constant comparative analysis also ensured categories closely represented the data (Charmaz, 2014).

Memo writing (Appendix I) aided reflection on the use of GT methods as well as justification of the codes and categories constructed.

The notion of 'rigour' refers to whether the data provides sufficient detail for a comprehensive analysis (Yardley, 2000). This was achieved through the recruitment of people who had diverse experiences with the service and whose demographics differed, allowing for a more nuanced understanding of compassionate care in IAPT (Olsen, 2004). Rigour also addresses the level of appropriateness of research decisions (including ethical decisions) and how reliable the evidence provided is (Spencer & Ritchie, 2012). Information in the Appendices and the descriptions of

personal reflexivity below indicate how decisions were made and the thoroughness with which the analysis was done.

The notion of 'coherence' refers to the clarity and cogency of analysis (Yardley, 2000). In order to address internal coherence, the consistency of the research aims, the epistemological position adopted, and GT methods were all considered. For instance, in order to ensure that the objectives and methods were congruent with the critical realist perspective, it was determined that a GT constructionist approach would be most suitable for the research (Madill et al., 2000). Feedback on the model and the coherence of the themes and ideas put forward was sought in supervision and in discussions with peers as well as from participants.

4.2.3. Transparency

Transparency involves reflecting on the influence of personal assumptions, motivations and practices on the research process (Yardley, 2000). Within GT methodology, a reflexive diary is recommended to help recognising how theoretical understandings and personal expectations shape the data (Charmaz, 2014); key themes are demonstrated below. Supervision was also used as a space for exploring pre-existing ideas, personal reflections and research conduct.

Procedures followed for data collection and analysis were outlined in the Methodology to facilitate the reader's understanding of the process of the GT method, adhering to the criterion of transparency. Moreover, extracts have been provided in the Analysis chapter and excerpts from coding and memos were included in the Appendices to promote transparency and enhance understanding (Spencer & Ritchie, 2012).

4.2.4. Impact and Importance

Impact and importance of a research relate to its contribution to the knowledge base and to its pragmatic and academic utility (Cohen & Crabtree, 2006). This study was the result of considering an under-researched area in the compassionate care literature and endeavoured to provide new insights into the phenomenon. To my knowledge it is, as yet, the first UK-based qualitative research to systematically and comprehensively examine compassionate care in IAPT from the perspective of service users. It was also original in its attempt to develop a theoretical model that prioritises the perspectives of those who access IAPT services. This is useful as

compassionate care policies and guidelines are often unspecific and regarded as top-down initiatives.

While many links with previous research into compassionate care and therapeutic relationships were identified, there are also aspects of this research which are novel or surprising. IAPT has been criticised for emphasising managerial and ‘technical’ aspects over real encounters (Watts, 2016; Williams, 2015). This study shines light on the importance of prioritising the humanising aspects of the therapeutic process which individualise and empower the person through effective (and humane) relationships. The inclusion of an explicit definition of these relational dynamics appears to be a novel finding which seems to complement the current person-centred framework.

Regarding the pragmatic impact and utility of this research, the model developed has led to clear suggestions for clinical practice and action which are presented below. Disseminating the research findings to diverse audiences is an essential aspect of research practice (Holloway & Freshwater, 2009). The research will be fed back to service users and clinicians at the IAPT services within the London borough in which this study was based. Broader dissemination is intended within an academic journal article and at relevant conferences within the clinical and the academic context.

4.2.5. Service User Involvement

Service users’ engagement in the design of this research was helpful in ensuring that the research process was as appropriate and sensitive as possible. For example, during the consultation with the IAPT Advisory Group, members highlighted the term compassionate care was rarely employed with service users. As a result, the interview schedule was modified to include some potential clarifying follow-up questions and pointers, which were helpful during the interviews as, as predicted, some participants did not recognise the concept. Nonetheless, compassionate care was perceived by participants as a valuable aspect to consider by mental health services. Their support and appreciation for this research is apparent in Morgan’s quote *“I think it is interesting that you are trying to provide a compassionate aspect behind it because I think is very important when it comes to mental health.”*

In GT, assessing coherence can involve the participants in the review of model development. Time constraints impeded the constant review of analysis with

participants throughout the research process. Nonetheless, an email was sent to all participants including a brief summary of the findings and the figure of the model, to review clarity and cogency. Six participants responded to the email, which also suggests the value of the research was recognised. Every participant who provided feedback reported the content in the compassionate care definition 'made sense' and provided a good synthesis of the themes they considered to be relevant.

With regards to the figure of the model, three participants found it to be clear and concise. However, three participants considered the design lacked clarity, with one of them commenting that the nested figure of the conditions did not reflect a flow or hierarchy. While this format is commonly used in psychology (e.g. Bronfenbrenner, 1992), it may be less accessible for lay people. Moreover, the model was not intended to be shared with participants without prior discussion with members of the Advisory Group. However, this was not possible as the group was cancelled due to Covid19 social distancing guidelines. On reflection, the information accompanying the model could have been expanded for clarity. Alternatively, it may have been useful to discuss the model individually with participants. Nevertheless, the feedback gathered adds to the validity of the findings and will inform further dissemination of the data.

4.2.6. Researcher Reflexivity

Consistent with the epistemology of this study this section aims to reflect on the bi-directional influences between the researcher and the research process (Charmaz, 2014). In order to develop the quality and credibility of the GT it is important for the researcher to be reflexive about how their values and experience might shape the data collection, analysis and findings (Willig, 2008).

My decision to conduct this research partly arose from my personal experience and opinions of IAPT which led to a desire to uncover a more comprehensive understanding of compassionate care in this context. I considered compassionate care could sometimes be absent in these settings due to systemic constraints, and I was curious to explore whether service users' perceptions coincide or differ with this. At the same time, throughout my Clinical Psychology training I had been exposed to a range of literature pointing to the importance of compassion in clinical practice as well as to criticism of the managerial style in IAPT services which seemed to reflect

an incipient lack of compassionate care.

Approaching this research, I reflected upon my professional background working within IAPT services and acknowledged how systemic ideas mediated my perception of the construct being defined. I, when working as a trainee psychological wellbeing practitioner in an IAPT service, found my ability to give the care I wanted compromised by organisational and structural factors, such as lack of time and an emphasis on manualised evidence-based practice. As I attempted to stay close to the data, this research has compelled me to consider other factors and theoretical models. By the end of the research process my position had shifted from seeing compassionate care solely as a systemic process to seeing more of the complexities involving relational and individual factors.

During data collection, my status as a trainee clinical psychologist may have influenced people's willingness to take part in the research or share their perspectives within the interviews. Participants may have perceived me as being part of the experience they were defining which may have affected their responses. Some participants may have felt reluctant to disclose negative views about the IAPT service for fear of offending me or being perceived negatively (Paulhus & Reid, 1991). They may have also questioned whose interests I represented. I took some steps to minimise these methodological limitations so as to improve the rigor of the findings. For example, I made clear that I did not work in IAPT and did not have any professional relationship with the service. Attempts were also made to address the power imbalance by working to put the participant at ease, considering non-verbal cues and encouraging questions throughout the process (Dickson-Swift, James, Kippen, & Liamputtong, 2007).

4.2.7. Study Limitations

Throughout the research process it was evident that participants often drew on experiences from their engagement with other therapeutic and healthcare services as well as from life experiences encountered in other contexts. Some participants in the sample worked in the mental health sector or in caring roles which may have impacted on the experiences that they shared. This highlighted potential difficulties to identify whether the definitions of compassionate care provided were connected in some way to their experience with IAPT. This may be a limitation, impacting utility of

the findings to an IAPT service. Nonetheless, it is in line with the epistemology of this research which considers individuals draw upon diverse social experiences to construct their unique perceptions of compassionate care in IAPT (Gergen, 1999). This supports the efficacy of adopting a constructivist GT methodology, therefore reinforcing the validity and trustworthiness of the research. However, despite using an open-ended interview guide which enabled participants to reflect on their experiences, responses cannot be considered naturally occurring speech as they were directed by the researcher's questions and, consequently, their own agenda and understandings (Potter & Hepburn, 2005). The consultation with the IAPT Advisory Group was useful in minimising the influence of the researcher's assumptions when developing the interview guide.

A further potential limitation arises from the recruitment process. Potential participants were those who had already agreed to participate in research and then self-selected for this particular study after receiving an invitation email. This creates the potential for respondent bias (Williams & Macdonald, 1986) as service users with stronger views about the topics and more willingness to share ideas may have been more likely to partake in the research. This may raise a limitation as it could be that those who chose to participate only represent a particular portion of service users in terms of their motivation or their views. However, views and experiences within the sampled group appeared to be diverse and participants were also diverse in terms of age, gender, type of therapy and number of therapeutic sessions attended.

The ethnicity of participants, however, was predominantly White British (n=11). Therefore, caution is advised in generalising the findings particularly as research shows there are some differences in how compassion is expressed and received by people depending on their ethnicity and culture (Singh, King-Shier, & Sinclair, 2020). Recruitment was also hindered by the inability to use interpreters. Service users whose communication with staff is mainly non-verbal, may experience compassionate care differently from English-speaking service users. Language differences between professionals and service users have been identified by service users as a considerable barrier to compassionate care (Singh et al., 2020). Larger numbers of participants may have shown some general differences in how compassionate care is perceived between groups. Recruiting more participants would also have generated further data, potentially yielding more saturated

theoretical concepts. Nonetheless, Guest, Bunce, & Johnson (2006) found that when using GT, twelve interviews are usually sufficient when trying to discern common perspectives among relatively homogenous people. Moreover, theoretical sampling, as described in the Methodology, was used to refine and challenge the categories constructed. Thus, it is possible that theoretical sufficiency was reached, especially as the theoretical account developed was regarded as robust and consistent, with adequate explanatory power and depth (Charmaz, 2014).

4.3. Research Implications

Future research that focuses on the ways compassionate care is conceptualised in IAPT and other psychological therapies services in a more detailed way is warranted. Such research might investigate, and elaborate on, the constructed model. For example, more detailed qualitative exploration, using perhaps a prospective design and multiple interviews, could provide a fuller understanding of the compassionate care process (Charmaz, 2001). Exploring the links between certain conditions and the elements within the 'humanising response' would allow for targeted interventions aimed at addressing these multilevel factors. Future research could also investigate further the relationship between compassionate care and service users' outcomes, including 'recovery'. While there is already a literature base relating to this (Cheng & Tse, 2015; Spandler & Stickley, 2011), none was identified assessing this relationship in the context of IAPT.

A comparison study of service users' perspectives in different types of mental health services (e.g. inpatient, community mental health) would be interesting to assess whether there are differences in how compassionate care is understood, including variations in the influencing conditions and in its perceived outcomes. It is also crucial to conduct research with service users from minority ethnic groups and those who do not speak English in order to validate the 'Humanising Responses to Distress' model with a more diverse group. This is particularly relevant as research examining the perspectives of compassion among diverse ethnic populations is limited (Singh et al., 2018). It may be interesting for future research to investigate how compassionate care is provided while using interpreters.

Although service users' perceptions are fundamental to an empirical understanding of compassionate care, the inherently relational nature of compassion requires the

incorporation of staff's perceptions to validate and inform the model constructed. To this avail, a study investigating staff's conceptualisations of compassionate care in IAPT was conducted alongside this research (Lupes de Souza, 2020). The empirical model constructed also emphasises the importance of recognising the person's individuality and humanity, defining compassionate care as involving the provision of a meaningful and personalised response to suffering by looking beyond service users' presenting problem. Participants highlighted they should also be provided themselves with meaningful support from the organisation, describing some of the strategies to support staff's wellbeing as 'tokenistic'. Opportunity for self-care, supervision and working in a supportive system were identified as key factors in enabling them to remain grounded and able to attend to service users. This adds to this research as, despite the structural barriers, many participants received high-quality care whereby their needs were met, and a meaningful and humane relationship developed.

4.4. Clinical Implications

A number of clinical implications are drawn from the present study which are described at therapeutic, service and policy levels. These are not intended to be separate alternatives as change at one level can make change at another level possible (Bronfenbrenner, 1992).

4.4.1. Therapeutic Level

IAPT has been criticised for failing to consider service users' individuality by operationalising distress in diagnostic categories and using standardised interventions (Samuels & Veale, 2009; Williams, 2015). The above findings highlight compassion must not be universally provided as what is experienced as compassionate by one person may be experienced as non-compassionate by others (Babaei, Taleghani, & Kayvanara, 2016). Among other things, this indicates the importance of enhancing therapists' cultural competence during training and continuing professional development (CPD) activities (Bhui, Warfa, Edonya, McKenzie, & Bhugra, 2007). However, while service users' ideas and experiences of compassion differ by ethnic background, clinicians need to be aware that they also differ within ethnic groups. This study warns against a 'one size fits all' approach across and within ethnic groups, emphasising that a key domain of compassion is seeking to understand the person's individuality.

The provision of choice was also identified as a key factor in compassionate care. Choice is also tied to the notion of respecting the person as an individual. When patient choice is ignored or devalued, service users are more likely to distrust and, perhaps, disregard therapists' recommendations. Cooper et al. (2017) also identified service user preference and choice as a predictor of outcomes in psychological therapy. Exploring preferences and providing choice in terms of location, time of appointment and therapeutic approach, has been found to affect the therapeutic value of treatment for service users (Williams et al., 2016). While therapists applying CBT in response to the person's needs were identified as compassionate, the need to offer other therapeutic approaches was highlighted. Evidence-based practice guidelines highlight the use of individual preferences to guide treatment selection (Papakostas, 2009). The 'CBT monopoly' is not beneficial as service users need to have choice for their therapeutic intervention to be effective (Omylinska-Thurston et al., 2019). Increasing the number of approaches, so that service users can be referred at first line of treatment to their preferred type of therapy, should be considered. Allowing greater choice for service users may conflict with policy and guidance requiring a standardised approach. Therefore, in order for therapists to be able to provide choice, the organisation must cooperate to make this acceptable and possible.

4.4.2. Service level

Many participants believed people are led to a career that involves helping others because they are fundamentally a caring and compassionate person. This is consistent with VBR strategies which aim to identify clinicians with compassionate values and attributes. While there is limited evidence to support VBR strategies (Patterson et al., 2016), the findings in this study suggest service users consider it as essential to ensure therapists demonstrate qualities related with inherent competence and motivation for compassion. Spandler & Stickley (2011) suggest recruitment for psychology-related professions involving the provision of talking therapies often prioritise academic abilities over compassionate qualities. Thus, the approach to recruitment and selection in IAPT may have to place a greater focus on identifying candidates' 'potential' for compassion.

Moreover, current studies have shown that aptitude for compassion can and should be cultivated within formal education (Sinclair, McClement, et al., 2016). Participants

in this research suggested incorporating more real-life case examples into training, as this could help therapists develop an insight into individual perspectives. Mills and Chapman (2016) argue training should also include explicit curricula to teach about compassion. This could incorporate the perspectives and conceptualisations of service users in this research.

However, these initiatives could give a misleading message by inferring that the “locus of the disturbance” is within individual therapists. These practices are not likely to be sufficient if IAPT settings and organisational values inhibit staff’s ability for compassion (Sinclair, Norris, et al., 2016). It was highlighted, for example, that workloads need to be reasonable and manageable, for therapists to be able to attend appropriately to the needs of the person. Nonetheless, IAPT working environments have been described as ‘intense’ and stressful (Walklet & Percy, 2014) due to high volume caseloads and an emphasis on targets. There are currently high levels of IAPT workforce burnout (Westwood et al., 2017) which has been negatively associated with compassion for others (Beaumont, Durkin, Hollins Martin, & Carson, 2016). Therefore, the current emphasis on outcomes and efficiency in IAPT services must be considered with regard to the effects that it places on both staff and service users’ wellbeing.

Moreover, to be compassionate, organisations should listen to service users’ feedback and incorporate these into practice (NHS England, 2014). In this study participants highlighted the importance of perceiving informational and relational continuity (Haggerty et al., 2003) in their engagement with IAPT. They suggested continuity could be preserved by contacting service users while on the waiting list. A recent small-scale project suggests sending regular updates via text message to service users on IAPT waiting lists may be helpful to increase engagement (Fussey & Kirkman, 2019). This is a low-cost intervention which could be scaled up.

4.4.3. Policy Level

By including service users’ perspectives, compassionate care could now be more clearly and specifically articulated in IAPT policies and manuals. In the current IAPT context which prioritises evidence-based practice and outcome monitoring (Watts, 2016), compassionate care may be regarded as requiring specific targeted outcomes to be evaluated (Sanghavi, 2006). However, the attributes associated

with compassionate care are difficult to measure (Spandler & Stickley, 2011). Moreover, with the growing demands therapists in IAPT are expected to meet (Binnie, 2015), promoting compassionate care may be best geared towards stimulating and facilitating humanising behaviour rather than introducing additional target measures (Fotaki, 2015). Top-down adjustments are proposed which may include lessening the emphasis placed on targets and outcome measures at the commissioning and policy level (Binnie, 2015; Watts, 2016).

This study also highlights the importance of considering whether and to what extent the model constructed can be sustained and developed in a service in the face of pressure from current neo-liberal cultures. With the number of people accessing IAPT increasing, and potentially even further due to the Covid19 crisis' psychosocial effects on people (Pfefferbaum & North, 2020), ensuring compassionate care in services by providing adequate funding should be a priority.

4.5. Conclusion

The latest IAPT manual states that effective and efficient service delivery should be balanced with compassionate and person-centred care (NHS England, 2019). This shows a tension in evidencing qualities such as 'compassion' within a market-based policy framework which monitors performance indicators, targets and outcomes (Rizq, 2012). This study shines light into this debate by providing a conceptualisation of compassionate care as experienced by service users. This definition suggests service users see compassionate care in IAPT as involving 'humanising' responses which recognise, accept and prioritise their uniqueness, self-worth and agency. Compassionate care was also described as humanising by involving positive and containing interactions and relationships between service users and staff which promote a sense of 'human' connection and safety. This highlights the need to prioritise individualised, relational and empowering approaches over rigid and prescriptive interventions which do not recognise service users' needs and preferences. Therefore, the current emphasis on standardisation and outcome measures may impact negatively on compassionate care in IAPT as perceived by service users. Top-down adjustments are proposed as it is likely that change at the policy and commissioning level will permeate to IAPT services and therapists. In contrast, if factors impeding compassionate care at higher levels are not addressed, staff may struggle to provide the type of humanising responses

described in this research.

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Appendix A - Literature search

The guiding questions in the literature search were:

- How has compassionate care been conceptualised in the literature to date?
- What factors have been identified as impacting the provision of compassionate care?
- What benefits have been identified from providing compassionate care?

The following search terms were used in an attempt to access relevant literature:

COMPASSION	STAFF	SERVICE USER
Compassionate care	Clinician	Patient
Compassion model	Counsellor	Client
Compassionate relationship	Psychologist	
	Practitioner	
	Therapist	
	Healthcare staff	
	Mental health staff	
	Professional	
	Hospital staff	

These key words were searched in varied combinations using the Boolean operators 'AND' and 'OR'.

Limiters included:

- English language only
- Adult only (18-65 years)
- Human only
- Keyword and abstract only
- Published after 2009

These search terms and limiters were used in the following databases: Psychinfo, Academic Search Complete, CINAHL Plus via EBSCO and Scopus. A total of 1747 articles were identified. Additional searches were conducted of the grey literature using Google Scholar.

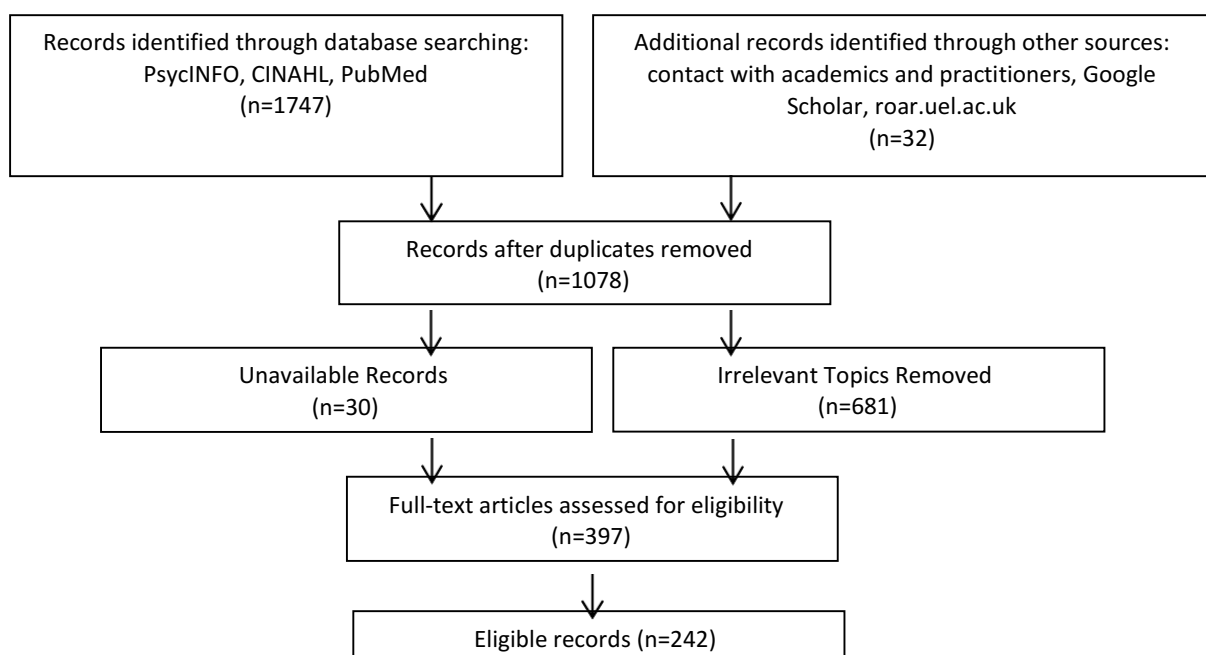
Inclusion criteria: In addition to the limiters applied, all studies were considered regardless of:

- the country of origin
- the type of methodology
- how compassion was investigated
- the sample of service users (i.e., they could be health, mental health, etc.)

Exclusion criteria:

- If compassion had merely been reflected upon or brought up in the conclusion section of the abstract as opposed to being a direct unit of investigation in the publication.

The search identified relevant pieces of literature including empirical studies, discussion papers and book chapters. A flow diagram of the literature review process is included below (adapted from Peters et al., 2015).



Appendix B – Recruitment Leaflet/Poster



An Improving Access to Psychological Therapies Service Research Project:

What does Compassionate Care mean for you?



I am Claudia Alonso. I am training to become a Clinical Psychologist.

I want to investigate people's views and experiences of 'Compassionate Care' in an Improving Access to Psychological Services (IAPT) service.

In an informal interview, I will be asking people to discuss and share what they consider compassionate care to involve and how this has been demonstrated through their experiences with the service.

The interview will be arranged at people's convenience, either at the IAPT service or at the university, according to their preference.

Your experience is important and I would like to meet with you.

Want to take part or know more?

- Tell a member of staff who will let me know you're interested.
- Contact me directly- Call me: ; Email me:
U1325917@uel.ac.uk

Appendix C – Participant information sheet

PARTICIPANT INFORMATION SHEET



Service Users' Definitions of Compassionate Care in an Improving Access to Psychological Therapies Service

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully and discuss it with others if you wish.

What is the purpose of this study?

Treating people compassionately has been shown to have wide-ranging benefits, including improving their wellbeing, satisfaction, clinical outcomes and the quality of information gathered. In line with this, mental health services now consistently include 'compassionate care' in their policies, manuals and training schemes. However, this term is not always well defined and there has been little research into service user perspectives on 'compassionate care', particularly in the context of a psychological therapies service.

This study aims to address this gap and investigate service user views and experiences of compassionate care in an Improving Access to Psychological Therapies (IAPT) service, such as X Psychological Therapies Service.

Who is conducting the study?

My name is Claudia Alonso Soriano and I am a trainee clinical psychologist. This study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London. It has been approved by the North West - Liverpool Central Research Ethics Committee. This means that my research follows the standard of

research ethics set by the National Health Service (NHS).

Why have I been asked to participate?

I am looking to involve English-speaking adults of at least eighteen years of age who have used IAPT services (such as IAPT) within the past three months.

Do I have to take part?

No, you are free to decide whether or not to participate. If you do not want to take part, you do not have to give a reason and there will be no pressure to try to change your mind. Your decision to take part or not in this research will not affect in any way the care you receive from the IAPT service.

What does the study involve?

If you agree to participate you will be asked to discuss and share your views and experiences of compassionate care in IAPT in an informal interview. I am particularly interested in finding out what you consider compassionate care to involve and how this has been demonstrated through your experiences with the service.

The interview will be arranged at your convenience, either at the IAPT service or at the university, according to your preference. The interview will be audio recorded and last approximately one hour. You do not have to answer all questions asked and can stop the interview at any time or reschedule. As the study progresses, you may be approached and asked if you would be willing to be re interviewed to elaborate on some elements of your experience. This interview would again last for approximately one hour.

Are there any risks or benefits of taking part in the study?

There are no expected significant disadvantages to you taking part in the research study. The only thing you are being asked to do is to give up some of your time to be interviewed and share your views and experiences of compassionate care in IAPT, which may be from positive or negative perspectives. You may find it helpful to discuss your experiences, but it is also important to acknowledge that there is a small risk that you could find participating distressing. The interview may bring awareness to unpleasant memories which may trigger difficult emotions. You would be able to interrupt the interview at any point, take breaks or reschedule. In addition, the researcher is experienced in working clinically and will be able to use clinical

judgement and skill to help you manage any distress that arises during the interview. There will also be a debrief at the end of the interview where you would be given the opportunity to ask any questions and details of relevant supporting agencies will be provided. Contact details of the lead researcher and their supervisors will also be provided should any questions or concerns related to participating in the research arise later on.

If you feel you wish to share your story, your contribution would be very welcome and highly valued. While taking part in this study may not lead to personal benefits for you, some people find it helpful to discuss their experiences and it would contribute to our knowledge of compassionate care, which may help to shape staff training, services and interventions.

I will not be able to pay you for participating in this research, but any travel costs to attend the interview(s) will be reimbursed.

What will happen to the information that I provide?

The University of East London is the sponsor for this study and will act as the 'data controller' in accordance with the General Data Protection Regulation. As a publicly-funded organisation, the University of East London has to ensure that using personally-identifiable information from people who have agreed to take part in research is in the public interest. This means your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, the minimal amount of personally identifiable information will be collected and your data will only be used in the ways needed to conduct and analyse the research.

The NHS Service you used (IAPT Psychological Therapies Service) will use your name and contact details to contact you about the research study and make sure that relevant information about the study is recorded for your care and to oversee the quality of the study. IAPT Psychological Therapies Service has passed these details to University of East London. The only people in University of East London who will have access to information that identifies you will be people who need to contact you to for the data collection process. If you decide to take part in the study, University of East London will keep identifiable information about you until the study has finished.

At the interview, you will be assigned a unique identifying code which will be attached to your data in place of your personal details. The interview will be recorded using a digital audio recording device. After the interview, the recording will be transcribed into a written format by the researcher (Claudia Alonso Soriano) and the audio recordings will be deleted immediately after transcription. All data will be anonymised and will not contain your name or any identifying details. All personal details will be kept in the strictest of confidence and deleted at the end of the study. All audio and written data will be stored securely and only the lead researcher and their supervisor will have access to this. Electronic data will be stored on the secured university computer network, accessible only by a unique personal user name and password. The anonymous transcriptions, which have the written information from the interviews, will be securely stored for five years as the results may be published.

The results of this study will be used as part of a doctoral thesis that will be submitted to the University of East London, which may later be shared in an academic journal or at professional conferences. Your personal information will never be disclosed, as only the unique identifying code allocated to you at the interview will be used. However, your words may be published in the form of brief quotations exactly as you said them during the interview. No identifying information will be included in any quotes. Your contact details will be deleted at the end of the study.

Will all the information that I provide remain confidential?

Yes. However, if during the study you disclose any information which highlights a potential current risk to yourself or others, the researcher may have to break confidentiality in line with the IAPT Psychological Therapies policy. If the researcher feels that it is necessary to break confidentiality, she will discuss this with you first and explain her concerns, unless doing so would be likely to increase the risk to yourself, the researcher or a third party. In discussing the issue with you, the researcher may also provide you with information about appropriate support or counselling, or may be able to encourage you to talk to a third party regarding the issue, to avoid the need for the researcher to breach confidentiality.

What if I want to withdraw from the research?

You are free to withdraw from the research study at any time without explanation,

disadvantage or consequence. However, if you withdraw, I would reserve the right to use any anonymised information that you have provided up until that point, if the analysis of the data has commenced.

Who can I contact if I have any questions or concerns about taking part in this study?

If you would like any further information or have any questions or concerns, please do not hesitate to contact me:

Claudia Alonso Soriano, Email u1325917@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please feel free to contact my research supervisor:

Dr Lorna Farquharson. School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: I.farquharson@uel.ac.uk

If you wish to raise a concern about how your personal data have been handled in relation to this study, you can contact the Data Protection Officer at the University of East London by emailing dpo@uel.ac.uk

What should I do if I would like to participate? If you would like to participate please email me, Claudia Alonso Soriano.

Email: u1325917@uel.ac.uk

Thank you for taking the time to read this information

Appendix D – Interview schedule

Thank you for agreeing to take part in this interview. This research is about people's experiences and views of compassionate care. For an hour or so we will discuss your ideas about compassionate care and your perspective on how this may be experienced and defined in an IAPT service. I will be recording and making notes during the interview. This is so that the discussion can be written up, so I can then look at the various themes and ideas that you generate. There are no right or wrong answers; this is just about your own personal experiences and views.

1. In terms of your own experience with the IAPT service, what does compassionate care mean to you? (*Prompts: What does the word compassion mean to you? What do you see as the key qualities of being compassionate? What does compassionate care in an IAPT service involve?*).
2. Please would you describe a situation, if there has been one, when you feel you have experienced care that was compassionate during your involvement with the IAPT service? (*Prompts: What was happening at the time? What was said? What was done? How did that feel? What happened as a result? What difference, if any, did it make to your overall experience of the service?*)
3. Please would you describe a situation, if there has been one, when you felt the care provided was not compassionate during your involvement with the IAPT service? (*Prompts: What was happening at the time? What was said? What was done? How did that feel? What happened as a result? What difference, if any, did it make to your overall experience of the service?*).
4. What do you see as the key qualities of a compassionate practitioner? (*Prompts: How do you know when a therapist is being compassionate? Do you think we can train people to be compassionate?*)
5. What do you think gets in the way of providing compassionate care?
6. What do you think helps the provision of compassionate care? (*Prompt: What might help to address the things that get in the way?*)

7. What else, if anything, would you like to tell me or comment on with regard to compassionate care in IAPT services?

Appendix E- Consent to Participate in the Research Study



IRAS ID: 258341

Participant Identification Number for this study:

CONSENT TO PARTICIPATE IN THE RESEARCH STUDY

Title of Project: Service Users' Conceptualisations of Compassionate Care in an Improving Access to Psychological Therapies Service: A Grounded Theory Study

Name of Researcher: Claudia Alonso Soriano

**Please
initial box**

1. I confirm that I have read and understood the information sheet dated 30.05.2019 (version 2.0) relating to the research study on compassionate care in an IAPT service. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand the purposes of this research and what I am being asked to do in this study.

2. I am willing to be interviewed with regards to my experiences of compassionate care in IAPT and for my comments to be audio recorded.

3. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the

study will have access to identifying data. If I wish to withdraw my data from this study I will be free to do so up until the point at which the researcher begins data analysis.

4. I understand that the researcher may have to break confidentiality if I disclose any information which highlights a potential current risk to myself or others. If this happens, the researcher will discuss this with me first and explain her concerns, unless doing so would be likely to increase the risk to myself, the researcher or a third party.

5. I understand that participation is entirely voluntary, and I can withdraw from the research at any point without any negative impact on the care I receive from the IAPT service. By signing this consent form, I am stating that I am over the age of 18 and I freely and fully consent to participate in this study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

Appendix F- Demographic Questionnaire



IRAS ID: 258341

Participant Identification Number for this study:

DEMOGRAPHIC QUESTIONNAIRE

Title of Project: Service Users' Conceptualisations of Compassionate Care in an Improving Access to Psychological Therapies Service: A Grounded Theory Study

Name of Researcher: Claudia Alonso Soriano

Age:

- Under 25
- 26-35
- 36-45
- 46-55
- 56-65
- Over 65
- Decline to answer

Gender:

- Male
- Female
- Other - please add details in comment box
- Decline to answer

Ethnicity:

- White / White British / White Other
- Mixed / Multiple Ethnic Groups
- Asian / Asian British
- Black / African / Caribbean / Black British
- Other ethnic group - please add information to comments box
- Decline to answer

Which of the following best describes your current use of the IAPT service?

- I have only completed the initial assessment and not yet started my therapy
- I am part way through my therapy
- I have completed my therapy sessions and no longer use the service
- I have completed my therapy sessions but I am planning to use the service further

How was your therapy delivered? (Please mark as many options as appropriate)

- Group therapy
- Individual, face-to-face therapy
- Telephone-based therapy
- Computer-based therapy

How many sessions of therapy have you had with this service?

Appendix G – Transcription conventions

Adapted from Banister, Burman, Parker, Taylor & Tindall (1994):

Symbol	Explanation
(.)	Pause
[inaudible]	Inaudible piece of transcript
[laughs]	Indicates laughter of participant
(...)	Indicates some speech has been removed – no more than 40 words
<>	Brief interruption by other speaker
[]	Square brackets indicate interviewer's speech rather than participant's speech.

Appendix H – Example of initial and focused coding (from Interview 8)

<p>P8: But I guess there must be more to it than the words don't just repeat themselves. So (.) I think compassion also is about being concerned with the individual. And I think through the IAPT service, they wanted to get to the bottom of what I needed. So, in that sense, although the model of treatment is quite standardised, the experience felt quite personalised, especially in terms of assessing or diagnosing and appraising what they thought and what treatment they thought I would benefit from. I found in the, in the CBT itself, I felt a little bit more of the force of standardisation and so there, the individuality or the, the nuances or blurred lines of what I was experiencing, I think one didn't feel to me to be fully accommodated. And it, and it almost came to feel a little less personalized. And I suppose that kind of personal attention and adjustment to the uniqueness of an individual is something I associate with compassion.</p>	<p>Being concerned with the person</p> <p>Striving to understand the what the individual needs</p> <p>Using a standardising model Perceiving experience as personalised</p> <p>Assessing individuals needs Considering what the individual person would benefit from Perceiving CBT intervention standardised and less individualised that the assessment Failing to acknowledge adequately the individuality and differences of the person Experiencing intervention as less personalised</p> <p>Considering personal attention and adjustment to uniqueness to be aspects of compassion</p> <p>Describing assessment questions as generalised</p>	<p>Being genuinely concerned</p> <p>Striving to understand the person's needs</p> <p>Tailoring support to the person</p> <p>Striving to understand the person's needs</p> <p>Failing to acknowledge individual experience</p> <p>Failing to adapt to the person</p> <p>Adapting care to the person</p>
<p>Interviewer: [What aspects you did find to be</p>	<p>Seeking support when lacking understanding/knowledge</p>	

compassionate?]

P8:

The aspects that were more compassionate (.) well, so it started with a phone triage. And the questions were quite generalised, but I could tell that when the person on the phone was not sure about what to do with my answers, she then took it to another member of her team. So, immediately I then felt that I was being taken more seriously or that it was being analysed with the level of detail that they felt it deserved, instead of a kind of a 'one size fits all'. And in fact, I was then, they then wanted me to see a psychiatrist, which again, I felt it was compassionate. Because it was, I don't know, bringing another member of the team with different expertise in, made me feel again, like I was receiving a thorough level of attention. And I guess that kind of thoroughness of attention to me implied that they cared, or that I mattered. And, and I think that contributes to a sense of being in safe hands. Because I think it's easy. Well, a lot of therapy is about making someone comfortable in the room with you, I guess. But, what

Being taken seriously

Completing a thorough assessment of difficulties

Going beyond 'one size fits all'

Making referral to appropriate specialist

Involving people with the appropriate expertise

Receiving a thorough level of attention

Showing genuine care

Feeling significant

Feeling in safe hands

Experiencing easiness

Making the person feel comfortable

Considering the person even when out of sight

Holding the person in mind

Feeling looked after

Feeling attended to

Considering multiple angles

Assessing needs with a great degree of scrutiny

Feeling comfortable

Taking concerns seriously

Striving to understand the individual experience

Adapting to the person

Taking concerns seriously

Attending to the person

Having genuine concern

Being made feel significant

Promoting sense of comfort and safeness

Holding the person in mind

Attending to the whole person

about all the times when the patient is not in the room with the therapist? and I think that sense of feeling well looked after or kind of attended to, with kind of multiple angles and a great degree of scrutiny. I think that, that made me feel comfortable throughout the process.

Promoting comfort

Appendix I- Excerpt from Memo Following Initial and Focused Coding of P1 and P2

Memo following Interview with P1 – Date: 12.08.2019

The participant spoke about CC involving, in her experience with IAPT, being supported to achieve meaningful change. She states that IAPT does this by providing service users with knowledge that they can then apply. She had the experience of feeling empowered so that she was able to make changes herself. *“I used to have panic attacks and I was anxious all the time since I was fourteen and they taught me how to deal with it, so it is not a problem when you understand all the process.”*

The participant also spoke about how, in order for service users to apply this professional knowledge, practitioners must gain their trust by displaying certain personal attributes and professional skills which, for her, are linked to CC (kindness, calmness, friendliness, patience, professional knowledge) *‘If I don’t trust you and I am talking to you I am with one foot on the front and another one on the back. And when I arrive home maybe I will not pay attention or I will say ‘okay, she said that but I don’t care’.*

Developing trust is a process which requires time. The participant describes feeling heard as a key experience as well as acting on her concerns (i.e. **being attentive to my needs- focused code/category?**). For her, this happens when the therapist adapts to the individual situation and offers tailored support (i.e. being with the person and meeting them wherever they are at in each session, seeking to understand their needs at each moment). While roles need to have clear and specific tasks and responsibilities, flexibility is needed in order to adapt to individual needs and provide CC. Having professional codes but knowing when crossing certain boundaries may be necessary - prioritising individual needs over other requirements. In order to do this, the practitioner must give the person their time and adapt to whatever the person needs, being flexible and providing an open space. *‘She just let me speak for an hour. She didn’t say anything. And that was very important. Because that was not kind of her job. It was not her job. But she knew it was important to me to put everything out and from there we start to work again’.*

For care in IAPT to be compassionate, the length of time provided to each individual must also be adapted to the person's needs. Important for the service not to give up on people who may have more needs or less level of motivation. Persistence is key. **I wondered if service users may experience CC differently depending on the length of their intervention. If so, there may be differences in the descriptions depending on the type of involvement/intervention (e.g. low intensity-step 2 vs high intensity-step 3).**

The participant states that CC comes from individual therapists' intrinsic values and attributes, and skills which are developed through personal and professional education. Training CC to staff is possible but each individual being trained must be open to change. She also believes the individual practitioner learns about CC through interactions with service users: **listening to them and learning from them (i.e. working in partnership- focused code/category?)**. She described working in partnership with service users and how they can provide the therapist with an experiential knowledge different from what they may learn academically. This way, CC develops with clinical experience as the practitioner learns how to tailor their attributes, skills and academic knowledge to different types of values and needs. **The link between experience and CC is something that I could investigate in further interviews or it may also come up in the study investigating staff's views on CC.**

CC in IAPT is also represented in the environment and interactions outside the therapeutic relationships. The participant named positive environmental conditions as a way of showing CC as this can make the person feel comfortable/safe and facilitate engagement.

Referring to experiences related to her professional background in customer services and connecting these to IAPT, the participant emphasised the role of systemic factors, particularly communication at all levels and leadership skills, as promoters or barriers for CC. **This is an idea which I have read about extensively in the literature about CC so it may be important to keep reviewing interviews to ensure the idea will not be forced.**

Memo following Interview with P2 - Date: 129.08.2019

The participant also speaks about the idea that the therapist must adapt to the individual situation and offer tailored support (i.e. being with the person and meeting them where they are at in each session, seeking to understand their needs at each moment). **This links to the ideas shared by P1 of relating CC to the provision of individualised/tailored care (focused code/category?).** She described wanting to feel heard and experiencing that they act on what she says, respecting her preferences. *'It's like I said, like in terms of checking in at the start, like if you weren't doing that, like that's a barrier because if someone's like, say one time when I went there and I was really stressed out and I had a really shit day, like if we started talking about, I don't know, a behavioural experiment in that moment, I didn't care about behavioural experiment, I just wanted to talk about how I was feeling.'*

The participant works with families that are at risk of homelessness or homeless. She acknowledged the impact of her professional background and experiences in shaping her ideas of compassionate care

She brought a new theme which was not discussed by P1- **Experiencing continuity. This reminded me of attachment theories** (e.g. Bowlby, 1969) as she referred to attending at the relational dimensions. Continuity allows for the service to get to know the person, for the individual to feel significant and to experience purpose in the engagement.

One of the aspects of continuity involves **'not giving up on me' (focused code/category?)** which includes: showing patience, persevering and considering my situation before making a decision. The participant states the service must be considerate in every interaction with service users (i.e. considering the impact actions can have on individuals' emotional state). She particularly speaks about not being contacted while on the waiting list and about DNA policies and the impact these practices can have on service users. *'Sometimes it's just about like, feeling like the service does care about you a bit and if they just sort of like then that you miss an appointment and 'there goes you' or whatever sometimes that does make people feel like it's not compassionate.'* This again appears to relate to showing the relationship is long-lasting (continuity) instead of fragile and ephemeral.

Similarly to P1, providing compassionate care is described as an inherent quality: therapists must have an intrinsic motivation to care for others (originating from relevant interactions/relationships and personal experiences)—but she also says compassion can be a set of skills that can be learned through training and clinical experience.

P2 also mentions '**working in partnership**' (**focused code/category?**), referring both to the relationship between the therapist and the service user as well as the one between the IAPT service and service users. *“So maybe having more like, I don't really know cause I don't know how much IAPT actually does outside of this, but like, if there was like, community engagement, events and things like that where like people could kind of also then like feed back into it as well.”*

Appendix J – Consultation with IAPT Advisory Group

Service Users' Views and Experiences of Compassionate Care in an Improving Access to Psychological Therapies Service

Treating patients compassionately has been shown to have wide-ranging benefits, including improving patients' wellbeing, satisfaction, clinical outcomes and the quality of information gathered. In line with this, current policies and manuals for Improving Access to Psychological Therapies (IAPT) require services to provide 'compassionate care'. However, there is not an agreed definition for this concept and practitioners are often unsure about what they should be doing to provide "compassionate care".

We are interested in finding out what service users consider compassionate care to involve and how it has been demonstrated through their individual experiences using an IAPT service. It is hoped that this research will add to the theoretical knowledge base and will also have practical implications for service development, staff training and therapeutic interventions. This study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London.

As well as any general feedback on the proposed study, we would like to gather feedback on the participant information sheet and the draft interview schedule. We would also welcome any ideas or suggestions for the debriefing process as well as for involving service users in the interpretation of the findings and the development of the recommendations. Some specific questions for the four areas are:

Participant information – any comments about the presentation of the information (structure, organisation, length), the word choice and tone? Is anything unclear?

Interview Schedule – any comments about the introduction to the interview, the wording of the questions or the order of the questions?

Debriefing- *A debriefing is a short interview that takes place between researchers and research participants immediately following their participation in a psychology experiment. The debriefing is an important ethical consideration to make sure that participants are fully informed about, and not psychologically or physically harmed in any way by, their experience in the experiment. What do you think should be covered in the debriefing for this research? (Keeping in mind some people might share negative experiences with the service).*

Involvement in the interpretation of the findings – would it be possible to come back to the group at a later date to discuss the results before completing the write-up? Are there any other suggestions for involvement in the interpretation of the findings and developing the recommendations?

Appendix K - Letter confirming NHS ethical application

IRAS 258341. HRA & HCRW Approval issued

nrescommittee.northwest-liverpoolcentral@nhs.net

Mon 10/06/2019 19:15

To: Claudia ALONSO <u1325917@uel.ac.uk>; Lorna Farquharson <L.Farquharson@uel.ac.uk>;

Cc: Research Ethics <researchethics@uel.ac.uk>;

📎 5 attachments (2 MB)

258341 - Letter of HRA Approval - 2019 06 10.pdf; 258341 19NW0312 FIFO 10.06.2019.pdf; 258341 HRA+Schedule+of+Events+CAS 2019 06 04.xls; 258341 Statement+of+Activities+CAS 2019 06 04.docx; SL-AR2_Non-CTIMP_Standard_Conditions.pdf;

Dear Miss Alonso Soriano

RE: IRAS 258341 Service Users' Conceptualisations of Compassionate Care in IAPT. HRA & HCRW Approval issued

Please find attached your HRA and HCRW letter.

Please also find attached your REC Favourable Opinion letter and the standard conditions document applicable to this study.

You may now commence your study at those participating NHS organisations in England and Wales that have confirmed their capacity and capability to undertake their role in your study (where applicable). Detail on what form this confirmation should take, including when it may be assumed, is provided in the HRA and HCRW Approval letter.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

If you have any queries please do not hesitate to contact me.

Kind regards

Michael Pate

Approvals specialist

Health Research Authority

3rd Floor | Barlow House | HRA NRES Centre - Manchester | M1 3DZ

T. 0207 104 8197

E. nrescommittee.northwest-liverpoolcentral@nhs.net

W. www.hra.nhs.uk

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Miss Claudia Alonso Soriano
Trainee Clinical Psychologist
Department of Psychology
University of East London (Stratford)
Water Lane, London
E15 4LZ

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

10 June 2019

Dear Miss Alonso Soriano

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Service Users' Conceptualisations of Compassionate Care in an Improving Access to Psychological Therapies Service: A Grounded Theory Study
IRAS project ID:	258341
Protocol number:	1
REC reference:	19/NW/0312
Sponsor	University of East London

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **258341**. Please quote this on all correspondence.

Yours sincerely,
Michael Pate

Approvals specialist

Email: hra.approval@nhs.net

Copy to: Catherine Hitchens – University of East London – Sponsor contact.

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster and leaflet information 17.04.2019]	1	17 April 2019
Covering letter on headed paper [Covering letter on headed paper 21.02.19]	1	21 February 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Certificate]		18 July 2018
HRA Schedule of Events [Assessed]	1	04 June 2019
HRA Statement of Activities [Assessed]	1	04 June 2019
Interview schedules or topic guides for participants [Interview schedule 21.02.2019]	1	21 February 2019
IRAS Application Form [IRAS_Form_26042019]		26 April 2019
Letters of invitation to participant [Letter of invitation to participant 27.03.19]	1	27 March 2019
Other [Introductory Invitation letter 30.05.19]	1	30 May 2019
Other [Debriefing Sheet 30.05.2019]	1	30 May 2019
Other [Ethical Review Response 30.05.2019]	1	30 May 2019
Participant consent form [Participant+Consent+Form+10.06.19]	3	10 June 2019
Participant information sheet (PIS) [Participant+Information+Sheet+30.05.19]	2	30 May 2019
Referee's report or other scientific critique report [Research Proposal Approval Letter 21.02.19]	1	21 February 2019
Referee's report or other scientific critique report [Research Proposal Feedback Form 21.02.19]	1	21 February 2019
Research protocol or project proposal [CAS Project Proposal 21.02.19]	1	21 February 2019
Summary CV for Chief Investigator (CI) [CAS brief CV 21.02.19]	1	21 February 2019
Summary CV for student [Student CV 21.02.19]	1	21 February 2019
Summary CV for supervisor (student research) [Supervisor brief CV 16.04.19]		16 April 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of protocol in non-technical language 21.02.19]	1	21 February 2019

North West - Liverpool Central Research Ethics Committee

3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ
Telephone: 0207 104 8196

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

10 June 2019

Miss Claudia Alonso Soriano
Trainee Clinical Psychologist
Department of Psychology
University of East London (Stratford)
Water Lane, London
E15 4LZ

Dear Miss Alonso Soriano

Study title:	Service Users' Conceptualisations of Compassionate Care in an Improving Access to Psychological Therapies Service: A Grounded Theory Study
REC reference:	19/NW/0312
Protocol number:	1
IRAS project ID:	258341

Thank you for responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) must be obtained from each host organisation prior to the start of the study at the site concerned.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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 management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For [clinical trials of investigational medicinal products \(CTIMPs\)](#), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

It is the 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).

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, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC 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” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster and leaflet information 17.04.2019]	1	17 April 2019
Covering letter on headed paper [Covering letter on headed paper 21.02.19]	1	21 February 2019
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Sponsor Insurance Certificate]		18 July 2018
Interview schedules or topic guides for participants [Interview schedule 21.02.2019]	1	21 February 2019
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Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Summary of protocol in non-technical language 21.02.19]	1	21 February 2019

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.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

19/NW/0312	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of;
Mr Paul Mooney
Chair

Email: nrescommittee.northwest-liverpoolcentral@nhs.net

Enclosures: "After ethical review – guidance for researchers"
Copy to: Research Integrity & Ethics Manager Catherine Hitchens

Appendix L - Letter confirming UEL ethical approval



25th June 2019

Dear Claudia,

Project Title:	Service Users' Conceptualisations of Compassionate Care in an Improving Access to Psychological Therapies Service: A Grounded Theory Study
Researcher(s):	Claudia Alonso Soriano
Principal Investigator:	Claudia Alonso Soriano

I am writing to confirm that the application for the aforementioned NHS research study reference **19/NW/0312** has received RRDE ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **25th June 2023**. If you require RRDE approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why RRDE approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing researchethics@uel.ac.uk.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

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

Yours sincerely,

Fernanda Silva
Administrative Officer for Research Governance
Research, Research Degrees and Ethics Sub-committee (RRDE)
Email: researchethics@uel.ac.uk

Appendix M – Participant Debriefing Form



Service Users' Definitions of Compassionate Care in an Improving Access to Psychological Therapies Service

Participant Debriefing Sheet

Thank you for participating in this research study. We hope that you have found your participation interesting and have not been upset by any of the topics discussed. **Having completed the interview, are you still happy for your data to be included?**

If you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact: **Claudia Alonso Soriano, Email: u1325917@uel.ac.uk**
A list of relevant supporting agencies has also been included. Please let us know if you would like more information about any of these agencies.

If you have any concerns about the care or treatment that you were provided within iCope Psychological Therapies Service, we encourage you to raise this issue with the therapist that you are seeing/saw in the past. They, or the team manager, will do their best to sort things out for you. However, if they're not able to resolve your concerns, you can contact the Advice and Complaints Service and they will liaise with the team on your behalf:

Camden and Islington Patient Advice and Complaints Service

Telephone

020 3317 3117

E-mail

complaints@candi.nhs.uk

The Advice and Complaints Service is open between 9am and 5pm, Monday to Friday.

There are also a number of organisations that you can contact 24 hours/ 7 days a week if you are feeling distressed or in crisis. A list with

In addition, if you have any questions or concerns about how the research has been conducted, please feel free to contact me or my research supervisor:

Dr Lorna Farquharson. School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: l.farquharson@uel.ac.uk

Thanks again for your participation.

Supporting Agencies Information Sheet

What to do when in crisis

1. Visit your GP.
2. Call the Camden and Islington NHS Trust Crisis Line on 020 3317 6333, open 24 hours a day. This hotline is for anyone needing urgent help with a mental health problem.
3. Go to your local A&E Department, open 24 hours a day.

A&E UCH

Accident and Emergency (A&E), Ground Floor,
235 Euston Road, London, NW1 2BU
Phone: 020 3447 0083

A&E Royal Free

Accident and Emergency (A&E), Ground Floor,
Royal Free Hospital, London, NW3 2QG
Phone: 020 7794 0500

A&E The Whittington Hospital

Accident and Emergency (A&E), Magdala
Avenue, London, N19 5NF
Phone: 020 7272 3070

Non-emergency support

The Samaritans on 116 123

Provides 24 hour confidential emotional support. All calls are free

Phone: 116 123

Email: jo@samaritans.org

The "Stay Alive" App

Available through App Store and Google Play on Smartphones. This app has useful

information and tools to help your stay safe in a crisis.

Website: <https://bit.ly/2GNNjls>

Other organisations which offer mental health advice and support

The following organisations offer support, help and advice to anyone affected by mental illness, their families or carers:

Drayton Park Crisis House for Women: 020 7607 2777

Drayton Park is an alternative to hospital admission for women with mental health problems living in Camden & Islington. It has 12 places available at any one time and can accommodate four children with their carer. The service works with the issues such as childhood sexual abuse and on-going abuse issues.

Open 24 hours a day, 7 days a week.

Rethink National Advice Service – Telephone: 0300 5000 927

Advice on how to get help and recover from severe mental illness.

Available Monday – Friday from 10am – 2pm. Not open on bank holidays.

Email: advice@rethink.org

Saneline – Telephone: 0300 304 7000

Advice to anyone affected by mental illness, offering support, advice, details of local services, treatment and mental health legislation.

Open every day of the year from 6pm – 11pm.

Visit website [http://www.sane.org.uk/what we do/support/textcare/](http://www.sane.org.uk/what_we_do/support/textcare/)

Mindinfo Line – Telephone: 0300 123 3393

Advice on mental illness, help and alternative therapies

Email: info@mind.org.uk

HOPELineUK – Telephone: 0800 068 4141

Confidential helpline service staffed by trained professionals who can give support, practical advice and information to anyone concerned about themselves or a young person they know who may be at risk.

Available Mon – Fri from 10am – 10pm, 2pm – 10pm on weekends, 2pm-5pm bank holidays.

Calls are free from BT landlines, other networks and mobiles may vary. The helpline advisors will call you back if you leave a message.

Email: pat@papyrus-uk.org

Text: 07786 209 697