Compassionate Care: As Defined By Individuals Who Have Used Mental Health Services And Are From An Ethnic Minority Background

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ABSTRACT

Background: Providing compassionate care is a key constitutional value of the NHS and there has been an increased focus to ensure this is delivered. However, there lacks a consistent and widely accepted definition of what this consists of. Current conceptualisations of compassion do not privilege the voice of service users, despite them being key stakeholders within the NHS, and the majority of studies have focused on physical healthcare settings. Additionally, there is lack of ethnically diverse perspectives across the literature. However, ethnically minoritised individuals experience more negative outcomes within the mental health system.

Aim: To investigate definitions and experiences of compassionate care, based on the perspective of individuals who identify with a minority ethnicity within the UK and have used secondary care mental health services.

Methodology: Semi-structured interviews were conducted with seven participants. Responses were analysed using a critical realist framework and reflexive thematic analysis (Braun & Clarke, 2006a).

Results: The analysis generated three main themes and 12 associated sub-themes. 1) *Growing the "seeds" of compassion* reflected ideas about compassion being an internal factor that was also dynamic and could grow with nurturing. 2) *Seeing the person* described compassionate care, which involved services recognising and respecting the individuality of service users and providing care according to their needs. 3) *"Power imbalances"* referenced the way services use judgements, control and language to hold onto power, leading to the delivery of uncompassionate care.

Conclusion: The study highlights the importance of relational care and cautions services to be more mindful of the inherent power differentials between them and service users. Recommendations to enhance compassionate care include services prioritising a person-centred approach and engaging with issues around stigma, intersectionality, cultural humility and religious beliefs.

CONTENTS

1 INTRODUCTION

1.1 Overview

Delivering compassionate care is a key NHS initiative. This chapter will outline the importance of compassion within healthcare settings, and in particular mental health services, and how despite a drive to improve compassionate practice there has been a lack of consensus around its definition. Relevant literature will be reviewed to see how compassionate care is conceptualised, with a focus on healthcare staff and service users' perspectives, highlighting the lack of research centred on service users, mental health services, and those from ethnically minoritised communities. The chapter will conclude with a rationale for the current study and the research questions.

1.2 Compassion within the NHS

Compassion has been associated with a number of positive outcomes and is widely recognised as important within healthcare. Research has highlighted the links between compassionate practices and good quality healthcare (Attree, 2001), improved outcomes (Lloyd & Carson, 2011; Vivino et al., 2009), as well as an improved ability to identify own needs and provide self-compassion (Arman & Hök, 2016). Additionally, it is highly valued by service users and has been linked to a greater likelihood of individuals returning to healthcare (Burroughs et al., 1999).

However, within the UK there have been several cases evidencing significant failings within the healthcare system (Department of Health, 2012; Francis, 2013; Parliamentary and Health Service Ombudsman, 2011). Findings from the Mid Staffordshire public enquiry highlighted a culture where services outcomes and operations were prioritised, there was low staff morale with high fear of repercussions, poor transparency, as well as patient feedback and complaints not being taken seriously, with management preoccupation on financial pressures rather than clinical governance issues (Francis, 2013). This led to patients needs not being prioritised and widespread incidences of neglect and abuse, highlighting a gap between the values espoused by the NHS and the care that was being delivered. Recommendations were made for an increased focus on the delivery of compassionate care within the NHS and there has since been a greater drive to ensure compassion is a more central feature within healthcare services (Department of Health, 2012; NHS England, 2013).

This agenda for greater compassion led to the NHS Constitution being updated to emphasise the six core values, including compassion, that all staff are expected to follow (Department of Health and Social Care, 2021), as well as the implementation of various policies, such as the ‘Compassion in Practice’ strategy. This sets out a vision of compassionate care delivery, underpinned by the fundamental values of nursing, known as the 6Cs (care, compassion, competence, communication, courage and commitment) (NHS Commissioning Board, 2012; NHS England, 2013). The Friends and Family Test was also introduced to gather service user feedback (NHS England, 2019), as well as a Values Based Recruitment (VBR) programme for employing staff (Health Education England, 2016).

There has been criticism that the policies lack clarity, which may serve to alienate staff and in turn reduce compassionate practice, as well as being reductionist (Dewar & Christley, 2013). For example, compassion is presented separately with other values within the 6Cs, when it can actually be considered at the core of them all (Dewar & Christley, 2013). Critiques also suggest that the focus on personal values does not consider leadership within the NHS or structural factors of the service, which inhibit the delivery of compassionate care (Dewar & Christley, 2013; O’Driscoll et al., 2018). This has been met with frustration from some professionals who see policies as a top-down initiatives with little information provided about how to enact changes (O’Driscoll et al., 2018).

Much research has since been directed around interventions to improve compassion within healthcare, (Crawford et al., 2014; Egan et al., 2017; Farr & Barker, 2017), as well as identifying potential barriers to this, such as lack of adequate staffing and support, and high workloads, all of which are often associated with compassion fatigue and burnout, characterised as the exhaustion caused by providing care (M. Durkin et al., 2016; Jenkins & Elliott, 2004). It has been suggested that the design of compassionate care therefore needs to look at structural and organisational factors (Crawford et al., 2014)

Additionally, improvements in increasing compassion needs to stretch to mental health services, where there has tended to be a language of 'recovery' and 'wellbeing', rather than a focus on the importance of social connection (Spandler & Stickley, 2011). Furthermore, within the NHS there has traditionally been a greater focus on physical healthcare, as well as physical and mental health being viewed and addressed as distinct (NHS England, 2014). More recently the NHS Long Term Plan commits to investing further in mental health, as well as expanding services for individuals in crisis and community mental health (NHS, 2019).

1.1.1. Compassion within secondary mental health services

Secondary care mental health services are often seen as a 'step-up' from primary care services, such as Improving Access to Psychological Therapies (IAPT) services, usually providing more specialist input and requiring a referral to access the service. Service remits, practices and working cultures can differ greatly between services and within similar services in different locations.

The set-up of mental health services has changed over time, and with the move towards providing greater community support (Department of Health and Social Care, 1999), the number of psychiatric beds has reduced (Giburt et al., 2014; Killaspy, 2006). However, demand for beds has risen and there is inadequate provision to support this demand (Galante et al., 2019; Hellewell & Atakan, 2004). This has led to waiting lists, higher inclusion criteria for services, transfer of care to neighbouring areas and pressure to discharge early (Galante et al., 2019), all of which are detrimental to individuals. Although services do provide support and are of value to their service users, it must also be acknowledged that the structure of delivery does not always allow for compassionate care.

For example, perceptions of mental health services have often been viewed in an unfavourable light, with feedback being more negative than other areas of health and social care (Healthwatch, 2018). Feedback about community mental health teams include concerns around inconsistent guidance, long waiting times to access support, as well as a lack of continuity of care, coordination between services, and effective discharge planning (Healthwatch, 2018). Similarly, crisis services are also viewed predominately negatively, with service users citing a lack of communication, empathy and respect and not feeling listened to (Healthwatch, 2018). Stigma and discrimination is also a feature of mental health services (Thornicroft et al., 2007). For example, Doyle et al. (2007) found nurses experiences of working with suicidal service users included care and sympathy but was also mixed with judgements about how genuine patients were being. Additionally, harm from psychiatric and psychological treatment (Boisvert & Faust, 2002; Crawford et al., 2016; Rose et al., 2015) is well reported.

Inpatient wards in particular are seen as unsatisfactory (Hellewell & Atakan, 2004; Rose et al., 2015; Weich et al., 2012). They have been characterised by service users as untherapeutic, coercive and controlling, with restraint and forced medication seen as a form of violence, and a ‘them and us’ mentality expressed by staff members (Gilburt et al., 2008; Rose et al., 2015; Staniszewska et al., 2019). They are also described as overcrowded, providing inadequate environments and little in terms of engagement with inpatients (Hellewell & Atakan, 2004; Rose et al., 2015). However the importance of relationships with staff have also been consistently highlighted (Gilburt et al., 2008; Staniszewska et al., 2019).

Within acute psychiatric wards, most individuals have been detained under the Mental Health Act (MHA, 1983), in situations where it is deemed there is significant risk of harm to self or others. Individuals can be held without their consent under various sections of the MHA, commonly known as sectioning, with rates shown to be rising (Galante et al., 2019). As a result, care delivered in wards in enclosed by a legal framework that has often restricted people's liberties, is more focused on risk management (Spandler & Stickley, 2011) and where there are significant power dynamics between staff and service users (Rose et al., 2015). An absence or deficit of care and compassion in such services can therefore be seen in relation to power differentials within institutions (Brown et al., 2014; Cutcliffe & Happell, 2009; Foucault, 1994). Additionally, the lack of compassion experienced by service users has led to the direct development of many survivor movements, where it is important to note that the message of survival is often *from* the services purporting to support individuals (Everett, 1994; Spandler & Stickley, 2011).

It is also important to note that although research and wider feedback from service users has often indicated uncompassionate responses from services, this will not of course be the same experience for all individuals who have used mental health services; for example participants in Weich et al.'s (2012) study expressed favourable experiences with home treatment teams. Nonetheless any instances of negative care, let alone widespread incidences suggests greater consideration and exploration is needed.

Experiences of racialised communities

There is a large amount of literature highlighting the inequalities within mental health, particularly for individuals who have been racialised (Department of Health, 2005). Research has consistently shown how individuals from a minority ethnicity are less likely to voluntarily access mental health services, are more likely to be sectioned (Bhui et al., 2003; Halvorsrud et al., 2018) and are more likely to experience discrimination once within the system (Department of Health, 2005). A lack of cultural awareness and exclusion of faith-based knowledge and understanding has also been reported (Race Equality Foundation, 2014). Additionally, individuals are less likely to be offered talking therapy (Race Equality Foundation, 2014), are more likely to be medicated (Bignall et al., 2019) and are disproportionately represented within inpatient wards (Bhui et al., 2003; Mental Health Foundation, 2016). African Caribbean individuals in particular are three-five times more likely to be diagnosed with schizophrenia and admitted to hospital with this diagnosis, than other groups (Bignall et al., 2019). The use of crisis services by individuals from racialised groups were also consistently considered to be impersonal and lacking in compassion, with individuals preferring to access alternative services, which they better trusted (Race Equality Foundation, 2014).

Potential reasons suggested for this overrepresentation include the over-diagnosis of more severe mental health diagnoses, such as schizophrenia (Bignall et al., 2019) and a distrust of services, preventing early access to support (Keating et al., 2002). Keating et al. (2002) proposed that there existed ‘circles of fear’ between Black communities and mental health services. They state that Black individuals are more likely to be classed as ‘other’ and viewed with suspicion and fear, which increases the likelihood of discrimination and coercive practices within services. As such, they too fear coming into contact or being associated with mental health difficulties and services, leading individuals to avoid this. This may then result in people not receiving support when they may need this, and so they are more likely to come into contact with services during times of crisis, thus increasing the likelihood of coercive and restrictive practices. Therefore, fear perpetuates between both Black communities and mental health services, and inequalities in care persist. Additionally, a reason which further encompasses these suggestions is the presence of institutional racism (Fernando, 2017), which is a social determinant of health (Paradies et al., 2015).

Literature around the disparities faced by ethnic minority individuals within mental healthcare thus highlights poorer care, an increase in fear and worse mental health outcomes (Bignall et al., 2019). This is despite the current compassion agenda and policies (NHS Commissioning Board, 2012). It is therefore argued that the need for compassionate care within mental health services and for racialised communities in particular, is greater. To consider what this might look like, conceptualisations of compassion will need to be explored.

1.3 Definitions and Conceptualisations of Compassion

Despite the large literature base on compassionate care and policies around its implementation, there has been a lack of consensus around the definition, with variations prevalent (Perez-Bret et al., 2016; Strauss et al., 2016). Within the NHS constitution compassion is said to consist of humanity and kindness to others pain or need, and actions to provide comfort to relieve the suffering (Department of Health and Social Care, 2021). A common feature of definitions appears to be around ideas of attunement to someone else’s suffering and a desire to reduce this (Gilbert, 2005; Goetz et al., 2010). Additionally, although empathy is considered to be similar, it does not have the action component generally implicated within compassion and so is a distinct term (Sinclair et al., 2017; Vivino et al., 2009). Following a systematic review, Strauss et al., (2016) consolidated definitions within the existing literature, and suggested that compassion is composed of five elements, which involve recognising suffering and the universality of this, feeling for another’s suffering, tolerating uncomfortableness and acting to alleviate this.

Furthermore, although understandings of compassion have been more recently discussed within Western countries (Gilbert, 2014), they have been prevalent within Eastern traditions, with compassion also being a key feature of all major religions. For example, in Buddhism, compassion is a core principle where it is seen as an empathetic wish to relieve suffering, which is informed by a wisdom to recognise this (Makransky, 2012). Compassion is also viewed as a mental capacity which can be strengthened, and within different Buddhist traditions there are variations in how this is regarded (Makransky, 2012). Within Islam, compassion is also seen as an overarching feature of the religion, exhibited for example, in the prayer recited before performing any act, which invokes names of Allah, as the Compassionate and

Merciful, and reminds individuals to also act in this way. It is also seen within the obligations to provide charity and exhibit actions which help others (Alharbi & Al Hadid, 2019). Within Christianity and Judaism there is also reference to a Compassionate God, who is thought to serve as a model for the treatment of others, with compassion also involving identifying with the suffering of another (Käppeli, 2008). Additionally, in Sikhism compassion is thought to be a divine quality with compassionate acts bring individuals closer to their Creator (Kak, 2016), whilst compassion is seen in terms of morality and ethical conduct in Hinduism, which includes consideration of all sentient beings (Jammu, 2016).

Similarly, from a sociological perspective, compassion is also seen in terms of morality, and it being a requirement to address the suffering of others, including those who are unknown to the individual. As such it can be conceptualised as "public compassion" and denotes a sense of human equality (Sznaider, 1998, p. 117). Compassion is thought not to be reliant on feelings, but rather a moral obligation (Sznaider, 1998). von Dietze and Orb (2000) also reference compassion as being more than just emotion, but a process that requires deliberation and action, and a sense of solidarity with those who may be suffering. As such, this leads to actions related to social justice, and individuals receiving compassion are seen as more than an individual (von Dietze & Orb, 2000), but part of a wider collective.

From an evolutionary basis, compassion is seen as something which has adaptive value and has evolved due to its ability to enhance wellbeing of offspring, as well as increase cooperation and desirability (Goetz et al., 2010). Compassion focused therapy is also based on evolutionary ideas, drawing on the importance of caring and prosocial behaviours, with these seen as being rewarding. Within this framework, it is believed there is a three-way flow of compassion: towards others, to the self, as well being able to receive compassion from others, with compassion being defined as "a sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it" (Gilbert, 2014, p. 19). The model posits three emotional regulation systems, which are activated by threats and fear, a drive to accomplish and a sense of soothing, safety, and self-compassion, and utilises the three-way flow of compassion to increase activation of the soothing system and reduced distress.

1.2. Conceptualisations of Compassion Within Healthcare

It will be also important to consider the specific definitions of compassion within healthcare. This section will outline the literature review method used to locate the relevant literature and discuss conceptualisations of compassion from the perspectives of staff and service users, with a distinction made between physical health and mental health setting.

1.2.1. Literature review method

The literature review search was conducted using PsychInfo, Academic Search Complete and CINAHL Plus databases, and was restricted to papers written in English. A combination of search terms was used including: ‘compassion’, ‘compassionate care’, ‘patient’, ‘service user’, ‘client’, ‘staff’, ‘perspective’, ‘experience’, ‘conceptualisation’, ‘definition’, ‘health’, ‘mental health’. Boolean operators ‘AND’ as well as ‘OR’ were used to combine search terms.

Title and abstracts were read to ensure relevancy to the topic and that they were focused on definitions and conceptualisations of compassion and compassionate care, from the perspective of staff and service users of health services. Papers were excluded if compassion was not the main focus of investigation or if they were solely on self-compassion, compassion-focused therapy, burnout, compassion fatigue, fear of compassion or compassion satisfaction. Opinion pieces and book extracts were also excluded. Further searches were conducted with Google Scholar and the university’s research repository, and reference lists of relevant articles were also reviewed to find additional papers.

1.2.2. Staff conceptualisations

Physical health:

Studies looking at staff perspective within physical health care will be outlined.

Nurses from 15 different countries, generally defined compassion as a “deep awareness of the suffering of others and a wish to alleviate it”, although there was a significant difference in definitions of compassion between nurses in the UK (Papadopoulos et al., 2016, 2017) indicating how cultural differences may play a part in defining the concept. Themes were also identified around the ‘conscious and intentional nature of compassion’, including the need to defend and advocate for patients and ‘socio-political structures’ of countries which adversely impacted on the delivery of care (Papadopoulos et al., 2017). However, it is also important to note that the majority (60%) of countries included within the sample were from Europe and none from Africa. It would be interesting to see whether different themes may have developed had more non-Western countries been included.

Other studies with nurses have also noted the organisational impact on providing compassion, including the support they themselves receive with compassion mainly spoken with reference to times it did not occur (Horsburgh & Ross, 2013b). This is similar to findings by Tierney, Seers, Tutton, et al., (2017) who developed a compassionate care flow model from staff working with diabetes patients. Compassion shown to patients was embedded within a system, which was defended (e.g. by sense of autonomy, supportive colleagues and work culture) or drained (e.g. by multiple work demands, difficult interactions, lack of time). Compassion therefore sat along a continuum and was said to encompass good communication, kindness, alertness and action towards patients’ needs, in order to improve health.

Intensive care nurses in Norway working with patients with chronic obstructive pulmonary disease highlighted themes around creating trusting relationships and caring for peoples as individuals (Kvangarsnes et al., 2013). Specific health needs were also discussed in relation to managing patients’ fear, preparing to care for them, cooperating with colleagues, alleviating pain and ensuring their independence.

It was also noted that small gestures which allowed patients to feel in control were considered compassionate, as also found amongst older adult nurses in Canada (Perry, 2009).

Hospice workers conceptualised compassion as involving the processes of recognising, relating and (re)acting (Way & Tracy, 2012). This involves understanding communication cues and what may not be communicated, forming shared connections, and acting either before or after the emergence of empathic feelings for the other person, including through giving individuals time and space. This study highlights how empathy was not a prerequisite for action and the importance of reflection in this process.

Within a similar setting of palliative care, Sinclair et al. (2018) conducted a grounded theory study. Five main themes developed within the model: virtuous intent, relational space, coming to know the person, forging a healing alliance and ameliorating suffering. Compassion was defined as purposeful, involving healthcare practitioners' values and reasoning to understand a persons' needs and taking action. Finding are similar to Way and Tracy (2012), suggesting perhaps key themes within palliative care staff. This model is comprehensive and is also complemented by the research team's earlier model from a service user perspective (Sinclair, McClement, et al., 2016). However, when considering transferability to UK health care, their Canadian health setting is likely to differ from the NHS, with different cultural and organisational practices. Additionally, palliative services are specific in providing specialised end of life care and may operate differently, providing different experiences to other healthcare departments.

Lastly, US family physicians were asked about their understanding of compassion and spirituality (Anandarajah & Roseman, 2014), something that has not been specifically explored in the other studies. Meanings of compassion were not recorded, but the study highlights how most participants felt there was a relationship between spiritualty and compassion. Compassionate practice involved understanding patient’s spiritual/religious beliefs and own beliefs were also drivers for being compassionate. Interestingly, it was proposed that time for spiritual self-care would help to increase compassion for patients, and that providing compassionate care clinically was a part of spiritual practice that further increased compassion. Additionally, as noted amongst other studies (Horsburgh & Ross, 2013; Papadopoulos et al., 2017; Tierney, Seers, Tutton, et al., 2017), organisational and work demands were barriers to being compassionate.

Conceptualisations of compassionate care from staff perspectives within physical health settings have emphasised the intentional nature of compassion (Papadopoulos et al., 2017; Sinclair, Hack, et al., 2018; Way & Tracy, 2012), the significance of relationships and small acts (Kvangarsnes et al., 2013; Perry, 2009), as well barriers to the delivery of care (Horsburgh & Ross, 2013b; Tierney, Seers, Tutton, et al., 2017). Findings have also suggested differences in definitions based on cultural and spiritual factors (Anandarajah & Roseman, 2014; Papadopoulos et al., 2016).

Mental health:

Five studies will be discussed looking at staff perspectives in mental health settings.

Definitions given by psychotherapists spoke of compassion as a “state of being”, allowing them to connect with their clients’ struggle and motivating them to help clients find relief (Vivino et al., 2009, p. 167). They spoke of compassion being an innate factor that could be awakened. It was also felt that compassion was deeper than empathy and compassion manifested itself in therapists’ behaviours. Being compassionate was also perceived to have positive effects on their clients, in terms of feeling heard, understood and accepted, as well as eliciting symptom relief. The study highlights conceptualisations of compassion in a field where clients are offered spaces to talk through deeply personal and often distressing stories. However, the findings are specific to the psychotherapists interviewed, all of whom worked privately in the USA and likely without the large organisational pressures faced by psychotherapists working within state funded healthcare services, such as the NHS. The majority of the therapists were also European-American and practising long-term psychodynamic/humanistic therapies, rather than the cognitive-behavioural model, predominant within NHS services (Pilgrim, 2009), all of which may have impacted on their understandings around compassion. Additionally, the psychotherapists were chosen to participate, having been nominated as compassionate. It would be interesting to note how accounts of compassion may have differed from therapists not deemed as compassionate, particularly as this is more likely to impact on client care.

In the UK, Armstrong et al. (2000) conducted a Delphi study, where ‘rounds’ of questionnaires were sent to mental health nurses for thoughts around ethical decision making. The meaning of compassion was a prominent topic that arose during the first round, which was investigated in the next rounds. All the responses received were different, but included giving time, listening, showing care and understanding, as well as assisting clients to make their own decision, not denying their rights and acting in their best interests. The majority of the nurses recorded that acting compassionately was a part of being an ethical nurse, although there were a small minority who felt that acting compassionately “may not be appropriate” in certain instances (Armstrong et al., 2000, p. 301). There is no elaboration on situations where compassion was deemed unsuitable. Thus, a limitation of the study was the extent to which meanings could be explored fully and adequately with questionnaires, as opposed to focus groups or individual interviews.

Where interviews have been conducted with mental health nurses, there has again been difficulties coming to a consensus around the meaning of compassion (Barron et al., 2017). Nurses from a community mental health team struggled to define compassion, despite stating it was a core part of their profession. Definitions given by professionals in an acute setting had a very practical element to it, and was generally described as “‘something done to’ another with a view to reducing destructive behaviour” (Brown et al., 2014, p. 394). Thus compassion was seen as involving power and control, used to ‘manage’ service users (Brown et al., 2014).

The same researchers highlighted the distinct lack of compassionate talk within this sample and language indicating emotional distancing (Crawford et al., 2013). An example described within the study, illustrated how speech around ‘care’ was often related to processes and practical work, rather than emotional affect or engagement with another person. It was also noted that there was no mention of reducing distress and instead there appeared to be a “production-line mentality” (Crawford et al., 2013, p. 724).

Therefore research looking at mental health professionals understanding of compassion have spoken about the innate nature of compassion, a novel finding thus far, as well as the importance of values and taking action, similar to staff within physical health care settings. Additionally, there is a clear emphasis in conceptualisations by staff within the UK studies, of the systems in which they work. A key theme highlighted was how the ability to provide, or indeed talk about compassionate care, was linked to and hampered by organisational demands, targets, workloads, limited time and resources, and individuals’ own emotional reserves (Barron et al., 2017; Brown et al., 2014; Crawford et al., 2013). It is telling that the inhibiting factors noted by US psychotherapists in the study by Vivino et al. (2009) however, focused on individual client or therapist reasons, such as perceived lack of client involvement in therapy or therapist feeling incompetent.

1.2.3. Joint conceptualisations

Studies looking at the perspectives of both staff and service users will now be discussed.

Babaei et al. (2016) conducted field observations and interviews with nurses and patients on medical and surgical wards to investigate compassionate behaviours of Iranian nurses. They posited that the use of non-verbal behaviours, expressions of empathy and providing bedside support encompassed compassion. Specific cultural behaviours were noted, such as physical touch only being used with patients of the same gender and the use of Persian literature. The research is helpful in providing a perspective outside of the Western culture, however there are limitations. The study did not specifically define compassion, instead focusing primarily on behaviours considered to be compassionate. The use of observations added to the analysis of the study, although this meant researchers classified certain behaviours as compassionate, and so findings were not based solely on participant conceptualisations. Additionally, nurses and patient views were not delineated, so it difficult to establish whether certain themes were more predominant in one group over the other.

Kneafsey et al. (2016) used focus groups with academic staff, students, clinicians and members of the public. Compassion was defined as something complex and innate, consisting of empathy, wanting to support others and requiring action. Positive relationships requiring engagement and communication with others was consider important, as well as consistent compassion. Barriers to compassion included structural system factors, insufficient time and staff burnout, whilst facilitators of compassion included education, positive role modelling and good leadership. A framework for compassionate inter-personal relations was created, which included connecting, recognising feelings, becoming motivated, taking action to help and sustaining relationships. The sample was ethnically diverse, however it is unclear the proportion of people from a minority ethnicity and how much their voice was represented.

Lown et al. (2011) looked at 800 patients and 510 doctors' views on a survey, checking their agreement with statements said to indicate compassionate health care. They did not define care themselves, however there was general agreement on most points, such as being treated respectfully and being seen as an individual. Patients also reported concerns they were not involved in their care as much as they would like.

Interviews with nurses and older adults in the Netherlands identified compassion as involving seven dimensions: attentiveness, listening, confronting, involvement, helping, presence and understanding (van der Cingel, 2011). Suffering was seen to be the trigger for compassion, which was considered to be different from pity, similar to previous studies (Sinclair et al., 2017). These findings were also similar to a participatory action research conducted by Smith-MacDonald et al., (2019) which consisted of interviews and focus groups with residents, family, healthcare providers, and managers from long-term care sites in Canada. Themes were created around providing a virtuous response, attempting to understand an individual, relational communication and attending to needs. Organisational factors were also stated, with some participants believing compassionate training could be helpful, and others feeling this would lead to non-genuine expressions of care. The importance of time and feeling undervalued by other staff were also raised. Additionally the researchers reported a concordance with previous compassionate care models they had developed (Sinclair, McClement, et al., 2016), suggesting a sense of universality in what compassionate care consists of. However it is important to note that researchers are actively involved in the generation of themes (Braun & Clarke, 2006a), and so their previous research may have influenced what was generated in the current study.

Research on joint conceptualisations have once again highlighted the importance of values and interpersonal relationships within compassionate care (Lown et al., 2011; Smith-MacDonald et al., 2019; van der Cingel, 2011), with wanting to reduce suffering and taking action being important (Kneafsey et al., 2016). They have also highlighted cultural differences in behaviours considered compassionate (Babaei et al., 2016).

1.2.4. Service user conceptualisations

Physical health:

Studies focused on service user perspective will be reviewed, starting with those in physical health settings.

In a study by Kret (2011) medical-surgical patients were asked to rate their nurses on a compassionate scale, as well qualitatively describing a compassionate quality. Overall, it was found that nurses were rated as compassionate with little variability amongst the ratings. Reported qualities include being caring, attentive, dedicated, approachable, professional, and keeping the patient informed. Although this study goes some way to describing what compassion may look like within the personal traits of a nurse, single characteristics were reported with no further contextual information or examples provided. There appears to be limited analyses of the qualitative results, which may be due to there being little opportunity to gather in-depth information. Additionally, pre-selected characteristics were initially provided to participants, before they added their own, which may have influenced the subsequent responses given. Participants were also selected by their nurses, which may also have biased the ratings provided and could also be a potential explaining factor for the high levels of concordance to the compassionate qualities on the scale. Only one participant was chosen to take part for each nurse, however there may have been additional or varied information provided had there been multiple patients treated by the nurses selected to take part.

Schneider et al. (2015) also used a questionnaire to ask individuals diagnosed with complex pain what advice they would give to healthcare professionals about the best way to show more compassion. Themes reported included listening, believing in individuals, taking them seriously and not minimising their pain, as well as becoming more educated about chronic pain. This study provides some information around what compassionate care may look like for those living with pain, although this may differ from groups of people with different health conditions. Additionally, 95% of survey responders listed their ethnicity as White/Caucasian and the use of a questionnaire also means there was limited scope to fully explore compassion further.

Badger and Royse (2012) looked at compassionate care from the view of burn survivors in USA. They identified three major themes: showing respect, interpersonal and informational communication, and providing competent care. Although respecting people was reported to be the most prominent theme, the researchers highlighted the interconnected nature of all the themes and how compassionate care was not described in a singular fashion. Rather, they suggested compassionate care was best represented when all three themes came together and overlapped. Although important in contributing to the research base, the study is specific to burn survivors based in America, the majority (77%) of whom were White. Additionally, focus groups were used to explore the topic and participants were recruited from a burns conference. It may have been that data would have looked different had participants had the opportunity to speak privately, and away from the conference setting.

Bramley & Matiti, (2014) spoke to inpatients in acute medical wards about experiences of compassion within nursing care. Themes focused on what compassionate nursing involved (knowing individuals, providing individualised care and time); being able to empathise with the patients and understanding the impact of both compassionate and uncompassionate actions; and ways to be more compassionate (focus on communication, training, change in ward culture, recognising compassion as the essence of nursing). However, all participants were White British and different responses and themes may have resulted from a more diverse sample. Interviews were also conducted within the ward setting, which may have impacted on responses provided. It is also noted that consent was withdrawn from one participant, who became distressed whilst discussing their care, and as such may have provided different insights regarding compassionate nursing care.

The first empirical theory of service user conceptualisations around compassionate care was conducted by Sinclair et al. (2016) with palliative cancer patients in Canada, using grounded theory. They proposed seven themes to their model (virtues, relational space, virtuous response, seeking to understand, relational communicating, attending to needs and patient reported outcomes), with the central aspect of the model being a “virtuous response to suffering” (Sinclair, McClement, et al., 2016, p. 195). Compassion was said to be based on health care professionals’ virtues, such as genuineness, honesty, kindness and tolerance, and then delivered via a virtuous response, within a relational space. This involved knowing the person as an individual, prioritising their needs and healthcare providers doing their best for patients. More specifically this involved seeking to understand the person and their needs, and then attending to needs in a timely manner. Patients described being able to intuitively sense when compassion was being shown to them, as well as more specific factors shown by engaged caregivers, through their demeanour, affect, behaviours and engagement. Compassion was said to reduce suffering whilst also being a protective factor for wellbeing. This model was later presented to non-cancer palliative patients, with all themes endorsed and nothing further identified (Sinclair, Jaggi, et al., 2018). The study greatly adds to the research base around compassion, particularly from the view of service users, although the setting is specific to palliative services and the Canadian health system.

In another grounded theory model developed by Straughair et al. (2019), looking at nursing care across NHS, private and voluntary settings, five categories were proposed. This included a core category of “humanising for compassion”, as well as a “self-propensity for compassion”, “attributes for compassion”, “socialising for compassion” and “conditions for compassion”. The model described how nurses required an innate ability to be compassionate, which may then be influenced by personal attributes, (kindness, effective communicator, being gentle and reassuring), as well as external factors (early experiences, role models, training, education) and contextual factors (workloads, staffing ratios, targets). At its core, individuals and their experiences are centred and treated as humans. It is noted that participants used their experiences of nursing care, as well as wider experiences to conceptualise compassion. The model is based on perspectives of individuals from a university ‘service user and carer’ group, however it is unclear whether this specifically includes mental health nursing as well and there is no reference to the ethnic demographics of participants.

Finally, a recent study by Singh et al. (2020) explored the views and experiences of South Asians who have used Canadian healthcare systems. They identified three main categories: South Asians understanding of compassion; cultural sensitivity of staff; and the importance of compassion and patient recommendations to overcome barriers. Compassion was described as being viewed through specific qualities within healthcare professionals (kindness, understanding, viewing individuals as a person) and relational interactions (listening and providing time, forming personal connections, non-routine acts of care), similar to previous studies (e.g. Sinclair et al., 2016). However, it was also highlighted that religious teachings shaped participants' understanding of compassion. It was also considered to be universal, and not isolated to specific cultures or ethnicities, although the way it was expressed or perceived could vary. Healthcare professionals were deemed to be more compassionate when recognising this and showing cultural awareness, compared to those who did not, even if the medical care they provided was of good standard. Expressions of cultural sensitivity included involving family members in decision making and acceptance of cultural beliefs and practices that were different from professionals', as well as taking steps to overcome language barriers. Additionally, the value of compassionate care was highlighted, such as being able to reduce distress, increase health, build staff-patient relationships, encourage sharing of health information and overcome cultural barriers, with all stating it was a key feature for healthcare services. It was also noted that a single incident of uncompassionate care could reduce trust and impact of positive experiences, with individuals more likely to seek alternative treatment.

The study is significant in being the first to look at ethnically minoritised service user conceptualisations of compassion. It highlights similar themes around the concept of compassion as seen in other studies whilst also emphasising the importance and need for healthcare professionals to show cultural awareness. The research adds to the nascent evidence base looking at compassionate care within minority ethnic communities, however it is again based within the Canadian healthcare system, which not only will have its specific organisational culture that differs from the NHS, but different immigration and attitudinal differences between the countries.

In summary, research focusing solely on service user views within physical health care have also looked at personal staff characteristics (Kret, 2011), as also found in previous literature. Additionally, relational factors were again seen to be important, such as giving individuals time (Bramley & Matiti, 2014), communicating effectively (Badger & Royse, 2012), listening to and believing in their experiences (Schneider et al., 2015), as well as being cared for with respect (Badger & Royse, 2012; Bramley & Matiti, 2014). Key findings that were highlighted from these studies include the importance of humanising individuals, as well as the importance of religion in understanding compassion, also mentioned by US doctors (Anandarajah & Roseman, 2014), and the need for cultural sensitivity. Additionally, the negative impact of uncompassionate care was highlighted.

Mental health:

Studies focused on service user views within the mental health context will be discussed in this last section.

In the first such study by (Pauley & McPherson, 2010), the main focus was around self-compassion, however they also explored the general meaning of compassion, amongst individuals diagnosed with depression or anxiety. Amongst the participants, compassion was posited as being kind as well as taking action. However, all participants were White British, thus limiting the transferability of findings to individuals from other ethnicities. They were also recruited from the caseload of the lead researcher, which is likely to have impacted the responses they provided due to their pre-existing relationship. Additionally, individuals were excluded from the study if they had also been given other diagnoses (e.g. schizophrenia or substance misuse), which were deemed by the researchers to significantly impact on their experiences of depression or anxiety. Inclusion of such participants may have provided different experiences and insights, which were just as relevant to the topic.

In the second identified study, Lloyd and Carson (2011) interviewed users of consumer-led charities about their experiences of mental health care involvement and how this could be improved. Themes identified within the study include "universality" of values such as compassion, dignity and respect; the acknowledgement of the “diversity” of individuals and their needs; and “recovery” and hope through support and treatment. These themes were considered to signify compassionate care and stated to be a key factor for involvement with mental health services. Three areas of compassionate practice were then elucidated: presence, collaboration and persistence. Presence refers to being physically present, as well as the ability to effectively support an individual’s recovery. Collaboration involves genuinely working together as equals to achieve outcomes. Finally, persistence is required to offer hope and optimism, and foster continued engagement. Lloyd & Carson (2011) state that these three areas can be used to develop a dialogical relationship with service users, which allows for compassionate engagement with services and an equal recognition of their narratives, rather than narratives imposed by practitioners.

Whilst this study is valuable in eliciting the factors that affect involvement with mental health services and provide three indicators of compassionate care, the concept of compassion was developed through the researchers’ analyses. Participants were not specifically asked to define compassion or what this looked like for them during their involvement with mental health services. Additionally, it is unclear what mental health services participants had previously used and whether factors relating to engagement with services is more applicable to a particular setting. There is also limited demographic information provided.

Lastly, in her recent doctoral thesis, Alonso (2020) looked at users of an IAPT service and developed a model around compassionate care, entitled “humanising responses to distress”. This consisted of five key categories, which appeared to follow a process. The “distress” category preceded contact with IAPT services and led to support being sought, after which participants received a “humanising response”, or “dehumanising response”, which were related to expressions of genuine concern, understanding individuals’ experiences, acting to meet needs, empowerment and the creation of secure therapeutic relationships. This was influenced by mediating “conditions” at the individual, relational, service-related and contextual levels. Finally, there were the resultant “response dependent outcomes”, on individual’s perceived levels of trust, relief, importance, satisfaction and engagement. The study is the first within the UK to develop an empirical model conceptualising compassionate care from the view of service users in a mental health service. It explored the relational factors as well as individual factors of compassionate care and highlighted the impact of contextual factors on service users and the perceptions of their care. The study touched on ideas around culture being important to take into consideration, however the London participants predominately fell within the White British/White Other ethnicity category (85%), which does not reflect the demographic of the city. Additionally, IAPT is commissioned to work with individuals considered to experience symptoms of depression and anxiety (NHS England, 2021). Although this may encompass a large percentage of the population, it does not account for individuals who experience so called more ‘severe and enduring’ conditions, for whom secondary care mental health services may be involved. The culture and ways of working in such services are diverse and differ from the IAPT model, and so the findings from this study need to be considered within this context.

In summary, there are fewer research papers on service user views based on mental health settings compared to the other contexts. Although studies outlined have been important in highlighting a person-centred approach, ensuring care is humanising and that there is effective communication and collaboration, there is only one that directly asks service users about definitions of compassionate care (Alonso, 2020). Additionally, across all the contexts there is limited research from individuals from a minority ethnic background. Furthermore a systematic review by Singh et al. (2018) identified how studies with ethnically diverse samples tended to use pre-defined definitions of compassion (Papadopoulos et al., 2016), instead of eliciting definitions directly from participants, or used compassion as a theme to interpret results, rather than this being the focus of the study (Lundberg & Boonprasabhai, 2001). The review similarly highlighted the limited evidence base, with a need for further studies to focus on ethnically diverse populations. This is also echoed within other studies (Alonso, 2020; P. Crawford et al., 2013; Singh et al., 2020).

1.4 Gaps In Literature

Within the literature, the voice of service users has been limited, despite compassion being a factor directly affecting the care they receive and research showing the value of listening to their testimonies (Bradshaw, 2014). Few studies have focussed solely on service user perspectives in conceptualising compassion (Sinclair, Norris, et al., 2016), and where this has occurred, the settings have tended to be in health, rather than mental health and are not applicable to UK healthcare settings, aside from a recent unpublished doctoral research study focused on an IAPT service (Alonso, 2020).

Delivering compassionate care within mental health services is considered important, particularly as they are thought to be “compassion deficit” (Spandler & Stickley, 2011, p. 5). Services are also working to improve race equalities (Department of Health, 2009; NHS England, 2020) and developing greater compassion forms a part of that. Additionally, secondary care mental health services, and particularly acute services often see people at times of high distress and crisis, when they are very vulnerable and perhaps in need of most compassion. The first step in the process of changing the way care is delivered and experienced, involves defining the concept of compassionate care, through the eyes of service users.

Furthermore, most of the research around compassion has focused on Western populations and consist of samples which significantly lack ethnic diversity. The existing literature therefore point to a dearth of studies focusing on the perspectives of individuals from an ethnic minority background, with only one recent study looking specifically at those who have also used services, although this is not set within the UK (Singh et al., 2020). This poses an issue when considering the drive for compassionate care within the UK and the pre-existing structural inequalities and discrimination faced by individuals from a minority ethnic group.

When combined together, there has been no research looking at conceptualisations of compassionate care from the perspective of mental health service users who are ethnically minoritised.

2 AIMS & RESEARCH QUESTIONS

This study aims to address the identified gap and explore the definition of compassionate care, from the perspective of ethnically minoritised users of secondary care mental health services. This is likely to highlight implications for the way care may be delivered to users of such services, and the subsequent outcomes of this care.

2.1 Research Questions

- How is compassion and compassionate care defined by service users, from an ethnic minority background?
- What influences their definition?
- How does this definition relate to their experiences of compassionate care within secondary care mental health services?

3 METHODOLOGY

This chapter will outline the epistemological framework of the research and the researcher position, before outlining the methods of the study. There is a consideration of ethical issues and the data analysis process.

3.1 Ontology and epistemology

It is important to outline the philosophical basis of the research, as this highlights the assumptions on which the research is grounded (Chamberlain, 2014). This then shapes how the research is conducted and its findings, helping to evaluate whether the study has met its objectives (Willig, 2013). This research adopts a critical realist approach, taking a realist ontological position and a relativist epistemological position (Willig, 2013).

The philosophical field of ontology refers to the nature of the world and asks questions about reality and what knowledge there is to know (Chamberlain, 2014). Within this, a realist position assumes that there exists a real material world (Chamberlain, 2014), which is made up of underlying structures and objects (Willig, 2013). In relation to this study, compassion is viewed as a concept which exists within reality, and therefore it can be defined. Although compassion per se may not be directly observable, the effects of receiving compassion and compassionate care are real and can be felt by individuals, in a cause-effect type relationship (Willig, 2013). It also views compassionate care as an underlying structure within mental health services, and therefore expressions of it should be expected.

Epistemology refers to the theory of knowledge and asks questions about how to investigate the world (Chamberlain, 2014). A relativist epistemological position assumes that the data collected does not reflect a wholly accurate or direct representation of reality, but instead provides a subjective account (Willig, 2013). As such, different versions or interpretations of reality are constructed, and are influenced by individual, social and cultural contexts of the participants, as well as the researcher. Therefore, meanings and experiences provided around compassionate care by individuals from a minority ethnic background can be understood in relation to the individuals involved within the research and their wider contexts.

Through adopting a critical realist position, this study therefore attempts to examine an objective reality whilst acknowledging that this may not be directly possible, and will highlight my interpretations of compassionate care based on the participants' perspectives (Willig, 2013). This position allows for a greater understanding and exploration of the concept, considering multiple contexts.

3.2 Researcher position

Reflexivity is important within qualitative research, particularly as the chosen epistemological position highlights that my own positioning and context will inevitably impact on the research (Willig, 2013). I will outline some information about myself that I feel is important to situate the research, and the perspectives with which I approached it.

I am a British-Bangladeshi Muslim woman. Growing up between two cultures has influenced the way I see things and my sense of identity, and has helped me to recognise how ideas and concepts can be viewed in different ways. My religion also contributes to this and impacts the way that I live my life on a day-to-day basis, as well as being somewhere I turn to more in times of happiness and distress. Additionally, showing compassion to others is an integral part of my religious beliefs. As a minoritised individual I've been very aware of the sense of othering that can occur in different contexts, as well as the importance of acceptance. I've also been aware of the discrepancies and discrimination faced by individuals from racialised backgrounds, particularly within mental health services and the psychology field.

My interest in this research topic partly stemmed from my working experiences within mental health services, including secondary and acute services. I had felt that service structures were not set up in ways that encouraged consistent compassionate care. Stigma and biases, particularly against individuals given certain psychiatric diagnoses, were also apparent and further impacted the delivery of compassionate care and minimised individuals' identity. I had also felt that religion and spirituality were generally erased from discourses, except where religious beliefs were used to problematise an individual. However, I've also seen how for some, myself included, faith can be used to help enhance wellbeing. To me, this all seemed to be contradictory to the aims of mental health services.

Additionally, particularly during clinical training, I had become more aware of how a lot of therapies and theories were based on a certain, limited demographic and were then alluded to be or accepted as universal, even if this was not specifically claimed. I would hear about adaptations made for minoritised individuals but queried why they were never the starting point and whether it was adaptations that were needed or new ways of working. I wondered what would be the view of such individuals if they were asked; for example, would they say similar things and/or would they say certain elements had been overlooked? Reviewing the compassionate care literature base, I was aware that current ideas around this appeared to be formed more by researchers or staff members, rather than the individuals who were directly affected, and even less so by people who looked similar to myself.

I have also personally accessed mental health support, although I have not used secondary or acute care services, and this has also shaped my ideas about what compassionate care should look like. For me, compassion forms the basis of healthcare, and healthcare without compassion is an oxymoron. I feel that central to this would be a delivery of care that is personalised to the individual and includes a genuine desire to understand and accept an individual as they are, collaboratively working to alleviate distress. I also feel that services need a working culture and an infrastructure which enables and prioritises this, otherwise compassionate care would be lacking.

Through the use of supervision, discussion with peers and a reflective diary, I attempted to remain aware of my own views, whilst being open-minded to the views shared by participants and not let my own ideas unduly influence my ability to hear theirs. There is further information regarding reflexivity during the analysis process, within the Discussion section.

3.3 Methods

3.3.1 Participants

Seven participants were recruited into the study, five females and two males. Eligibility criteria included the requirement that individuals were adults (aged 18 and over), who self-identified with a minority ethnicity within the UK and had used NHS secondary care adult mental health services, including acute services.

Participants were able to self-record their ethnicity, in order to prevent them from feeling restricted and needing to choose from pre-selected groups. Four participants were from a South Asian background, one participant identified themselves as Black African, one as Black Caribbean and one as Mixed other. Within the last UK census (Office of National Statistics, 2011), the majority ethnic group was reported to be White British, so individuals identifying with this particular group were excluded.

Participants had previously used a range of mental health services, including community mental health teams, secondary care psychology teams, specialist mental health services, as well as inpatient wards, home treatment teams and access and assessment teams. Some participants had accessed multiple services. Table 1 provides further details of each participant.

In order to reduce potential distress from participation and prioritise emotional wellbeing, individuals were excluded from participating if they were using acute services at the time of interview, were in the process of accessing these, or had contact with acute services in the last three months, as involvement with such services usually signifies crisis for an individual. Additionally, only English-speaking participants were recruited, due to limited funds in paying for an interpreter. All participants were judged as having the capacity to consent to taking part in the project.

Table 1.

Participants' Demographics

Pseudonym	Age range	Gender	Relationship status	Ethnicity[1]	Religious/ spiritual status	Mental health service[2]
Nihal	66-75	Male	Single	Asian British	Spiritual but not religious	Inpatient
Deborah	46-55	Female	Single	Black Caribbean	Spiritual and religious	Community
Nazia	18-25	Female	Single	Asian British	Spiritual but not religious	Community
Amira	56-65	Female	Married	Asian British	Spiritual and religious	Community
Sophea	46-55	Female	Single	Mixed other	Spiritual and religious	Inpatient, community
Farah	46-55	Female	Married	Asian British	Spiritual and religious	Inpatient
Isaac	46-55	Male	Single	Black African	Spiritual and religious	Community

[1] Participants were able to self-record their ethnicity, however the ethnic groups recorded here have been broadened in order to maintain confidentiality

[2] The mental health services used have been presented as either inpatient or community service, in order to maintain confidentiality

3.3.2 Recruitment

In order for the study to be widely advertised, recruitment posters (Appendix A) were sent to: a number of local and national service user groups and organisations across England; service user participation groups for clinical psychology programmes; as well as mental health organisations and those that support ethnic minority community groups. Additionally, the study was advertised at a service user network meeting and on social media platforms (Twitter, Facebook, Instagram). Snowball sampling techniques were also used.

Recruitment began during the Covid-19 pandemic, which is likely to have had an adverse effect, with service user organisations closing or moving online, and individuals and organisations having to adapt to all the changes and losses associated with the pandemic. Following initial difficulties in recruitment, the process was expanded to increase recruitment opportunities. Initially, this included widening the number of places where the research could be advertised, from three specific mental health organisations to other mental health organisations and user groups across the country, as well as social media. The inclusion criteria were also later widened from needing to have used acute services initially, to including secondary care services as well. Additionally, service user group leaders or facilitators, who had supported individuals with a minority ethnicity in accessing mental health services, were also able to participate. However, no participants were recruited under this category and all participants had personal experience of using mental health services.

Interested participants were able to contact me via email and were sent the participant information sheet (Appendix B) outlining full details about the study. Participants were also given the opportunity to ask any questions they may have had. For those who agreed to take part, an interview date was scheduled.

Of those who expressed initial interest but did not take part, the majority did not reply back and no reason was provided, or they did not meet all the eligibility criteria. Other reasons provided were lack of remuneration for their time and disappointment at the restricted ways to get in contact and lack of mutual sharing of personal information.

3.3.3 Interviews

The use of interviews allowed the collection of qualitative data directly from the selected participant group. This format was chosen over focus groups as it was deemed likely to provide a rich data source and allow participants more confidentiality in speaking about their experiences. Semi-structured interviews were conducted with participants, allowing a flexible guide to ensure answering of the research questions, but enabling interviews to not be too restrictive or constrain exploration of the views raised.

The interview schedule (Appendix C) consisted of eight questions, initially developed after reviewing the literature base and refined following discussions with my supervisor and an expert by experience from the UEL DClinPsych People's Committee. It had been advised that originally there were too many questions and the wording could be made simpler. This led to the removal of some questions, from 12 to eight, and the rephrasing of others so that the questions were clearer. For example, '*Could you give me an example on when you felt compassion was shown to you when you were using this service, if there was one?*' was changed to '*Are there any examples of when you felt compassion was shown to you within a mental health service?*'

Before the interviews took place, full informed consent was sought, and participants completed the consent form (Appendix D). They also completed the demographic questionnaire (Appendix E). As a result of the Covid-19 pandemic and social distancing procedures, participants were given the choice of telephone or online interviews. Due to participant preferences, as well as some technical difficulties, the majority of the interviews were conducted via an audio call, and one interview was held via a video call. Interviews lasted between 36 and 100 minutes, with the average length being 58 minutes. All interviews were audio-recorded.

3.3.4 Transcription

All interviews were transcribed verbatim, and any identifiable information was removed or anonymised. The transcripts were compared back to the recordings to ensure accuracy. I completed the transcription process myself, in order to maintain participant confidentiality and to ensure increased familiarity with the data set, as this forms a part of the initial data analysis (Braun & Clarke, 2006a). Transcription notations (Appendix F) were adapted from Jefferson (1987).

The extracts included within the Results section have had a “tidy up” (Willig, 2013, p. 114) to improve clarity and continuity of the speech. As a result, repetition of words, non-verbal utterances and brief overlapping speech (such as “umm” and “yeah”) have been removed.

3.4 Ethical Considerations

3.4.1 Ethical Approval

Initial ethical approval (Appendix G) and two further amendments (Appendices H and I) were granted by the University of East London’s School of Psychology Research Ethics Committee.

3.4.2 Informed Consent

Informed consent was sought from all participants prior to them taking part. The information sheet outlined full details of the study, including the research aims, what participation would involve, potential risks and how their data would be used and stored. Participants were also informed that they were free to withdraw from the study without consequence. The information sheet was revisited before the start of the interviews and there were further opportunities to ask questions, before participants signed the consent form electronically and returned these.

3.4.3 Minimising harm

Participants were asked to talk about compassion, as well as speak about their own lived experience and times when compassion was either shown or was missing within mental health services. I was aware this may remind people of potentially negative or upsetting experiences, which could be distressing to speak or think about. In order to minimise potential distress, all participants were informed of the possibility of the interview raising distressing feelings, prior to consenting, and that they would also be debriefed at the end.

Additionally, participants were made aware that they did not have to share anything they did not feel comfortable with, were able to take breaks in the interview as needed, complete the interview at a later date, or choose to end the interview whenever they wanted. It was also discussed that if there were any concerns about a participant's safety, this was something that would be raised with them and support options explored, as well as discussed with my research supervisor as a minimum.

During the interview, there were check-ins employed to gauge how participants were feeling about the process and if they were happy to continue. Participants were also debriefed at the end of the interview and given some time to talk about the process of doing the interview. They were provided with a debriefing sheet (Appendix J), containing details of mental health support organisations, as well as other support systems that may be available to individuals, such as their GP, mental health team, local service user groups, family and friends.

3.4.4 Confidentiality and Anonymity

All identifiable information was anonymised at the point of transcription and pseudonyms used in place of participants' names. Audio recordings were deleted after transcription. Transcripts and consent forms have been password-protected and securely stored, with only myself having access to the storage base. My supervisor and examiners will also be able to see full anonymised transcripts. Transcripts will remain securely stored for five years, in line with the university's data management policy.

Participants were informed that confidentiality would only be broken if there were serious concerns about their safety. However, this was not the case for any participants.

3.4.5 Remuneration

Participants were not paid for taking part; however, all were placed into a £100 voucher prize draw. The prize draw was initiated after two participants had already taken part, and was used to attract potential further participants, however all participants were entered into the draw and one winner was chosen at random. The draw was also a way of acknowledging people's time and contribution, and an attempt to respect this due to the potential difficulties in participating given the pandemic.

3.5 Data analysis

3.5.1 Rationale for thematic analysis

Reflexive thematic analysis (TA) was the method of analysis chosen for this project (Braun & Clarke, 2006a), as it was in line with the purpose of the project and the research questions (Braun & Clarke, 2021b; Willig, 2013), which were focused on meaning as well as personal experiences. TA acknowledges researcher subjectivity as key in generating codes and that themes are developed from these codes using an analytical and reflexive approach, with the results situated within a wider context (Braun & Clarke, 2021b). Additionally, TA is theoretically flexible which meant that it could be coherently applied with my chosen epistemological stance of critical realism (Braun & Clarke, 2021b). This project also aimed to look at patterns of meaning across participants, which is consistent with TA, rather than the analysis of speech or biographical and idiographic data (Braun & Clarke, 2021b).

3.5.2 Process of analysis

Braun and Clarke's (2006, 2021a) six-step guide to completing a thematic analysis was used for this project, as described below. As indicated by Braun and Clarke (2006) this process was recursive, rather than linear, with movement through the steps taken as needed.

Additionally, an inductive approach to analysis was taken, where the codes were generated based on the dataset rather than a pre-conceived framework (Braun & Clarke, 2006a). A mixture of semantic and latent themes were created, which highlighted the explicit content of participants' speech, as well as going beyond this and interpreting views and underlying assumptions (Braun & Clarke, 2006a), in line with the critical realist epistemology.

Familiarisation with the data:

This began during the interview process, where I collected the data myself, and continued during the transcription of interviews. Transcripts were read and re-read and initial notes were made highlighting areas of interest and initial reflections.

Generating initial codes:

Transcripts were uploaded to the Nvivo software programme to facilitate the coding process. Codes highlight something meaningful within the transcripts and helps to organise and group together different sections of the dataset (Braun & Clarke, 2006a). Working through the entire dataset, both descriptive and interpretative codes were created. Examples of coded extracts are shown in Appendices K and L.

Generating (initial) themes:

Once all the data had been initially coded, they were further analysed to see how they may group together to form broader themes and sub-themes. Themes define the overall relationships between the codes, and represent “patterns of shared meaning, united by a central concept”, which help to answer the research questions (Braun & Clarke, 2021a, p. 341). Tables and thematic maps were used to help identify patterns, and an example of an earlier version of a thematic map is shown in Appendix M.

Reviewing themes:

After some initial themes had been created, this was refined. Data extracts for each theme were reread to check for coherency and the themes were also checked against the entire dataset to ensure validity and accurate representation of the data collected. This process led to the reworking of themes, including separate sub-themes being merged together where they appeared to be less distinctive, as well as extracts moved to fit better with certain themes. The final thematic table can be seen in Appendix N.

Defining and naming themes:

A narrative was created for each theme, which helped to define what they represented. This led to further refinements to ensure a coherent story was being presented and the research questions were being answered. Participants’ words were used to help provide concise names for the themes, and ensured the themes were grounded within the data, as well as my interpretations.

Producing the report:
The Results and Discussion sections of this thesis were written up with the aim to provide a comprehensive account of the analysis, which both described the data and provided a response to the research questions, using extracts to help illustrate the points made.

3.6 Evaluating the quality of research

It is important to be able to evaluate the quality of the research and Yardley's (2000) four criteria have been used to do this: sensitivity to context, commitment and rigor, transparency and coherence, impact and importance. This is evaluated in the Discussion chapter.

4 RESULTS

The results of the thematic analysis led to the construction of three main themes and 12 sub-themes. This chapter will describe these using selected extracts from the participants' interviews. The full thematic table, including the participants who contributed to each theme, is shown in Appendix O.

4.1 Growing the "seeds" of compassion

This main theme reflects participants' ideas around the nature of compassion, where this arises from and how it may evolve, and uses the metaphor of compassion as "seeds" to illustrate this. Participants spoke about compassion as something which existed within people but had the ability to grow and change. This was also discussed in relation to services.

4.1.1 “Internal” factor

Compassion was described as an “internal” factor, which formed a part of an individual’s character and was a “way of being”. There was a suggestion that individuals needed to have “enough” internal compassion “seeds” for it to be felt by others, and it could not just be manufactured if not already present.

> Nihal: *Compassion to me means, it's a internal urge*

> Sophea: *…it’s something core, it's something innate. You can't create it if people don't have enough of it already within*

> Farah: *I believe that some people are generally just very compassionate people, in their nature, therefore they give an aura of compassion even just when they speak to you*

Compassion was also said to consist of key inner traits, such as kindness, the ability to recognise suffering and the desire to help with this.

> Nazia: *I think compassion, like, if we really break it down, it’s just kindness*

> Deborah: *With compassion you’ve got that desire to help someone. You see someone walking down the street and then falling, you’ve got that natural compassion to run along and help that person*

Some participants felt that compassion involved also directing this energy towards the self, as well as others.

> Nazia: *… you can also have compassion for others, but compassion can also be for yourself, and I think usually, to be compassionate for others you need to be compassionate to yourself*

They spoke about how self-directed compassion is a necessary step in being able to be compassionate towards others, and referenced self-compassion being more difficult than that directed towards others. This suggests a process involved in the expression of compassion, and perhaps a difficulty moving onto this next step.

> Sophea: *…you're trying to be compassionate to others, but you're also being compassionate to yourself, and sometimes you can't get past that bit*

4.1.2 Nurturing compassion

Although participants spoke about compassion being an innate factor found within individuals, they also described how it was not something that was just static, but there is the opportunity to grow compassion, as well as reduce or lose it.

> Sophea: *…you have to sow seeds and you have to water it to grow things yeah. And then compassion grows, like lots of other things grow*

Participants spoke of compassion and their understanding of it being shaped by early life experiences, as well as through work and interactions with others, including family and friends, indicating that the "seeds" of compassion needed nurturing through outside factors to help it grow.

> Farah: *First and foremost the compassion really comes from the upbringing of the person*

> *Amira: And to have my own family and my own family needs, it's just made me more adaptable and flexible and understanding and, you know, supportive of my loved ones*

Additionally, they spoke of their religion playing a part in this, by providing ideas about 'being' and how to relate to others and allowing the practice of this.

> Isaac: *From my religion, you don't need to condemn people. You shouldn't condemn anybody, you shouldn't put anybody down, you shouldn't assume, think the worst of people, you should be supportive*

> Amira: *I think the religion helps a lot, the spirituality, because it tells you to be patient and have sabr*

Here Amira speaks of 'sabr', an Islamic concept of patience and steadfastness in spirituality, especially in times of hardship.

Participants also spoke about personal experiences helping this process, and many spoke about their own mental health journey, with overcoming difficulties helping to develop compassion further. It was suggested that this led to key skills such as listening, being empathetic and comforting others, all of which contributed to being compassionate. This also points to an active process of nurturing and growing compassion, rather than this being a passive process.

> Farah: *I don't think everybody's just compassionate just naturally, you have to go through difficulties in life to learn compassion. So I do believe that if people with mental health services have had past experiences in their personal life, in their work life and whatever sort of thing, where you know, they've had to deal with difficult situations, they would understand also how to be a good listener or be a good comforter for somebody else that's going through a difficult situation*

Additionally, participants identified experiences of receiving compassion being important in their own ability to be compassionate. They described how this helped their understanding of the concept, which was then applied in their relationships with others.

> Nazia: *I definitely think about the compassion that has been shown to me and kind of various experiences and trying to apply them to the people I work with, but also to the people in my personal life, to my friends*

Most participants compared their experiences from different people and services, which allowed them to gain a better understanding of what compassion meant to them and how they wished to express this, as well as what uncompassionate care looked and felt like.

> *Farah: …having the second hospital experience allowed me to compare, both the treatment plans that I was getting and therefore I was able to understand like 'oh, this was different from this one or that doesn't seem that different from this one', so it gave me a much deeper understanding of what compassion is*

4.1.3 Sustaining compassion within services

This sub-theme reflects participants ideas about the nature of compassion as internal and its ability to grow, as applied to services. Participants spoke about this predominantly at a staffing level, highlighting the relational nature of compassion and the importance of the impact of individual staff members, however there were also references to the wider system.

Participants spoke of keeping compassion at the forefront when recruiting staff, ensuring that individuals already had the internal compassion "seeds". There was a sense of incredulity that this would not be the case or that staff members would be told to think about compassion only after being employed. Participants implied that factors such as education levels were less important to them than how compassionate a staff member was, whereas the priority for services might be in ensuring their staff are qualified for the role.

> Farah: *…when employing staff members, it's not just to look at their background in terms of education and their experience and things like that, but certain questions should be geared towards how they deal with situations, how they've dealt with situations in the past with patients, in regards to how they've expressed compassion to that particular patient, or that particular*

> *ward or that particular staff member or to whoever. Questions should be based more around compassion to see how compassionate they actually are*

Participants spoke about training staff members in areas considered important to be compassionate, such as diversity issues, but emphasised that teaching someone to be compassionate per se would not be effective if they did not have this internal factor already. Again this highlights the importance of the recruitment process and ensuring the “compassion seeds” are available to grow with further training.

> Sophea: *…you can’t take people and then train them in the ‘health of our compassion course’, for example, if their core beliefs are that some people are less worthy than others*

> Amira: *…maybe around health inequalities, talking about how health inequalities and institutional racism, disability-ism, the barriers that we face, how it impacts on our life experiences*

Participants highlighted that the availability of staff, their level of work and their wellbeing impact on abilities to nurture and show compassion. They expressed how having more staff would enable more compassion towards service users. This is suggestive of wider organisational and resource issues, and should be a consideration for services.

> Nihal: *Because there's not enough psychiatrists, well-trained psychiatrists, who can deal the pain the way they should’ve done*

> Deborah: *…you've got the workers who are overtired, lack of staff, staff shortage, and they're miserable, they've spent too much. Then they just become so ratty*

The need for a supportive working environment to enhance compassion towards service users, was specifically highlighted by a participant who also worked within mental health services.

> Nazia: *…in the workplace, in terms of delivering compassionate care, I think that would only be possible if there was compassionate care for the person delivering that care*

There were also warnings of the dangers of “compassion fatigue”, and other emotions like “anger” being nurtured in place of compassion. This suggests that actively growing compassion within services is also important, and the organisational context plays a role in this.

> Nazia: *…it becomes more exhausting to express kindness to someone, when it’s impacted you negatively*

4.2 Seeing the person

This main theme highlights participants’ views that compassion involves recognising individuals as human beings, with multiple diverse aspects, including cultural and spiritual factors. Participants described a need and expectation for mental health services to be able to truly “see the person”, and how this required others to make attempts to understand them, respect their beliefs, prioritise their own narratives and support them to meet their unique needs.

4.2.1 “Treat me as a human being”

Participants made references to mental health difficulties and the pervasive stigma surrounding this, suggesting stigma was a result of a lack of education and understanding. The implication of this is individuals being treated as ‘less than’ others.

> Deborah: *…if you're not educated on mental health and you don't have no idea, you're just walking around blindly thinking that ‘oh you're better than these people, these people got mental health problems, they need to get help’*

> Nihal: *Instead of looking down upon the mentally ill people, just say, you will do a favour if you talk to them and help them to get better. That would be helpful, rather than just look down upon them and just make them feel like you're from the gutter*

Participants implied how difficulties could occur to anyone, that this did not change their status as human beings, and that compassionate care needed to involve treating them as such. This is an assumed basic need and right that should be afforded to all, particularly within mental health services.

> Sophea: *…you should treat me as a human. Treat me as a human being. Not as something that's subhuman, something's that toxic, something you don't wanna be near*

Sophea clearly articulates this need but insinuates how this has not been the case in her previous treatment within services, and how, in being seen as "sub-human", her treatment has actually been sub-standard and uncompassionate. This contrasts with Nihal's experience, which was classed as compassionate; he described being treated as a "normal person".

> Nihal: *…they just looked at me as just like a normal person*

Descriptions around truly valuing the person, regardless of any difficulties being experienced, were seen as important. For example, not being neglectful or ignoring individuals, and instead showing a genuine interest and getting to know people.

> Amira: *…valuing the person holistically. Looking at the whole person*

> Deborah: *…you're interested in that particular person, they're just not a number*

Deborah further describes how remembering a birthday can act as a simple way to show interest and humanise an individual:

> Deborah: *…cause then it shows that person, ‘wow they really was listening to me. They took an interest in me, I'm not just a number’. Remembering their birthday, you know. Just because you’re a staff, it doesn't mean that you can't remember someone’s birthday*

She mentions how being a member of staff shouldn’t prevent people from acknowledging such details about a service user. In doing so, she highlights the similarities in ‘staff’ and ‘service users’ as humans first and foremost, the bridging the narratives around ‘them’ and ‘us’ which are prevalent within services and mental health stigma.

Participants also spoke about remembering staff members who treated them as they would be expected to be treated. This further highlights the importance of being treated compassionately and the positive impression that is left with such an experience.

> Sophea: *I remember these people because they did what human beings should do to you*

4.2.2 “Putting yourself in somebody else’s shoes”

Compassion was also seen as involving empathy, with compassionate people attempting to understand an individual’s unique situation, as well as the thoughts and emotions they may be experiencing.

> Deborah: *It’s just putting yourself in somebody else's shoes*

> Nazia: *I think sympathy is kind of, sometimes more, it can come across more as pity. Whereas the way I think of compassion is having the ability to kind of think about things from another persons’ point of view*

Participants spoke about key features of putting oneself in somebody's shoes, which included listening and being non-judgemental, as well as validating someone's experience.

> Isaac: *…somebody listens to me and they will not judge me, so for me I see that as compassion*

> Deborah: *If you're judgemental then you can't have that compassion for someone else*

The need for recognition of wider systemic differences faced by groups of individuals, including factors like oppression, racism, discrimination and gender inequality, was also emphasised, with care delivered in a way which acknowledges and accounts for these.

> Amira: *looking at institutional racism, that it does exist for us from the BME community. And, for somebody like me there is the disability-ism, all the -isms, you know, create a lot of barriers for us*

This may also involve being aware of the stigma within cultural communities around mental health, which some participants spoke about.

> Amira: *…mental health is such as a taboo subject in our community so you can't talk about it*

> Nazia: *I often find that there's a lot of compassion with physical health, and when someone is unwell physically and going through a loss, or yeah, like financial difficulties, there's a lot of compassion in my community and then I find, and it's kind of my religious and I guess my cultural community more than religious maybe. But when it comes to kind of mental health, there've definitely been times where, I haven't experienced as much compassion*

However, in recognising stigma, again it would be important to ensure that this is individual-specific and does not lead to further discrimination or assumptions made about groups.

Although attempting to understand someone else's situation and what was going on for that person were considered an important part of being compassionate, some participants also questioned the extent to which this was possible and there was a view that it was difficult to truly understand what someone else was experiencing, unless one had that same experience themselves.

> Deborah: *How can you really, how can you understand if someone lost their legs and you're walking around with your legs*

> Isaac: *They've not been through that before, so they don't know how it felt, feels like or what you are actually going through. They have no experience of that*

> Nazia: *…sometimes you can't understand, and I think sometimes it's important to acknowledge that so rather than kinda of, you know, 'ok you're sad I get sad too, so I completely understand how sad you are', instead kind of acknowledging like, 'well I'm not you, and I'm not living your life, so I can acknowledge that maybe I don't quite understand the intensity of what you're feeling, but I can imagine it must be really difficult'*

In the above quote, Nazia describes how acknowledging that someone cannot completely understand is part of a compassionate response in itself, rather than pretending that there is that full understanding. She highlights this through the use of the words "I can imagine" - the process of *attempting* to understand and put oneself in another's shoes.

4.2.3 Respecting differences

Participants spoke about the importance of differences being respected and highlighted the desire not to be pigeonholed by a single characteristic, but instead valued for their diversity and the richness that they bring as an individual.

> Amira: *…don't try to place us in one box because we might not fit into one box*

Amira further describes the different intersecting identities that she holds, drawing attention to how these may have different positions within society and the impact this may have for her. She suggests a need for awareness around this, and with that, an understanding around the impact of discrimination and the lack of respect for differences that individuals may face.

> Amira: *So understanding, you know, the various identities of an individual. Like I said, I'm a mother, I'm a woman, I'm an Asian woman, I'm a Muslim woman*

Participants spoke further about how the process involved personal assumptions being set aside, as well as open-mindedness to recognise that alternative viewpoints exist, and that experiences can be understood in varying ways.

> Nazia: *I think it's acknowledging people's own experiences and being able to differentiate them from people's personal assumptions. So I would expect that a mental health professional, who is providing compassionate care, would be able to separate what they assume depression is for example, or what they assume anxiety is, what they assume a personality disorder is, and put that to one side to be able to appreciate an individual's experience as an individual*

> Farah: *Especially if somebody comes from an ethnic background where they have religious beliefs and things like that, it's to recognise and appreciate their understanding towards even the suffering, may be a totally different outlook*

These quotes suggest an appreciation and perhaps a prioritisation of an individual's experiences and beliefs, which may differ from that of mental health professionals, and a recommendation to see everyone anew, with fresh eyes.

Religious and spiritual beliefs were highlighted by most participants and how this helped them to cope with difficult experiences in relation to their mental health. This suggests that this is something that services should pay particular attention to.

> Sophea: *…the spirituality side of it is absolutely core to me being able to manage what can be frightening*

> Isaac: *My church has been so supportive to me. Very, extremely supportive, so it has helped me, it has shown me a lot about compassion*

Participants spoke about how their religion provided them with strength and the resilience to carry on and acted as a protective factor during periods of extreme distress.

Amira also speaks about how services should aim to ensure individuals remain connected to their spirituality and religion, but there was also mention about the lack of ethnic and religious diversity within staff, which raises questions as to how much such needs are being recognised and met.

> Amira: *I'm thinking that service users do get lost sometimes, out of religion and that, out of anger, maybe divert them back because they have to fit into their own community, moving them away from their own community and their beliefs, isolates them even more*

> Sophea: *…you don't get a diverse population of mental health workers at all, who reflect the community*

Times when it was felt that individual differences and belief systems were accepted and incorporated into their treatments plans, were considered to be respectful and compassionate.

> Farah: *…obviously she wasn't a Muslim but at the same time she was recognising that 'ok, this is her beliefs, we can't go against her beliefs, so how do we do like a recovery plan, including your belief system?'. And that was more respectful and more towards what I wanted my recovery to look like*

> Sophea: *…she just accepted that my thoughts, my world, stuff in my head was as valid. So she didn't then change something to fit in with her worldview*

Being able to respect differences also indicated an acceptance from services about the participants as an individual.

4.2.4 Being in "charge of their own story"

This sub-theme follows on from respecting the differences an individual might bring, to thinking about the importance of then allowing individuals to remain in control of their own narrative.

> Nazia: *…just allow that person to be able to stay in charge of their own story, as opposed to, get kind of wrapped up in the professionals' understanding of their story*

This included allowing individuals the space to share aspects of their story in their own time, as and when they wished, rather than needing to follow a service timeline.

> Nazia: *…acceptance of it as a journey and not having that kind of pressure of, 'you need to tell me your life story right now'*

Participants provided examples of individuals who they stated were compassionate and supported them to remain in control of their story.

> Sophea: *And she didn't try and change the words that were coming, it was my words that were going on to page*

> Farah: *She kind of like, let you take over. You was in control of your sessions, the way you want it to go*

Additionally, it was felt crucial to involve people more throughout the service pathway, recognising the knowledge they hold of themselves. It was implied how this was often minimised and professional knowledge emphasised instead. The need to check that a care plan is appropriate and suggestions to change it if required was also highlighted.

> Nazia: *I just think sometimes the person's voice gets lost along the way. So I think it's keeping them involved through every step of the assessment, treatment, intervention process, and checking in with whether they think it's working and acknowledging actually if they think that they need something different*

> Sophea: …*even if I needed a huge amount of help to communicate that, even if I had to draw it out, or write it on the walls to express it, or go through biblical ch-, or however I did it, I was the expert in myself and their job was to explore how to get my expertise out of myself*

Here Sophea describes how she is the expert in herself and that the role of mental health professionals is to help in obtaining that expertise, even if an individual is unwell, frightened or needs support in communicating their expertise.

4.2.5 Meeting needs

Participants emphasised that compassion is *expressed* rather than just being a conceptual idea or something which is merely thought about or felt. This sub-theme therefore links with previous sub-themes within 'Seeing the person' and reflects how this is put into action.

> Farah: *…compassion isn't just words and listening to a person and trying to give them advice, but it's through actions as well*

> Nazia: *…that's a really big thing with compassion, is just being able to understand and almost foresee what someone needs and be able to provide it*

Actions which were compassionate were related to understanding what the individuals' specific needs were and what "needs doing", as well as considering a person's thoughts and feelings and then acting in line with these. Participants highlighted how care should be personalised to that person and thought about in a holistic manner, including their emotional, physical and spiritual needs.

> Amira: *And a more person-centred service. Looking at him as a whole person. The need for like shelter, the need for food, the need for environment, the need for transport, for, you know, all of his acute care needs, right from his mental health perspective as well as his physical health perspective*

> Farah: *So they had Jummah prayer so in terms of accommodating people's needs, again which is a sign of compassion, they were very good with that. Ramadan you know, I got my meals, I got lovely meals for Ramadan really compared to the daily food that we would get on the trolley, so Ramadan they catered for me*

Farah describes religious needs being met within mental health services, with the organisation of Friday afternoon prayers (Jummah) and meals during the month of fasting (Ramadan).

Participants also spoke about times when individuals were considered to have gotten their "hands dirty", did something they did not have to do or was inconvenient, and generally went above and beyond to act compassionately.

> Farah: *…you do get a lot of the staff attending, but he was actually the one physically grilling all the food, so he was willing to get his hands dirty and be a part of the group and mingle, in a way where it was more, he was more very down to earth and very interactive and very with all the patients at the time.*

> *So that really stood out for me, in terms of like the compassion that he showed towards people was through his actions*

> Sophea: *And this social worker was a team manager. She could have just said eff off [laughter] and not taken any notice of the fact that I was living in sewage or something, or thought it was someone else's job, but she didn't. She just literally came and she came with other stuff too, she came with a mop or something, like literally*

> Isaac: *And sometimes when she couldn't come she will send me her [family member] to me, to go and get the stuff. So, for me that changes everything, that is super compassion for me, it's extreme compassion. You know, out of that busy schedule and stress and everything*

Participants also spoke about receiving continued or ongoing support as needed, which also indicated compassion to them, and that the care was genuine or "real".

> Isaac: *And they're still continuing. So it shows me it's something that is not superficial. It's real*

However, there were also instances reported of a "small gesture", indicating that it wasn't just larger acts that were considered compassionate.

> Nazia: *I had attended A&E following an overdose, it's such a small thing, one of the nurses who, when she kind of sat me down and I was waiting for a kind of, have a proper psychiatric assessment, she just made me a hot chocolate and gave me a packet of crisps. And it was a really kind of small gesture, but she was like, she said to me like 'you've been here for about five-six hours, and I haven't seen you eat, so I just got you this'. And that was really nice, that was very kinda of a compassionate experience*

> *Deborah: Like they might be a keen footballer back in their days or whatever, and being able to like the next day, having a conversation from the week before, and then maybe the next day buying them some football cards or something like that. I mean that's a minor, but it just, it shows that you took on board what they're saying*

Examples were also provided about the importance of touch and someone's presence.

> Deborah: *I've met with the mental health worker, the acute setting and I was in floods of tears, I couldn't stop crying. I was just in a mess. I was suicidal (inaudible). And when I was leaving he just stretched his arm out and gave me a hug. And for me, that was the best thing that anybody could've done to me at that point. Whereas, if anyone, professionals say, 'oh she overstepped boundaries', etc. But sometimes you actually need that and I needed it*

Deborah also reflects on how this may be seen within services, as perhaps unprofessional or overstepping boundaries, but it was what she "needed" in that moment.

Although meeting needs was considered a key aspect of compassion, participants also spoke of individuals "just doing their job" or "ticking boxes", highlighting that just completing actions was not enough to be considered compassionate in itself. Kindness, as well as action was needed.

> Farah: *And there's some people who just, who are there to do their job, they're good at their job, but they just don't have a compassionate nature*

> Deborah: *Rather than looking at tasks, I think. Like a tick box, rather than looking at, focusing on the person*

4.3 "Power imbalance"

A major theme running through the examples given by participants where compassion was lacking within services, was around power imbalances with services and professionals holding greater power over service users, and this being used in a detrimental way. This was described in various ways: how individuals were spoken about and spoken to; how they were thought about; the narratives highlighted or dismissed; how they were acted towards, as well as the support they could or couldn’t receive.

4.3.1 Judgement and assumptions

It was highlighted that staff views and assumptions were prioritised over viewpoints of service users, preventing further curiosity, exploration and respect for individual differences, which likely impacted on outcomes for individuals.

Participants spoke about the experience of being judged and how this leads to a negative picture being painted of them. This appeared to further cloud interactions and inhibit attempts to understand the individual and interact with them in a sincere and caring way. It may also lead to help being unfairly withheld from someone, which is problematic.

> Deborah: *You’ve already projected a negative on that person. So, it's going to be very hard to be genuine if you're going to be that judgemental*

> Nazia: *I had a therapist who basically said to me that I'm too closed off and they can’t help me, or [sigh] alongside that maybe like a kinda attitude, ‘if you don’t try, then I can’t do anything for you’. So basically like ‘you’re not trying hard enough’*

Here Nazia describes how professional judgements about her perceived effort led to a conclusion that positioned the blame on her for difficulties within the therapy. She speaks about recognising this narrative and it is likely that the dynamic this created played a part in any therapeutic issues.

Most participants spoke about instances where prior views meant individuals were unable or less willing to try to understand and put themselves in their shoes.

> Farah: *You know, I was lonely, I was depressed, I was lonely. She was keeping me company, I was keeping her company. Those questions wasn't asked, it was more like just saying, 'your comforting somebody and you haven't even dealt with your own trauma'*

Farah describes how whilst she was told to "deal" with her own difficulties rather than spend time with another person on an inpatient ward; attempts were not made to find out why she was spending time with this person, how this could be beneficial and how the need for connection in this instance was important to her.

Some participants also described incidences where they felt their personal beliefs were different from services and not adequately considered, as staff understanding of issues were given greater importance.

> Farah: *…the psychologist in the mental health setting, they only take it as far back as either stressed that caused it, depression that caused it, or all these other things like that they recognise in mental illness. But they don't actually go that further step to believe that person has got a different belief system*

Where the importance of beliefs was not truly valued, there was mention of the cultural appropriation of Buddhist principles with the use of mindfulness, widespread within mental health services. In reducing something spiritual to "clinical", this was seen as disrespectful and erasing the history and practice of a whole religious group.

> Sophea: *I find it really quite insulting to people's religious beliefs, when the NHS decides to use mindfulness and send people on a weekend course and say, 'oh it's a tool and things'. It's like saying a whole load of someone else's religion is meaningless and we're going to make it something clinical*

Additionally, it appeared there were difficulties challenging pre-conceived assumptions due to the power imbalance, and instead these were likely to be imposed on others and alternative viewpoints dismissed.

> Farah: *Now I explained to them that in my religion, if you're [belief], ultimately God, Allah says that the pen has been lifted from somebody who's insane. And, what happened to me was a result of insanity so I tried to explain that to them, that basically, I can't take responsibility of an action that I was not in control of, where they wanted me to accept responsibility*

> Sophea: *Even if the voices are telling me to do something that would end this life violently, yeah, because they're distressing and I think that maybe it would harm other people or whatever. But it's to invite the voices in for tea, right, that's the approach. And you try, [laughter] if you try saying that to a mental health professional they lock you up. Right, that's considered like risk and stuff, and so there's no room for, and they have to impose their own assump- their own interpretation on it. There's no room for any of my very longstanding belief systems*

Sophea explains how sharing her belief systems might be deemed too risky within mental health services and staff interpretations of this would take precedent. It also highlights how individuals may be silenced and dissuaded from sharing their belief systems for the fear of being sectioned.

Where prior assumptions took over the ability to respect differences, individuals' experiences and beliefs were likely to be pathologized.

> Sophea: *…they decided that was because I must have some sort of eating thing. Well no I'm vegan and I'm vegan because I am a practicing Buddhist, and, you've not actually asked me and I have gone down and looked at the food. There isn't anything there and I've given up explaining, 'cause actually, apparently I'm mentally ill in a crisis*

Sophea provided a number of examples of being pathologized and the impact of this had been significant. The lack of curiosity and attempts to understand her as an individual is highlighted, as well as how this prevented the act of speaking out, further reducing the power of her own voice.

4.3.2 Control and choice

This sub-theme highlights the lack of choice and control that service users can experience within systems and was spoken about in relation to a number of factors.

There was reference to being sectioned and the huge loss of freedoms and rights that came as a result of this, including the inability to decide where one could be treated, even if care was deemed to be harmful. This highlights specific treatment that users of mental health services face, which is not found within physical health care.

> Sophea: *…you don't have a choice. Unlike any other part of the NHS world, you don't have a choice about which trust you're under, yeah, there's no choice of provider. And some trusts can be very abusive. But they have huge power. They could detain you and lock you up, send you hundreds of miles away.*

There were descriptions of delays in support being provided and a lack of control in when or if they would be seen by services. Some participants also warned about the serious consequences of individuals' not getting the help they may need at the time that it's needed, including loss of life.

> *Deborah: And then the weeks went on so it was about three weeks before I, after my referral was made, that I got the treatment I need, and in that three weeks that was vital. I think it could've been a lot worse*

> Isaac: *I didn't get the support I needed in this journey, until things went pear shaped for me. Until I almost, I tried to take my life. That was when I was, I*

> *started getting support, so I don't think they should wait till that to happen. 'Cause I'm just one of the lucky ones that is still alive*

Isaac described several instances where he had sought help whilst in a crisis and the resultant care was lacking and insufficient in meeting his needs. He spoke of appropriate action not being taken and his needs not been taking seriously, even after attempts to end his life. This appeared to reflect an underlying sense that his difficulties were being minimised by services. It was also implied that his treatment provided an indication of how much services valued his life. Additionally, it also highlights the rightful expectation of mental health services being able to provide support.

> Isaac: *I said 'look, I've been trying, I couldn't get through to my care coordinator, I've been trying her and that's why I called'. And he only said, 'oh, keep calling you would get through' and he just hang up. And I was really in crisis, so is that the way to treat people. I don't know how I got through the night, because it was in the night, I don't know how I got through. I don't know, it was serious. So, it was terrible and I needed support, I needed help, that was why I called the crisis line. And I didn't get it*

Where care was provided, participants reported decisions made on their behalf without their involvement, as well as not being informed of decisions.

> Nazia: *…you do an initial assessment and then that decision, the discussion then goes to you know their own team, and then the decision comes back to you already made, and you have very little input into what goes on*

> Amira: *But I think they should have listened to me then, and I don't think they did, and that's the only one fault I think I had at the centre. And I think because I was mentally sick at that time because of what was going on for us, [diagnosis] and all that, to me that time they made me feel that they didn't value what I was saying*

There are underlying feelings of not being heard and valued within these quotes, implying that services considered their decisions to be more important, perhaps due to unfavourable or biased views around participants' mental health. It also seemed that sometimes service users had no choice but to do things in the way required or set up by services, even if this was unhelpful or made things more difficult.

Some participants also spoke about the gatekeeping of psychological therapy and who could access this. They suggested seemingly blanket rules, or exclusion criteria, used to decide who was 'appropriate', which may have felt unfair and confusing.

> Nazia: *I know a lot of people sometimes experience therapists kind of saying, 'if you self-harm during our treatment process then we're going to stop the treatment'*

> Sophea: *…people like me unless we get to the [hospital] we don't get therapy, yeah. You've got to remember in psychosis you don't get access to therapy, 'cause it's decided that you can't cope*

Additionally, some participants spoke about being forced into certain situations by staff members, which felt "intrusive".

> Nazia: *…she had kind of asked, 'where do you self-harm', and I said 'my arms and my legs', and she said 'can I see', and I said 'ok that's fine', and I put my arm out and she like grabbed my hand and like pulled it towards her. And I hadn't rolled my sleeve up, and she rolled my sleeve, she like pushed my sleeve up*

> *Farah: …we was going through the steps of what happened to me, and I was talking about it in quite depth and, then on the last day, he kind of like bullied me into crying*

These quotes gave an impression of insensitivity by staff members and them being in control, with participants implying a sense of feeling exposed and put into positions of vulnerability when they were not ready for it.

4.3.3 Use of language

This subtheme reflects the way language has been used to exert power over the participants.

Incidents of uncompassionate acts were highlighted by a “mismatch” between words and actions. Power imbalances were displayed by services using words to indicate one thing, whilst their actions told another story. There were reflections around the intentions behind words used and queries around how “genuine” they were, and by implication, whether genuine compassion was being shown and how much this could be trusted.

> Sophea: *…so you know the difference when someone says something, but it's not part of their deeds, their actions, their way of being. There's a mismatch*

> Nazia: *…it almost feels like less genuine then when you're saying it to the service user that ‘actually I can really understand how this is feeling’, and then you close the door and you go and talk to your colleague and you say ‘they just want attention’*

Participants also highlighted how the use of language could be used to change, set and control narratives around a person, which also means there is the opportunity for services to misuse words.

> Sophea: *…the words that are used to, you know, what you say will be written down as something else, it’s their interpretation, which is a huge power because they can lock you up*

> Farah: *…when I was explaining that to the doctor, he was saying ‘yes we've all heard of [the particular] story, let's get past that point now’*

These quotes highlight how service views and judgements can be prioritised and expressed in a way that is unhelpful and leads to less control for service users.

Additionally, participants spoke about being “labelled”, or “branded” either through diagnoses or words like “attention-seeking”, which they described as causing distress and are also implicated in how service users are seen and responded to. The use of words like “labelled” indicates that the categorisation is not something that the participants agree with and it is something which has been done *to* them.

> Nihal: *Maybe they're just walking normally, until they’re told or until they fell ill with the condition. Then only they had been branded, ‘oh you are mentally ill or schizophrenic’*

> Nazia: *…words like ‘attention-seeking’, as you probably know, get thrown around a lot in mental health and I think that’s a big one, and you know I’ve definitely been in the room when colleagues have said that, and felt kind of crap about myself after that*

This draws onto ideas around stigmatisation of mental health difficulties and services’ role within this. It is suggested that re-evaluating the language that services use may help to alleviate stigma and increase access. It is implied that currently a barrier to this are services themselves and they are actually perpetuating stigma.

> Nazia*: …if we just rethink the languages that we’re using without the service users present, it will just make us more aware of the language we’re using when they are present and that might see a shift in kind of breaking down some of the barriers that people have in accessing mental health services, in terms of that fear of kind of being stigmatised or being labelled as attention-seeking*

> Deborah: *…because some people, like myself, go into that setting and you're already thinking, 'oh you're being judged' and stuff like that. And they need to be able to alleviate that fear. They need, professionals need to be able to alleviate that fear*

4.3.4 Impact of power imbalances

Many examples were provided of the impact of power imbalances and the resulting uncompassionate care. Participants spoke about how this led to worse outcomes for themselves, such as feelings of invalidation, decreased trust, and increased distress and isolation.

> Nazia: *…make me feel invalidated, and it makes me reinforce that invalidation to myself*

> Sophea: *…you're just not trusting anyone in the end*

Participants also spoke about a heightened fear of services and the treatment that may come from this. They described how this leads to them avoiding services, even if it was felt that their difficulties may warrant access to the service.

> Isaac: *Because of the experiences I've had. I don't want to go through that again. So it doesn't, it makes me not to take the step I need to take. Yeah for my recovery or for any crisis I have. Just to leave now or to pretend as if things are fine, when things are not fine. So it has impacted me so much, in using these services again, because I know what to expect. I have no expectation there anymore*

It was underlined how expectations about receiving support were diminished whilst memories of uncompassionate treatment were heightened, with participants suggesting doing whatever they could to prevent returning to services.

As well as the avoidance of further mental health services, this was also extended to physical health services for Sophea, whilst others spoke about avoiding specific individuals who they felt were uncompassionate.

> Sophea: *…do you think I'm gonna go get treated, on the NHS? I mean, no. You know, and that's the impact poor mental health services have on other areas of your life because you get frightened about the cruelty*

There was also mention of utilising alternative systems to meet needs, for example, family and friends, as well as religious institutions, community and third sector or private organisations, sometimes in place of services.

> Sophea: *I've had really good support, I mean literally from the [organisation], literally from [organisations and descriptions] to [organisations]*

> Amira: *…for me to go private, what if you know, I didn't have the funds, you know. That you know, it should've been done from them, if that makes sense, from the care team, or the [specific team], they should have picked all that up. If that makes sense you know, all the agents that we were involved in, that were supporting us, they should have supporting us in that way a bit better. Been more compassionate*

Here Amira also describes taking action herself to get a private assessment completed, which then led to appropriate support being provided. She describes being able to do this financially but highlights how this would not be a possibility for everyone and how it should not have been needed had there been more compassion shown. She also spoke about the "right" for services to support and meet needs, rather than needing to go elsewhere.

Furthermore, there was also reminders of the tragic consequences of uncompassionate care.

> Sophea: *…there’s a coroner’s inquest with the coroner’s yet again saying the same things about the really cruel care someone’s had, and then no care someone’s had*

This contrasts with experiences of compassionate care which participants spoke about directly acting to prevent suicide.

> Deborah: *I think they saved my life to be honest. 'Cause I was so far, I never dreamed that I would even be here today having this conversation with you*

Additionally, where power was used appropriately to genuinely see the person and provide compassionate care, participants spoke about various positive outcomes, leading to improved wellbeing. Participants spoke about feeling better, making friends and meeting new people, regaining hope, rediscovering things they enjoyed, being able to carry on with day-to-day tasks, the alleviation of fear and anxiety, feeling more confident and empowered.

> Nihal: *…well once the doctor came and took me to the hospital, I enjoyed my stay and that’s when I increased my social life and friend circle in the hospital and, slowly the changes came over. And I became well and then I came home*

> Isaac: *The one that supported me, helped me a lot and I improved a lot. You know because I'm still now, I'm still wary of people, but I started meeting people, I started going out, I started doing things, I started discovering, ‘oh I like this thing, I like that thing’, before I never, I didn't see anything I liked*

> Farah: *…she empowered me again, to feel like ‘you can't let bullies win’. She kinda like broke my psychic down in a way where I felt very empowered by her, and very in control of, very confident. She gave me a big confidence boost basically*

They also described improvements in their therapeutic relationships and increased trust, as well as feelings of companionship and family, particularly within the inpatient wards.

> Farah: *I would actually look forward to our meetings, even if it was a random meeting, I would look forward to just seeing her*

> Nihal: …*a very homely feeling. And, made possible by the staff of the hospital, they're very helpful*

Participants spoke about the impact of receiving compassionate care in momentous terms, such as it being "life changing" or coming out as a "new person", and the benefits being ongoing, thus emphasising the importance of services being able to yield the power they hold positively.

> Farah: *…when I left hospital, I came out as a new person you might as well say*

> Deborah: *For me it was very important. It was very unexpected, but it was, to me it was life changing*

> Isaac: *…she did a huge improvement, a huge one. And some of the things she did now, I'm still enjoying it up to now*

5 DISCUSSION

This chapter will discuss the findings of the analysis and answer the research questions documented in the introduction, linking back to relevant literature. There will be a critical evaluation of the study, including personal reflections and limitations. Finally, there will be consideration of the clinical and research implications of the findings.

5.1 Findings in relation to the research questions and literature

5.1.1 How is compassion and compassionate care defined by service users, from an ethnic minority background?

Participants defined both compassion and compassionate care broadly, as something which was multi-faceted and complex. The first two sub-themes of the '*Growing the "seeds" of compassion'* main theme generally describe participants' definition of compassion, whilst the last sub-theme and the two other main themes (*Seeing the person* and *"Power imbalance")* relate more to compassionate and uncompassionate care, although there is overlap between all the themes.

Growing the "seeds" of compassion

Similar to existing research, participants spoke of compassion being innate and residing within people (Kneafsey et al., 2016; Straughair et al., 2019; Vivino et al., 2009). There was reference to compassion as a way of being, which is similar to definitions provided by US psychotherapists (Vivino et al., 2009). It was thought to rely on traits such as kindness, recognising the suffering of others and wanting to help (e.g. Sinclair et al., 2016; Singh et al., 2020; Straughair et al., 2019).

Although compassion was thought to be internally located, it was generally said to be outwardly expressed, with interpersonal and relational qualities being important in interactions between at least one other. As with other studies, participants referenced qualities of others that they felt were necessary for being compassionate, such as being interested in others, non-judgmental, open-minded, and a good listener (van der Cingel, 2011).

Two participants also spoke about self-compassion being an important but difficult component and needing to be able to embrace this first before being compassionate to others. Previous research has suggested a connection between compassion and self-compassion in that both require similar skills, but suggests that the mental construction of the ‘self’ and ‘other’ is different and so can be applied separately (Gilbert, 2014), with individuals being able to show compassion to others despite finding this difficult to administer to themselves (Pauley & McPherson, 2010) and self-compassion increasing after expressing compassion towards others (Breines & Chen, 2013).

Additionally, compassion was seen as a dynamic concept which needed nurturing in order to flourish, for example through early childhood experiences. This links with evolutionary-based research which highlights parental caring behaviour as being important in the development of compassion (Gilbert, 2014; Goetz et al., 2010). As with other research, compassion was defined as something which had the ability to grow and expand, and this was influenced by receiving compassion from others (Gilbert, 2014), overcoming difficulties (Lim & DeSteno, 2016) and personal development (Kneafsey et al., 2016).

Seeing the person

A main feature of participants’ definitions of compassionate care involved care being person-centred, as highlighted in the ‘Seeing the person’ main theme. Compassionate care was said to involve valuing an individual as a whole person, with varying needs and beliefs, and helping individuals to meet these needs, as also found in previous research studies (e.g. Alonso, 2020; Kvangarsnes et al., 2013; Sinclair, Hack, et al., 2018).

Participants spoke about being treated as a human being, and not be seen as a “number” or through the lens of a diagnosis, label or mental health difficulty. This is consistent with recent research from the perspective of service users, where compassionate care was conceptualised as receiving humanising responses

(Alonso, 2020; Straughair et al., 2019). In the current study, this was spoken about in the context of the stigma that individuals with mental health difficulties can face (Thornicroft et al., 2007), which may be more likely for those from minority ethnic backgrounds, who experience a “double stigma” due to their dual group membership (Gary, 2005, p. 981). Compassionate care therefore involved professionals humanising service users to reduce discrimination, help alleviate stigma and ultimately allowing them to be equally valued.

Participants also described how empathy was an important feature of compassion. There was a distinction made between sympathy and empathy, with empathy being implicated in compassion, as found in other studies (Sinclair et al., 2017). Compassionate care therefore involved others attempting to understand someone’s situation. This was spoken about on an individual level, for example thinking about how a person may be feeling emotionally, but also included understanding the impact of wider factors, such as racism and discrimination. Similarly to participants views in Alonso (2020); Bramley and Matiti (2014) and Kneafsey et al. (2016), attempting to ‘put on somebody’s shoes’ acted as a precursor for support being provided. There was a query around how possible it would be to understand when individuals had not experienced similar circumstances, however participants mentioned the need to try and do so, and reflected ideas around “guided discovery” (Gilbert, 2014, p. 25).

Definitions of compassionate care also included individual differences being respected. Participants spoke about their identities, cultural views and religious beliefs, and how this might be different from that of mental health professionals, also found by Singh et al. (2020) in their sample of South Asians in Canada. The need for professionals to recognise and accept that understandings of mental health and distress may differ, and to work together around this, was highlighted. The definition also included individuals being able to control their narrative and their expertise of themselves being respected, rather than the knowledge or understanding of professionals taking over, as also highlighted in Lloyd and Carson's (2011) analysis of mental health care involvement amongst UK service users.

Within the sample, all participants reported that they were spiritual, and all but two also reported that they were religious. The participants specifically highlighted spirituality and religion as a key part of their individuality, which also helped them to deal with difficulties, including mental health issues. Previous research has highlighted the important role that such beliefs can play in supporting an individual to cope with adversity and increase wellbeing (Dein et al., 2010; Ögtem-Young, 2018; Pargament & Cummings, 2010), and participants in this study spoke about how their faith gave them “strength” and “hope”. They spoke of compassionate care including religious and spiritual beliefs being respected and incorporated into their care. This was also reported in two other studies, with US family doctors (Anandarajah & Roseman, 2014) and South Asian users of the Canadian healthcare service (Singh et al., 2020), where there was also a high level of religiosity and spirituality within the participant samples.

In the 2011 UK Census, data from England and Wales show that, of those who had indicated a response, approximately 87% of individuals from ethnic minority backgrounds identified with a religion (Office for National Statistics, 2011). This highlights a high proportion of individuals for whom religion may play an important part of their life. This is significant, particularly when considered with the disproportional impact of social determinants to poorer mental health on minority ethnic communities and their disproportional representation within inpatient settings (Bhui et al., 2003; Bignall et al., 2019; Mental Health Foundation, 2016), coupled with the religiosity gap between mental health professionals and the individuals they support (Dein et al., 2010; Smiley, 2001). It raises questions as to whether and how much religion and spiritual beliefs will be held in mind within secondary care mental health services.

There was also reference to intersectionality (Crenshaw, 1991) and how this leads to specific experiences for individuals, and how the impact of oppression and discrimination would also differ. There was the belief that this also needed to be considered in order for them to be truly understood and valued as one whole person.

The impact of racism, poverty, trauma has been widely implicated in mental health difficulties (Allen et al., 2014; Bignall et al., 2019) and compassionate care involves services recognising this and not replicating further inequalities for individuals from a minority ethnic background.

Additionally, participants highlighted that compassion involved putting things into action, and went beyond just empathising with somebody or feeling a certain way for them. This is consistent with previous research (e.g. Alonso, 2020; Kneafsey et al., 2016; Sinclair, Hack, et al., 2018; Way & Tracy, 2012). Compassionate care thus included actively meeting an individual's needs in a holistic manner, and care being personalised. However, participants also emphasised how action or the completion of 'tasks' without empathy or understanding was unhelpful (Kneafsey et al., 2016). They spoke about the importance of "kindness in action", also suggested previously by participants with a depression or anxiety diagnosis (Pauley & McPherson, 2010). Where there was discrepancy between words and actions, this went against their definition.

As with previous studies, participants described acts which went above and beyond (Kneafsey et al., 2016; Singh et al., 2020), as well as actions which were considered to be smaller (Bramley & Matiti, 2014; Kvangarsnes et al., 2013; Perry, 2009), but were still significant in terms of their impact. There was reference to the use of touch and how important this had been for an individual, which is similar to findings by (Durkin et al., 2021). However, previous research has also cautioned about the cultural appropriateness of touch (Babaei et al., 2016), and this would again need to be considered in relation to the needs of specific individuals (Kneafsey et al., 2016). Additionally, similar to other findings, compassionate care was also described in terms of consistency and remaining present to the needs of the person as required, which may be over a period of time (Kneafsey et al., 2016; Perry, 2009).

Within this theme, participants implied that not being fully 'seen' meant parts of their self (such as their humanity, expertise, beliefs, as well as situational and sociocultural contexts) were invisible to services. They empathised how compassionate care was reflective of recognising them in their entirety and acting in line with this.

“Power imbalance”

Finally, compassionate care was also spoken about in relation to incidences of uncompassionate care and what compassionate care did not consist of, similar to studies looking at staff conceptualisations (Horsburgh & Ross, 2013a; Tierney, Seers, Tutton, et al., 2017). The participants within this study included judgement and a lack of respect for their values and beliefs to be inconsistent with their definition of compassionate care. Additionally, instances where their voices were silenced or undermined by service and professional voices, as well as times where they lacked control and choice over their care, were deemed to be uncompassionate. Compassion care was therefore also defined in terms of how much power was exercised by services over service users. This theme is spoken about further in relation to the third research question.

5.1.2 What influences their definition?

Participants spoke about how their understanding of compassion was developed through their experiences, both in early life and later on. This signified how their definitions of compassion were flexible and may be subject to further change as they encounter further experiences.

As with a previous study looking at individuals from a minority ethnicity (South Asian Canadians) (Singh et al., 2020), participants highlighted their religion and spirituality, as a key factor in understanding what compassion meant to them. Participants in this study spoke about Islam, Christianity and Buddhism encompassing ideas about what compassion meant and how others should be treated. They spoke about religious values around patience, commitment, hope, being supportive, non-judgmental, mindful and reflective. Indeed, compassion-focussed therapy, which is used within mental health services, is based on Buddhist concepts and definitions of compassion (Gilbert, 2014).

Ideas around compassion were also spoken about in relation to participants' experiences and treatment from others, particularly during times of mental health difficulty. Participants highlighted both positive and negative treatment from others, including cultural, societal, and service stigmatisation, and being able to compare their experiences and the impact of this to help them distinguish compassionate instances. This is similar to a large sample of nurses across 15 different countries, who felt that family, cultural values and personal experiences were similarly involved in the development of compassion (Papadopoulos et al., 2016).

Receiving compassion was said to not only help develop understanding around compassion, but led to increased desire to support others and 'pass on' the compassion. Participants spoke of reflecting on experiences, similar to findings by Tierney, Seers, Reeve, et al. (2017), and actively applying what they had learnt and experienced towards others, which is suggestive of a process of experiential learning (Kolb & Kolb, 2009) in increasing their knowledge of compassion.

Additionally, participants viewed overcoming difficulties as a feature of personal and compassionate growth, and again experiences of their own mental health were highlighted. This may be linked to religious ideas about resolve and resilience (Ögtem-Young, 2018). Previous research has also shown a link between experiences of adversity and increased compassion, empathy, and prosocial behaviour (Lim & DeSteno, 2016). Lim and DeSteno (2016) reported increased likelihood to think about the perspective of others and value their welfare, although this was dependent on how recent the adverse experience was, indicating a period of time is required for such growth.

5.1.3 How does this definition relate to their experiences of compassionate care within secondary care mental health services?

Participants described instances of receiving both compassionate and uncompassionate care from services and being able to compare differences between experiences. As such, their definitions of compassionate care were not consistently applicable to their experiences within secondary care mental health services. For some, the compassionate experiences outweighed the uncompassionate ones, whereas for others it was the reverse. The former was more likely when participants felt they were truly being seen and respected as individuals, whilst the latter was more likely where imbalances of power were greater and applied in multiple ways. Additionally, participants who generally shared more positive experiences within services spoke of wanting others to also share this experience and those who described more negative experiences spoke about wanting and needing changes within mental health services. Participants also spoke about the impact of receiving both types of care, both of which were said to have profound effects.

Where compassionate care was experienced, participants referred to the individuals providing the care as being “naturally” compassionate, linking in with definitions around compassion being internal, whilst uncompassionate examples were also said to be performed by those lacking the “innate” trait. This highlights the relational nature of participant’s definition and the importance of mental health professionals’ actions. This is even more significant when thinking about the context in which individuals enter services. For example, participants spoke about their personal mental health experiences, which were described in terms of being frightening, distressing, and fostering hopelessness. As such, and also noted in previous studies, there was an expectation that mental health services would support with this and participants expected respect and positive interactions with staff members (Gilburt et al., 2008; Hopkins et al., 2009).

Examples of compassionate care included those where the participants were treated like a “normal person” and valued as an individual. They described instances were kindness and action were combined, for example a nurse recognising that someone hadn’t eaten for a long time whilst waiting for an assessment and providing them with a snack, or a social worker helping to clean up outside someone's home when they were unable to do this themselves. They recounted mental health professionals attempting to get to know them in a non-judgmental way and spending time with them, for instance by doing a puzzle together on an inpatient ward, or incorporating their religious beliefs into their care plan. Participants described being listened to and given some control over their own care, such as negotiating with a psychologist that treatment wouldn't just stop if they self-harmed, or appointments with a care-coordinator could be held at their home when they were unable to leave the house. Compassionate care examples also included times where the expectations and actions of service were consistent, for example with crisis teams coming to visit regularly or being given appropriate time during a crisis call.

Similar to previous research, participants spoke of compassionate care allowing them to be accepted and understood, with improved outcomes (Singh et al., 2020; Vivino et al., 2009). They described care increasing hope and confidence and preventing action on suicidal thoughts (Cole-King et al., 2013), as well as better relationships with staff and an increase in trust (Gilburt et al., 2008).

In instances where compassion was deemed to be lacking or absent, some participants had mentioned service issues, such as lack of staffing and staff being overstretched, similar to previous studies (Alonso, 2020; Kneafsey et al., 2016; Tierney, Seers, Tutton, et al., 2017). However, primarily their focus was on the impact of individual staff members. This highlights the importance of the relational nature of compassion and of relationships in mental health care (Gilburt et al., 2008; Kneafsey et al., 2016). Although wider systemic factors may be implicated in instances of uncompassionate care, what was largely felt and recalled by participants, was their treatment at the hands of another.

A distinct finding of this study is how uncompassionate care described by participants was generally characterised by imbalances of power between them and the services and professionals who were providing care. Social power is defined as a “socially situated capacity to control others’ actions” either by individuals or on a more structural basis, for example through institutions (Fricker, 2007, p. 13). This is thought to be an inherent feature within mental health services (Cutcliffe & Happell, 2009; Foucault, 1994), and was reflected for participants in a variety of ways, such as within decision making, how much their views were valued or incorporated, as well as communication with and about them.

A key feature of uncompassionate experiences and the use of power was where service beliefs and judgements were prioritised over service users. These were then used to define individuals in a certain way, and dictated potential treatment, often in an uncollaborative and detrimental way. Participants spoke about struggling to get their voice heard over professional narratives - how this was disempowering and ultimately led to them being silenced. For instance, with a doctor dismissing an individual’s explanation of difficulties and wanting to “bypass” this and move onto psychiatric explanations instead. Participants also spoke about feeling judged, their personal beliefs not being respected or valued, and at times, being pathologized. A lack of curiosity was highlighted as evident within these instances. For example, with professionals not enquiring further about an individual’s behaviour, combined with a disregard for religious beliefs, which led to an application for a section of the MHA to be renewed for one participant. In inpatient settings in particular, where there is the power to remove people’s rights, a fear of remaining on or being sectioned again was mentioned. The examples provided by participants highlighted mental health services representing themselves as the bearers of “truth production” with their expertise (Foucault, 1994, p. 44), and holding onto power through this. It is reflective of a hierarchy of perspectives, with service and professional views valued over that of service users. This is also a feature of epistemic injustice, where participants are seen to have less credible views and understandings of their own mental health (Fricker, 2007).

Additionally, non-western views and those which emphasised religious or spiritual beliefs were seen as less valid, leading to greater distress for the participants. An example that come through from this study was jinn possession, a belief prevalent within Muslim communities (Khalifa et al., 2011), but thought to be incompatible with the treatment offered by services. Where mental health interventions were religiously informed, for example with mindfulness which is a key component of Buddhism, this was thought to be implemented in a way that was devoid of spirituality and no longer met the essence of the practice. Such examples may point towards ‘Whiteness’ within services, which encompasses power relationships through certain ideas and practices, and ensures that racialised hierarchies and oppression of minoritised individuals are maintained (Wood & Patel, 2017). Certain ideas and values were viewed as the norm, which then further served to ‘other’ the participants.

It was also highlighted how judgements were projected onto individuals, which could then stick with them through their care. There were descriptions of how words were used to create a particular narrative for people; previous literature has shown how language contributes to the upholding of power over others, with the embedding of assumptions and ideologies (Fairclough, 1989). Consistent with previous studies (Boisvert & Faust, 2002; Cutcliffe & Happell, 2009), language was used to both enact power, for example a psychiatrist using his position to tell a participant to “deal” with her own mental health first before comforting others, as well as create power, for instance, by raising the status of professionals and reducing that of service users through labelling them as “attention-seeking” or “neurotic”. It also introduces a new discourse and way of thinking and speaking about individuals (Fairclough, 1989). This contributes to stigmatisation, which is associated with discrimination (Gary, 2005; Thornicroft et al., 2007) and decreased help-seeking behaviour (Clement et al., 2015; Keating et al., 2002), both of which are more likely to impact individuals from minority ethnicities. Indeed, an impact of uncompassionate care for participants was the avoidance of services.

Additionally, participants spoke of a discrepancy between the words and actions of mental health professionals, who may project an image of compassion, for example by stating they empathised, but act in a way that was deemed to be uncompassionate, such as doubting the genuineness of a service users presentation to the rest of the team. This was also reported by nurses working with individuals who had self-harmed or attempted to end their life (Doyle et al., 2007).

Furthermore, there were experiences which highlighted a lack of control in the choices that could be made. Similar to previous studies in inpatient settings (Gilburt et al., 2008; Rose et al., 2015), participants reported feeling coerced and forced into specific situations, such as having to speak about distressing topics or show self-harm scars. Participants described expectations of receiving timely support (Hopkins et al., 2009) but spoke of delays, even when experiencing suicidal ideation or having acted on suicidal thoughts, as well as being denied certain types of support, for example, psychological therapy, the use of meditation beads or speaking to another patient on the ward.

Power and control have also been highlighted in staff conceptualisations of compassionate care within acute mental health settings in the UK (Brown et al., 2014; Crawford et al., 2013; O'Reilly, 2021). Mental health nurses' speech focused on how to 'manage' service users rather than reduce distress (Brown et al., 2014; Crawford et al., 2013), whilst staff from crisis teams described compassionate care both in terms of going above and beyond for service users, as well as in relation to the power located across the service, with service demands impacting on how much compassionate care was expressed (O'Reilly, 2021). This study corroborates these findings, from the perspective of service users who have at times also noticed and felt the lack of compassionate talk and action within services. For some participants, mental health services were viewed as harmful, as also noted by others (Boisvert & Faust, 2002; Rose et al., 2015). Participants also spoke about a fear of services, which lead to them avoiding contact, consistent with the idea of mental health services' involvement in 'circles of fear' within racialised communities (Byrne et al., 2017; Keating et al., 2002). Additionally, the results indicate how despite a greater focus on compassion within the NHS, uncompassionate care is still prevalent.

5.2 Critical evaluation

A critical evaluation of the study is presented according to Yardley's (2000) criteria outlined in the Methodology, and I have attempted to interweave reflexive thinking throughout. Some specific limitations of the research are also discussed.

5.2.1 Sensitivity to context

The study demonstrates sensitivity to context by recognising the previous literature on compassionate care, as well as literature on the experiences of racialised individuals within mental health settings and has identified a gap on conceptualisations of compassionate care from both users of mental health services and ethnically minoritised individuals. I was also aware of the wider context at the time of the study being conducted, in relation to the Covid-19 pandemic, Black Lives Matter protests, and increased conversations within the public and media about race. I was sensitive to participants’ cultural and religious backgrounds, and how my position as an ‘insider’ with regards to this may have facilitated more discussions around religion and spirituality, due to perhaps fostering a sense of trust and shared identity (Hayfield & Huxley, 2015). Although I had not specifically disclosed my ethnicity or religion with participants, I was aware that my name also revealed these affiliations (Khosravi, 2012).

Additionally, I was aware of my ‘outsider’ role of being a mental health professional within this context and the power implications of this. Participants may have viewed me as part of the ‘system’ or in a role which was associated with uncompassionate and harmful incidences, perhaps then limiting what they felt able to share due to a fear of judgement, offending me, or perhaps fearing consequences of sharing negative views. However, there were many perspectives given of both compassionate and uncompassionate care, indicating participants felt comfortable enough to speak.

In an interview there was reference to myself and “the world” I was “working in” and I was very aware of my own role and a desire to ensure that the interview process was not experienced as another uncompassionate and invalidating event. This was reflected in a priority to be ‘human first’, and a ‘professional’ second, however in some instances this may have impacted on fewer questions and areas being explored. Attempts were made to address the power imbalance during interviews by building rapport and trying to make participants feel more at ease. This included the use of verbal utterances and summarising to show listening, highlighting that they need only share what they feel comfortable with, offering breaks, checking in after disclosure of difficult events, as well as ensuring all participants were debriefed afterwards (Dempsey et al., 2016).

5.2.2 Commitment and rigor

Commitment was shown by engaging with the analysis process and immersing myself within the data, including during the transcription process (Braun & Clarke, 2021a); I spent four months with the analysis. The process had felt overwhelming during an emotionally challenging time for me. I had also wanted to ensure that participants’ voices were not lost within my own interpretations. I struggled with this and the personal sense that I was a novice researcher, while also feeling a responsibility to do justice to a group not represented within this literature base and often marginalised. Through the use of supervision, engaging with individual and peer reflection, as well as continuing to go back through the TA steps (Braun & Clarke, 2006b) I was able to generate and refine the themes, and develop my competence with these skills (Yardley, 2000).

In terms of rigor, the study sample size is smaller (at seven) than was initially anticipated and therefore the results reflect the shared definitions and experiences of a small group of people. Recruitment into the study took longer than expected and further recruitment was constrained by time limits, therefore the initial proposal to recruit 12 participants did not occur (Guest et al., 2006). However, this sample size was initially based on ideas around data saturation which not compatible with reflexive TA where the researcher is actively involved in generating meaning and making decisions about when to stop coding (Braun & Clarke, 2021c). Therefore, considering the concept of information power, how much relevant information is held within the sample, may be more productive (Malterud et al., 2016). Overall, the data collected was deemed to be rich and the final themes identified appear clear, comprehensive and ‘complete’ in terms of answering the research questions and fulfilling the aims of this study (Malterud et al., 2016; Yardley, 2000).

I also referred to recent papers by (Braun & Clarke, 2019, 2021a, 2021b, 2021c), which included current thinking around TA and questions to consider when assessing research quality, to ensure that the methodology and analysis of this study was in line with the reflexive TA process (Braun & Clarke, 2006b).

5.2.3 Transparency and coherence

The use of reflexive TA to analyse interview data aligned well with the adopted critical realist epistemology and exploration of the conceptualisation of compassionate care from the perspectives of ethnically minoritised users of mental health services. This indicated a coherence between the study aims and methodology (Yardley, 2000). Attempts have also been made to provide a clear account of the findings with reference to previous literature.

A summary of the themes, including a thematic map (Appendix P) with brief points for each sub-theme, had also been sent to all participants to check clarity and coherence. Only one participant replied, perhaps due to the length of time since the interviews were conducted. The feedback was positive with the participant indicating that the information was “great” and “well-summarised” and they had no further information to add. Facilitating greater opportunities for participant involvement during the analysis process may have aided the persuasiveness of the final narrative provided (Willig, 2013), whilst also acknowledging my involvement in the interpretation.

Transparency has been considered by outlining the epistemological position within the Methods chapter, as well as the step-by-step analysis process. Appendices K and L provide example coded extracts from the transcripts, to showcase patterns and codes that were generated. I have also outlined my own position and thoughts within this section and the Methods, and further reflections on the research process are provided below.

Reflexivity:

At the start of the research process, I had wanted to have more service user involvement and attempts were made to discuss the project with a wider group of people. However, the impact of the pandemic, as well as limited funding and time, made this difficult and did not progress in the intended way. This is something that I have been thinking about more with the generation of “power imbalances” as a main theme of this project, and how I may have also contributed to such imbalances within the research. Additionally, power could have been considered further at the recruitment stage, for example by ensuring potential participants could get in touch via phone, as I could for them, as well as through email and social media.

The use of semi-structured interviews helped to provide me with a structure, which I perhaps relied on more heavily during the first interview and hence restricted full exploration of ideas. Reflections after this interview and discussions with my supervisor helped me to think more about probing questions to open up conversations, ways to clarify points and my understanding of what was being shared, as well as fostering more curiosity and appreciation of the *flexibility* of the interview schedule.

The process of analysis was difficult and listening back to the recordings I recalled a sense of anger and injustice at some of the uncompassionate experiences shared, but also a sense of hope in hearing how powerful incidences of compassion were. As I didn’t have visual cues from the participants, their voices felt even more important. I noted how the transcripts removed the tone and emotion from participants’ speech, and although the written words were powerful, it felt limited compared to what I had been hearing. I have wondered whether the ‘Seeing the person’ theme is also a reflection of this process, with me also wanting to be able to truly see and hear the participants. Additionally, using supervision, I reflected on being drawn to a particular participant and their experiences helped me realise that I was initially selecting more of their quotes to include in the analysis, and the need to be mindful of this and representative of all the participants.

Part of the analysis process was completed during Ramadan, a time where I feel more spiritually connected. I could relate to participants speaking about their religion being particularly important to them during times of distress and their desire for services to understand this. I think this may have also contributed to me initially centring religion and having a specific sub-theme focused on this. However, in reviewing themes and adhering to the TA steps (Braun & Clarke, 2006b), I reflected that aspects of this was better merged with another sub-theme.

I have also noted that although the results speak to the power imbalances within mental health services, the message is not that the participants are devoid of power or powerless. Participants shared stories of overcoming difficulties and resilience, *despite* receiving uncompassionate care at times. I had chosen to highlight the operation of power within the definition and delivery of compassionate care, as I felt this helped to answer the research questions and leads to practical implications for potential change.

5.2.4 Impact and importance

This is the first known study looking at compassionate care from the perspective of ethnically minoritised users of mental health services. It provides a greater understanding of what compassion and compassionate care means to this group, who have thus far not been included within the research base. Although the results indicate similar findings to previous research in definitions of compassion, it provides a richer account combining findings from different studies and highlights the importance of relationships in balancing power to generate compassionate care. This is a finding which has only been seen in other studies within mental health services, suggesting the role of power is important within this setting and imbalances of power are distinctly felt by its service users. The study also draws attention to how definitions of compassion are shaped by people's personal experiences and beliefs, highlighting how its definitions as well as nature, are viewed as dynamic and able to grow.

A number of transferable implications have been raised by the findings and point towards the utility of the research (Yardley, 2000). The implications are discussed after the limitations section, and how much they are able to yield change within secondary care mental health services will provide greater insight into the study's wider impact. The intention is to disseminate the study within a research journal as well as share findings with mental health and service user organisations.

5.2.5 Limitations

The individuals who took part in the study had self-selected. It may be that those who chose to take part had more positive and compassionate experiences, which they felt more able to speak about, whereas individuals with more uncompassionate experiences may have been less likely to respond to a research advert titled 'compassionate care'. Themes within this study did indicate however both positive and negative experiences within services. Additionally, as noted within the results, compassion itself and the definitions of compassion were seen as dynamic. It may be that how compassionate care is defined varies in relation to the stage at which people are within their mental health journey. For example, it was noted that the current participants spoke from a position of having prevailed difficulties. Due to ethical considerations, individuals who had been in contact with crisis services more recently were excluded from participating, and individuals who did take part were less likely to be acutely distressed. It may be that individuals who had more recent experiences of services would have had additional or different contributions to raise, with definitions perhaps focused on more immediate needs.

Furthermore, this study aimed to look at the perspectives of those who were ethnically minoritised within the UK, after identifying a research gap. A broad stance in terms of ethnicity was taken, due to the lack of research with ethnically minoritised individuals and to increase recruitment options. However, in doing so, this may appear to homogenise experiences, and discount the challenges that individuals who are racialised differently face. For example, African Caribbean individuals are more likely to be sectioned (Bignall et al., 2019). As people's experiences are used to define what compassion consists of, their accounts of compassionate care may then differ compared to that of just Asian participants, for example. It is noted that within this sample there were more Asian individuals, which may be due to my own background, indicated though my name (Khosravi, 2012); therefore, the findings are perhaps more reflective of these voices.

Due to lack of funding for interpreters all participants also needed to speak enough English to communicate in an interview about this topic. This significantly restricts the sample of individuals who may be able to take part, perhaps also limiting refugees and asylum seekers. It may be that English-speaking participants are more familiar with cultural ideas about compassionate care within Western countries and hold more similar ideas about what this comprises, with definitions from non-English speaking individuals potentially differing. Also, Singh et al. (2020) found that there may be differences in expectations of compassion between newer and older immigrants, which may impact how they then identify and define compassionate. It was not recorded within this study whether participants were born within the UK or had resettled.

Furthermore, the mental health services that participants had contact with were varied. Initially the focus has been on acute services, however the inclusion criteria were widened to include secondary care service too. It is likely that services have different working cultures which impacts on people's care experiences and definitions. Additionally, the power held within services will be greater within inpatient services where there are conditions to restrict peoples' liberty with sectioning. It was not recorded whether participants had experienced voluntary or compulsory admissions, with the latter experience perhaps more likely to evoke care related to the operation of power. A narrower focus of the research project may have elicited a more service-specific definition of compassionate care.

5.3 Implications of the research

Clinical and research implications highlighted from the study findings and limitations are described.

5.3.1 Clinical

Clinical implications are situated at the individual, service and policy level.

Individual level

A key feature of compassionate care described in the study, involved truly seeing the person and working to understand, respect and meet their individual needs. This will differ from one person to another, and the importance of personalised care is once again highlighted (Bramley & Matiti, 2014; Perry, 2009). As part of this, there will need to be greater inclusion of service users within their care, with the provision that individuals are able to make meaningful choices about what this looks like and a reduction in restrictive practices. Staff being receptive to and actively seeking ongoing feedback about the experience of care will also help to evaluate compassionate practices. Mental health professionals focusing on the relational aspects of care and seeing the development of this as core to the treatment of individuals within services is likely to be helpful. This will lead to better relationships with staff, which has a positive benefit for both service users and services (Durkin et al., 2016) and is likely to lead to a more compassionate culture, with compassion being further nurtured.

Attempting to understand the individual may involve exploring the way *they* create meaning from their experiences, perhaps in place of diagnostic understandings and meanings being imposed upon them. This may include co-created formulations and ensuring genuine service user input into plans. The power-threat-meaning framework, for example, integrates an individual's understanding of the way power operates in their life, the impact of this, and how they make sense of this (Johnstone & Boyle, 2018), which could also be helpful to sensitively foster discussions around the experience of power within mental health services. Other approaches that help individual's identify meaning, such as faith-based approaches may also be helpful.

Findings from this study indicate a greater need for mental health professionals to be more curious about how religious beliefs impact on an individual's life, as well as exploring how beliefs can be used to aid recovery within services. It is suggested that a spiritual history should be taken as part of the assessment process to find out about individuals' beliefs (Chidarikire, 2012). This may involve the use of screening tools, such as The Royal Free Interview for Spiritual and Religious Beliefs (King et al., 2001), or keeping in mind certain acronyms to guide questioning (e.g. FICA; asking after Faith and belief, what Importance this has, whether individuals are part of a spiritual or religious Community, and how they would like these issues to be Addressed in care) (Puchalski & Romer, 2000). It may also be that a biopsychosocial-spiritual model (Sulmasy, 2002) as applied to mental health is helpful, ensuring a holistic understanding of an individual. Maintaining continued conversations about this with service users is also important, to ensure that information is not just gathered at the first point of contact and then not used effectively or at all.

As individuals with a religious belief system are more likely to turn to this in difficult times and religion often offers coping mechanisms (Pargament & Cummings, 2010), it pays for mental health services to utilise this in order to support such individuals who are accessing the service. Religion can give people meaning, provide hope, a sense of social connectedness, and is associated with greater empowerment and resilience (Pargament & Cummings, 2010). Given the religiosity gap (Dein et al., 2010; Smiley, 2001), mental health professionals may feel uncomfortable about discussing religion. However, participants in this study wanted to discuss their beliefs, as also found in previous research (Bergamo & White, 2016). Therefore, staff members being able to engage with service user's faith and incorporating this into their care is likely to be highly valued. Linking in with local faith institutions or chaplaincy services and perhaps joint working to ensure that care provided is considered and appropriate (e.g. with jinn possession) (Dein & Illaiee, 2013), may also aid this process, particularly if staff members feel out of their depth. It may be that further training around such issues is also appropriate; for example, a specific training programme for mental health providers in spiritual competencies is in development (Pearce et al., 2019).

Additionally, professionals will need to be aware of their own beliefs and values and consider other factors, such as their racial and cultural background, and how similarities or difficulties impact on their relationships and delivery of care towards service users. The use of the social GRRRAAACCEEESSS (Burnham, 2012), a mnemonic to help remember key features affecting social identity, is perhaps one way to reflect on differences and positions of power. Staff members fostering a sense of curiosity around cultural competence and humility is also felt to be important. This involves professionals being aware of cultural influences and able to interact effectively with those who are from a difficult culture, whilst also accepting a position of not being able to 'know' everything and wanting to find out more about service users (Betancourt et al., 2003; Greene-Moton & Minkler, 2020). Increased reflexivity within staff teams is to be encouraged and training around this may also be helpful.

Service level

Within the '*sustaining compassion within services'* sub-theme of the first main theme, participants provided some service level suggestions about ways to increase compassionate care. This included ensuring that individuals employed into services were already compassionate, and using compassion-focused questions during interviews to assess this. It was also felt that this process should begin at professional training courses. This is already a practice set-up within the NHS with values-based recruitment (VBR) (Health Education England, 2016), however there is currently limited research assessing the effectiveness of this (Patterson et al., 2016). VBR is based on the NHS constitution and it is unclear how much weight may be given to which of the six values, as well as how much focus there actually is on values during local recruitment procedures, compared to, for example, past working experiences. Reviews of recruitment procedures may therefore be helpful for services to conduct, as well as ensuring there is at least one service user on the interview panel to help substantiate the values and increase inclusivity in mental health services. Thoughtful considerations will be needed to ensure meaningful participation (Heaslip et al., 2018). Attempts to address the lack of diversity within certain professional roles may also help to increase representation of ethnically minoritised staff, to help address racial disparities in care delivery (Wood & Patel, 2017).

Additionally, considering the dynamic nature of being compassionate, it may be helpful for services to consider regular training programmes to help nurture compassionate practice. Prior research (Adamson & Dewar, 2011; Kelley & Kelley, 2013) have reported beliefs about compassion being taught, and research has suggested a focus on the development of interpersonal and clinical skills (Kneafsey et al., 2016; Patel et al., 2019). However, it is important to note that participants viewed compassionate training only being effective in individuals who were already deemed to be naturally compassionate; thus training can help compassion to *grow* rather than to *create* it. There was specific mention of training around structural inequalities and how this may impact on individuals. The social determinants of mental health have been widely researched (Allen et al., 2014) and minority ethnic groups are more likely to be faced with inequalities due to these (Bignall et al., 2019). Therefore, training centred around this may increase compassionate care by enabling professionals to: recognise barriers that the individuals they work with face; understand their situation better, and work to dismantle barriers. Within a clinical psychology programme, there have been workshops to address ‘Whiteness’ (Wood & Patel, 2017), which may also be an important consideration for mental health services. Such training programmes and discussions cannot be seen as one-off implementations but require ongoing engagement.

Participants also referenced the stigma associated with mental health, from within services and their cultural groups. Although campaigns like Time to Change have contributed to a shift in the wider societal discourses around mental health, it appears to have had little impact when considering ethnicity specifically (Henderson et al., 2020), and stigma and discrimination persists within society and services (Klein et al., 2021; Thornicroft et al., 2007; Vyas et al., 2021). However, working to alleviate stigma was seen as a key feature of compassionate care. As well as social justice and rights-based training (Stuart, 2016), it may also be important for services to consider the use of language within teams and how service users and their beliefs are discussed.

Additionally, it is important to consider the support structures that mental health professionals have for themselves to manage compassion fatigue (Berg et al., 2016). More supportive and nurturing staff environments also translate to better care provided to service users. This is supported by numerous studies which have looked at structural and organisations factors that are implicated in compassion being expressed, with service pressures and constraints seen as things that inhibit compassionate care (e.g. Alonso, 2020; Crawford et al., 2014; Horsburgh & Ross, 2013; Tierney et al., 2017). Increased staff numbers and more balanced workloads should mean greater capacity to spend with service users and meet needs within a timely manner. However, this would not be possible without effective leadership to ensure systemic changes. Leadership in compassionate care programme for nurses have indicated positive changes in understandings and preparedness for action, following participation (Dewar et al., 2011; Saab et al., 2019). Similar compassionate care leadership programmes may also be helpful for other professions working within mental health settings, as well as continuing within the nursing field.

Policy level

The Advancing Mental Health Equalities strategy is a positive first step in recognising inequality in relation to specific characteristics such as age, ethnicity, gender, sexual orientation and disability. However, it is noted that religion and spirituality are not a specifically mentioned within this strategy, therefore a consideration of these factors would be a useful policy implication for the future.

The NHS Long Term Plan outlines measures for the improvement of adult mental health services; from a policy perspective this would benefit from the inclusion of anti-stigma measures, as the participants of this study noted that stigma around mental health may have led to judgement and discrimination which impacted their receipt of compassionate care within services. The Time to Change campaign is an example of a notable nationwide campaign, however its closure in 2021 signifies a need for an ongoing and consistent policy-based effort to incorporate improvements to tackling stigma.

4.1.1. Research

It would be useful for future research to look at conceptualisations focusing on specific groups, (e.g., Bangladeshi's) rather than broad definitions to focus in on experiences and definitions. Additionally, research that delves deeper into the specifics of religious beliefs and practices relating to compassion may provide further insight into how compassion can be applied at a service level. If the introduction of spiritual care assessments is implemented in services, an intervention study might be helpful to evaluate the effectiveness of this on service user's care experience. Future studies could also incorporate those who speak other languages, allowing a wider range of participants to describe their definitions and experiences of compassion, as well as exploring whether a language barrier directly impacts the level of compassionate care a service user experiences.

5.4 Conclusion

Compassionate care is a valued component within healthcare; however, this is not always provided to service users, and there have been limited insights into what this means and looks like from their perspective, particularly those from minority ethnic backgrounds. This project aimed to investigate the definitions and experiences of compassion and compassionate care of ethnically minoritised individuals who had used secondary care mental health services. It has outlined what compassionate care looks likes to this group of participants, and how their definition is reflected within their experience of mental health settings.

Definitions were shaped by religious views and past experiences, including treatment by others and the individual’s mental health journey. Compassion was conceptualised as an internal factor that needed to be present within individuals in order for it to be expressed, however there were opportunities for it to grow and expand. It was summarised as kindness in action, with compassionate care reflecting services’ abilities to provide care that was personalised to the individual’s needs, which attempted to understand them, and respected and honoured their uniqueness. Although individuals spoke of experiencing compassionate care, there were also instances where this did not occur. Uncompassionate care was characterised by the exploitation of power by services, leading to services users’ voices and identities being minimised and them having limited control and choice over their care. The structure of mental health services can result in this being a common feature, which is more likely to disproportionately affect minoritised individuals. Therefore, this is something that services need to pay greater attention to.

It is suggested that a relational focus within mental health services should be prioritised. Services will need to address structural, societal, and individual stigma and aim to humanise individuals. Engaging with intersectionality, cultural humility, and religious beliefs are likely to be helpful for service users, but also foster better working relationships with services. The participants in this study described positive experiences with services as “life changing”. Implementing practices which are more in line with compassionate care, as defined in this study, allows mental health services the opportunity to ensure that lives are changed in a positive way.

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7 APPENDICES

7.1 Appendix A: Recruitment poster

Would you like to take part in research about compassion?

University of East London

Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background

I am looking for participants to speak to me about their views on compassion and compassionate care

The study will involve speaking to me confidentially, for approximately 1 hour

You may also be asked to attend another follow-up conversation

Interviews will be held via phone or online call

All participants will be entered into a prize draw for a £100 voucher

You can take part if you:

- Are aged 18 and over
- Identify with a minority ethnicity in the UK
- Can speak and understand English (to a level where you can communicate comfortably in an informal interview about compassion)
- Have used secondary care adult mental health services (such as community mental health services, inpatient wards, crisis services)
- Are *not* currently using crisis services (and have not used inpatient wards/crisis services in the last 3 months)

Please get in touch if you are unsure about whether you can take part

If you would like more information or want to take part, please email **Sabiha Kalam-Polli** at: u1120061@uel.ac.uk

This study has been approved by the University of East London School of Psychology Research Ethics Committee

Department of Professional Psychology, University of East London, Water Lane, London, E15 4LZ

7.2 Appendix B: Participant information sheet

University of East London

PARTICIPANT INVITATION LETTER

Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background

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.

Who am I?
I am a postgraduate student at the University of East London and I am studying for a Professional Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?
My research aims to look at the definition of compassionate care, from the view of people who have used secondary care mental health services and come from an ethnic minority background.

I am interested in how compassion is defined, what has influenced this and how definitions of compassion have been reflected within people's experiences of mental health settings.

My research has been approved by the School of Psychology Research Ethics Committee. This means that my study follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?
You have been invited to participate in my research as someone who can help me explore my research topic.

I am looking to involve people with **all** of the following characteristics:

- Adults (aged 18 and over)
- Ethnic minority background in the UK
- Can speak and understand English (to a level where you can communicate comfortably in an informal interview about compassion)

- Have used NHS secondary care adult mental health services (such as community mental health services, inpatient wards, crisis services)

You will **not** be able to participate if you:
- Are currently using inpatient or crisis services
- Are not currently using inpatient or crisis services, but are in the process of accessing these services and/or you feel you are currently in crisis
- Have used inpatient or crisis services in the last 3 months

Please let me know if this is the case.

I am **also** looking to speak with service user group leaders or facilitators, who have:
- Supported adults who are from an ethnic minority background and have accessed secondary care mental health services
- And had conversations with these individuals around compassion and/or care received within services

I am not looking for experts on the topic I am studying, but I am very interested in your views. You will not be judged or personally analysed in any way and you will be treated with respect.

You are free to decide whether or not to participate and should not feel coerced.

What will your participation involve?
If you agree to participate, you will be asked to provide some details about yourself and attend an informal interview with me. This can be via telephone, online call with Microsoft Teams, or face to face at the University of East London, Stratford campus (depending on government guidelines on social distancing).

During this interview you will be asked some questions around your views on compassion. You will be asked to share experiences of compassionate care in mental health services, both positive and negative. You will also be asked to fill out a questionnaire with demographic details.

The interview will be audio-recorded, and I will also be taking some notes. The interview will last for approximately one hour.

After the interview there will be a debrief, to talk about your experience of the interview.

As the research progresses, you may be asked to attend another interview to follow-up on certain themes raised in the study. You are again free to decide whether or not you participate in a re-interview and should not feel coerced.

All participants will be entered into a prize draw for a £100 voucher. Your participation will be very valuable in helping to develop knowledge and understanding of my research topic. Some people may also find the interview experience beneficial, as it gives the opportunity to share views and be listened to around this topic area.

Are there any risks in taking part in the study?
The interview is not designed to cause distress; however, speaking about personal experiences and care received whilst using NHS mental health services, may be hard to do and can potentially raise upsetting feelings. The interview may remind you of difficult times that you may not wish to think or speak about.

Please be aware that you do not have to share anything you do not feel comfortable with. You are also free to take a break during the interview, can decide to finish it at another time, or withdraw from the interview completely, without there being any disadvantages or consequences for you.

If you do feel distressed during the interview, you are welcome to discuss this with me. However, please note that I will be unable to provide counselling or therapy. There will be time to debrief whenever the interview ends.

If there are any concerns around your safety, this is something that I may raise with you and we can explore your support options. Contact details will be provided to all participants about organisations who offer further support, should this be needed.

Your taking part will be safe and confidential

Your privacy and safety will be respected. You will not be identified by the data collected in the write-up of the research.

Direct quotes from your interview may be included in the write-up, however, care will be taken to make sure this is anonymised. You do not have to answer all questions asked of you and can stop your participation at any time.

If there are serious concerns about your safety, this will be discussed with my supervisor and steps may be taken to raise concerns. If this is the case, this will also be discussed with you and you will be kept informed.

What will happen to the information that you provide?

The interview will be audio-recorded. After the interview, the recording will be transferred to the University of East London’s secure computer network.

The interview will be transcribed word-for-word, and any identifiable information will be anonymised or removed. Transcripts will be stored on a password-protected laptop. The audio recording will be deleted. All other documents containing personal information will be password-protected and stored on the university’s secure system. Only I will have access to the storage bases.

The full anonymised transcripts may also be seen by my supervisors and examiners at the University of East London.

Your name and contact details will not be linked to any responses you provide in the interview. No names will be used in the write-up of the study. Before starting the interview, you will be given a unique number which will be linked to your data instead.

Your interview will be analysed to identify themes and help develop a theory around compassionate care, as experienced by members of an ethnic minority background who have used mental health services.

The final write-up will be available in the University of East London’s open-access research database, called ROAR. The study may also be published in a research journal.

After the study has been completed, personal data will be deleted. Anonymised and password-protected transcripts will remain stored for 5 years. After this period, all data will be deleted.

What if you want to withdraw?
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 material that you provide, up until the point of my analysis of the data.

Data analysis will begin one week after you have completed the interview. If you choose to withdraw from the study during this time, all your personal details and the interview recording will be deleted and not used for this study. After this time, data analysis is likely to have begun and your anonymised data will form a part of the study.

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

Sabiha Kalam-Polli
(Email: u1120061@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: Dr Lorna Farquharson, Department of Professional Psychology, University of East London, Water Lane, London E15 4LZ. (Email: l.farquharson@uel.ac.uk)

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

7.3 Appendix C: Interview schedule

1. What does compassion mean to you?
   Prompt
   - How would you define compassion?

2. What has helped you to think about compassion in this way?
   Prompt
   - Have there been any influences which has shaped your thinking on compassion? (e.g. cultural, spiritual, religious, family views, friends' views, past experiences, media)

3. What should compassion look like within mental health services?
   Prompts
   - What would you expect to hear within these services?
   - What would you expect to see?
   - What would be an example of compassion in mental health services?
   - What might happen?

4. Are there any examples of when you felt compassion was shown to you within a mental health service?
   *Prompt*s
   - How did you know compassion was being shown?
   - What was said and done?
   - What was the situation?

5. What impact, if any, did being shown compassion have on you?
   Prompts
   - How did this make you feel?
   - Did this experience (being shown compassion) affect any other areas of your life?

6. Are there any examples of when you felt compassion was missing towards you or lacking, when within an acute mental health service?
   *Prompt*s
   - How did you know compassion was not being shown?
   - What was said and done?
   - What was the situation?

7. What impact, if any, did not being shown compassion have on you?
   Prompts
   - How did this make you feel?

   - Did this experience (not being shown compassion) affect any other areas of your life?

8. Is there anything else you would like to add about your views on compassion within mental health services?

7.4 Appendix D: Consent form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background

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

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. Only the researcher, and potentially supervisors and examiners will have access to the full transcript of the interview. I understand that direct anonymised quotes from my interview may be included in the write-up of the research and that the findings of this study may be published. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun, which will be one week after completing the interview.

Participant’s Name (BLOCK CAPITALS)

Participant’s Signature

Researcher’s Name (BLOCK CAPITALS)

SABIHA KALAM-POLLI

Researcher’s Signature

Sabiha Kalam

Date:

7.5 Appendix E: Demographic questionnaire

1. What age range do you fall under?

Please tick one box

☐ 18-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65
☐ 66-75 ☐ 76-85 ☐ 86 and over ☐ Prefer not to say

2. How would you describe your gender?

Please tick one box or specify below

☐ Male ☐ Female ☐ Non-binary
☐ Prefer to self-describe: ☐ Prefer not to say

3. What is your relationship status?

Please tick one box

☐ Single ☐ Co-habiting ☐ Married ☐ Separated
☐ Divorced ☐ Widowed ☐ Prefer not to say

4. How would you describe your ethnic background?

Please specify below or tick the box if you prefer not to say

☐ Prefer not to say

5. Do you identify as spiritual or religious?

Please tick one box

☐ Both ☐ Spiritual but not religious ☐ Religious but not spiritual
☐ Neither ☐ Prefer not to say

6. Which mental health service have you previously used?

Please tick one box or specify below

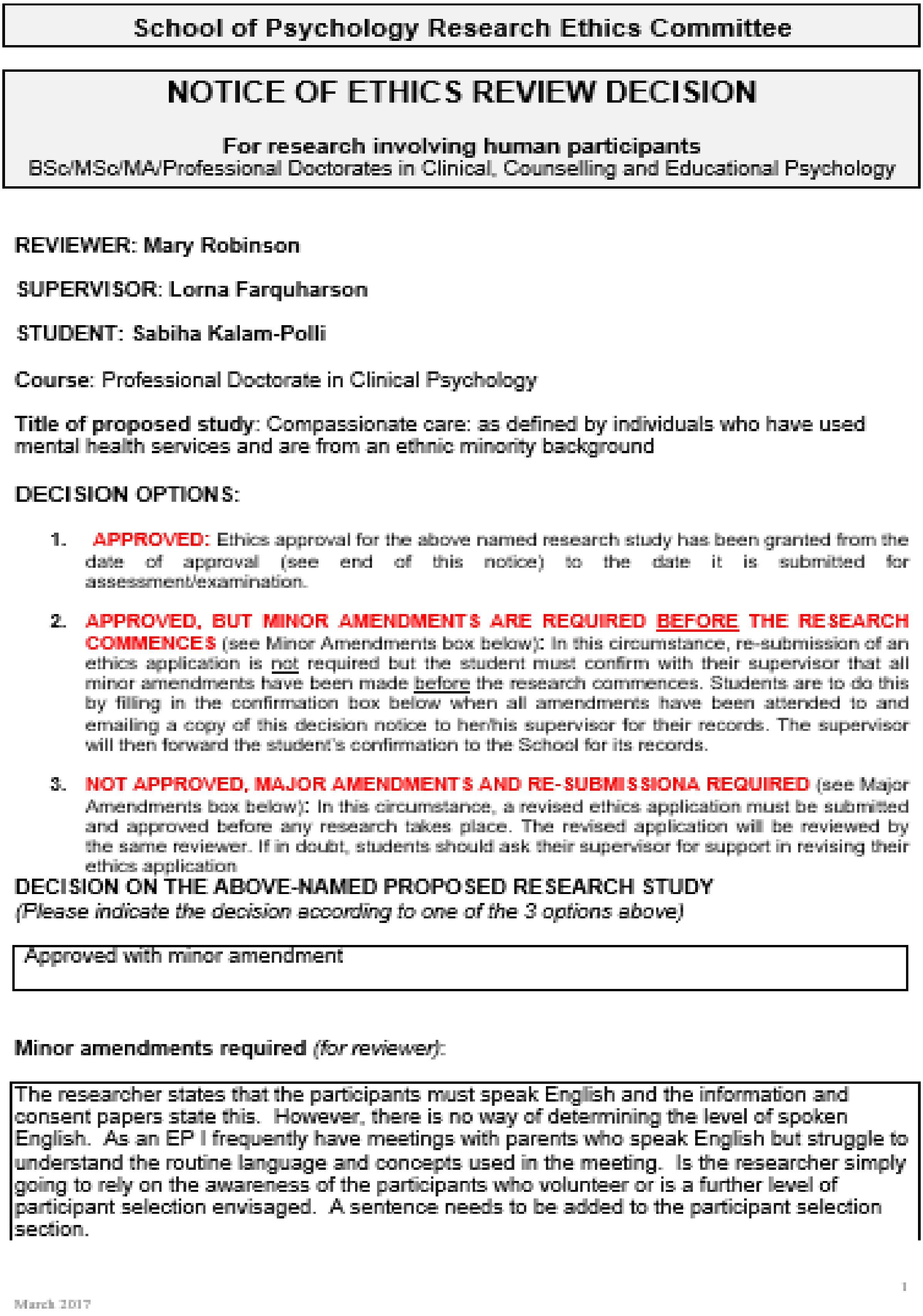
☐ Inpatient wards or crisis services ☐ Community mental health team
☐ Access and assessment team ☐ Early intervention in psychosis (EIP)
☐ 'Personality disorder' service ☐ Assertive outreach team
☐ Other: ☐ Prefer not to say

7.6 Appendix F: Transcription notations

Adapted from Jefferson (1987)

Symbol used within transcript	**Represents…**
(.)	Long pause between sentences
[ ]	Word(s) removed for anonymity reasons
/	Overlap of speech, or no gap between speech of the other person
[laughter]	Laughter
[sigh]	Sighing
< >	Brief interruption of speech by the other person
( )	Inaudible or uncertainty around words spoken

7.7 Appendix G: Initial ethics approval



School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: **Mary Robinson**

SUPERVISOR: **Lorna Farquharson**

STUDENT: **Sabiha Kalam-Polli**

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSIONA REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved with minor amendment

Minor amendments required *(for reviewer)*:

The researcher states that the participants must speak English and the information and consent papers state this. However, there is no way of determining the level of spoken English. As an EP I frequently have meetings with parents who speak English but struggle to understand the routine language and concepts used in the meeting. Is the researcher simply going to rely on the awareness of the participants who volunteer or is a further level of participant selection envisaged. A sentence needs to be added to the participant selection section.

Major amendments required *(for reviewer)*:

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature)*: SABIHA KALAM-POLLI
Student number: U1120061

Date: 10/07/20

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Mary Robinson

Date: 3rd July, 2020

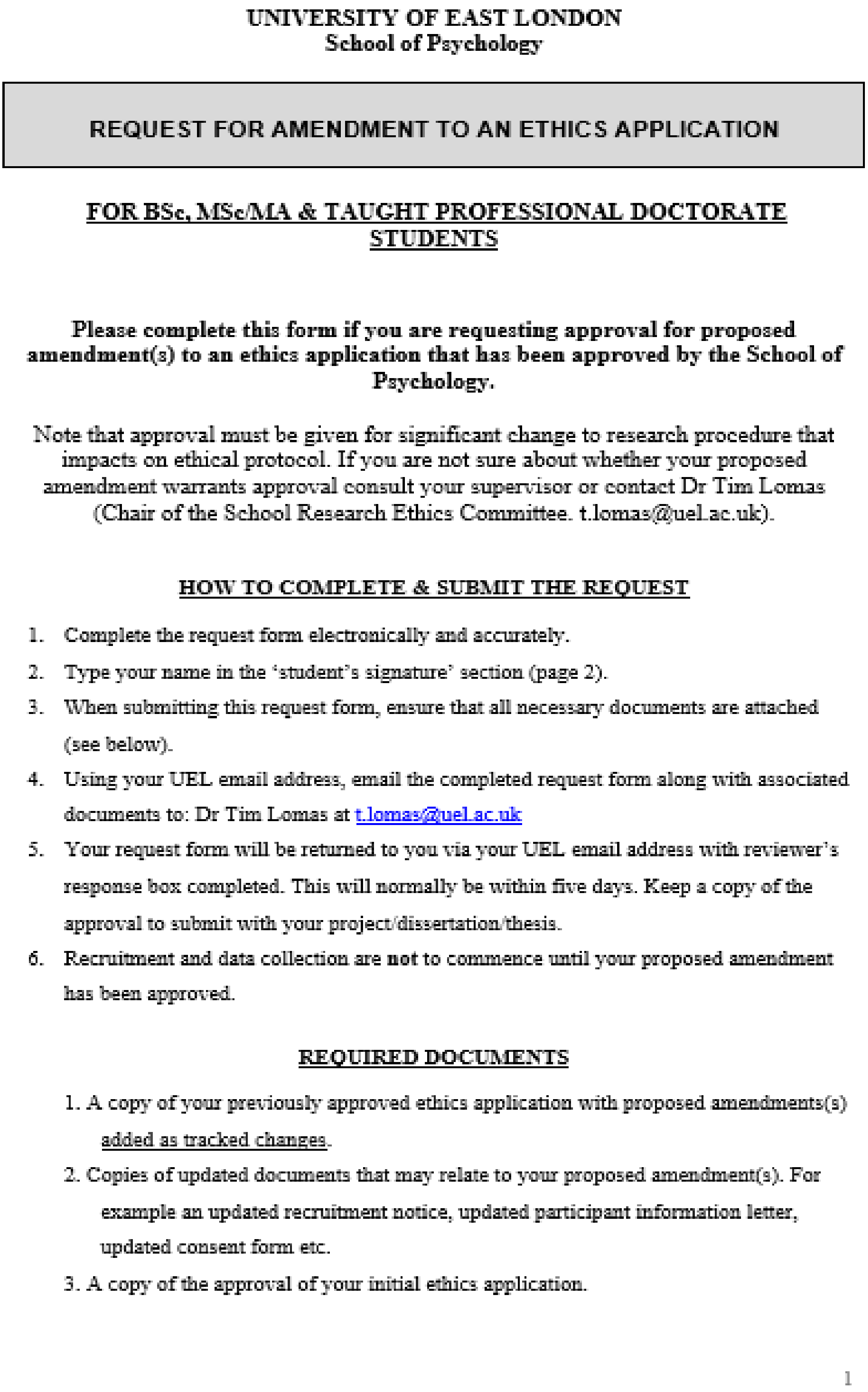
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

7.8 Appendix H: First ethics amendment approval



UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

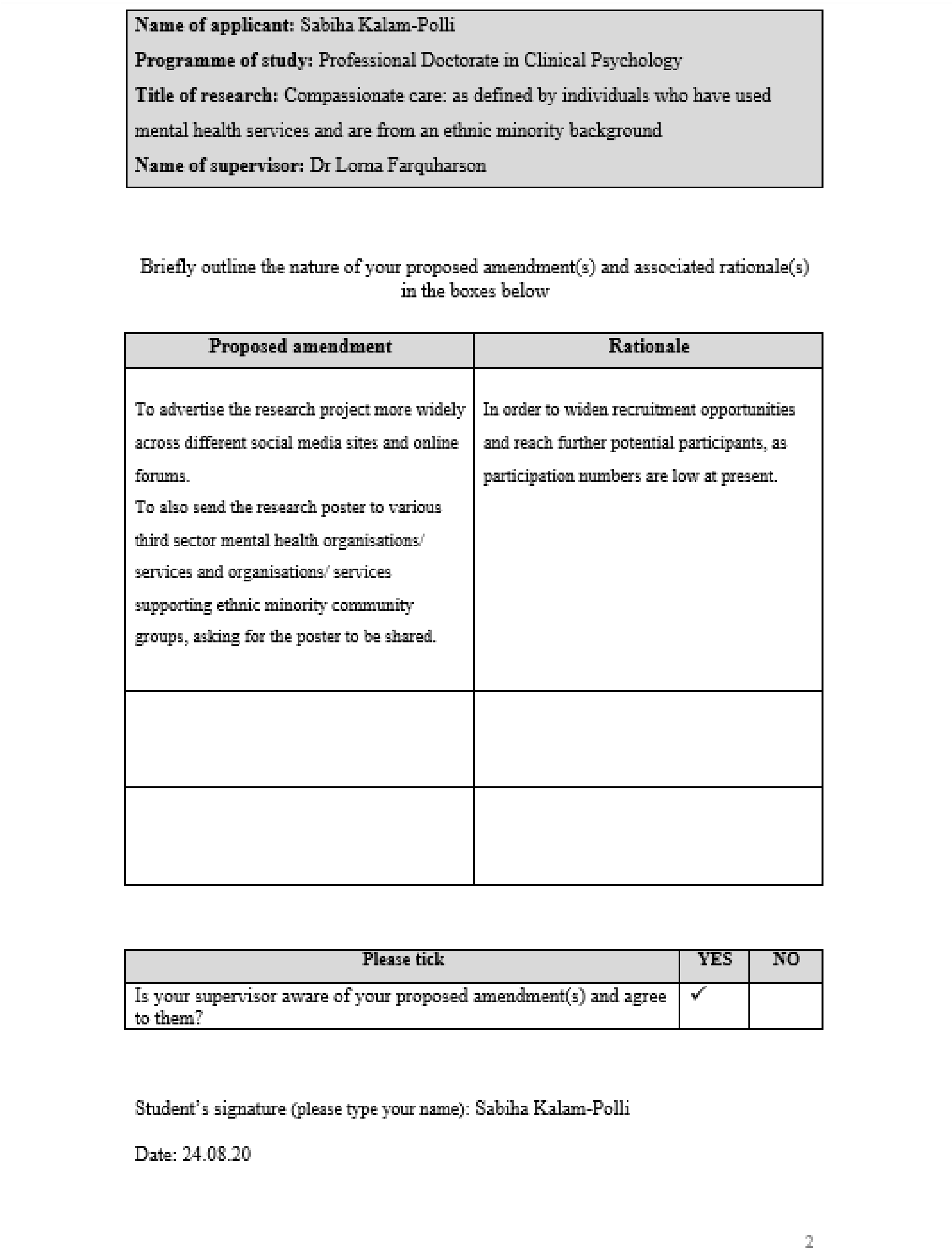
Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.



Name of applicant: Sabiha Kalam-Polli

Programme of study: Professional Doctorate in Clinical Psychology

Title of research: Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background

Name of supervisor: Dr Lorna Farquharson

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

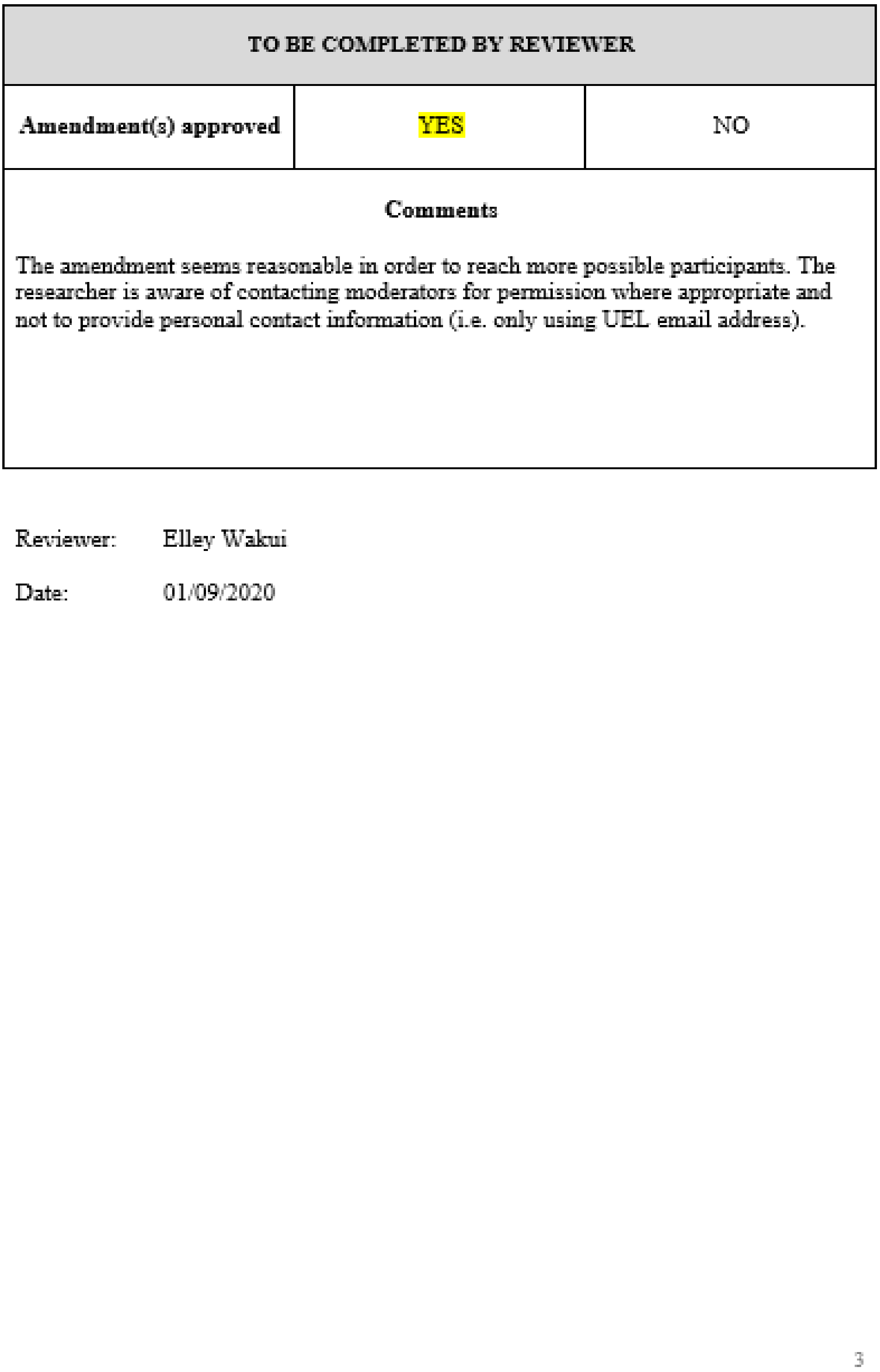
Proposed amendment	Rationale
To advertise the research project more widely across different social media sites and online forums. To also send the research poster to various third sector mental health organisations/ services and organisations/ services supporting ethnic minority community groups, asking for the poster to be shared.	In order to widen recruitment opportunities and reach further potential participants, as participation numbers are low at present.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	✓	

Student's signature (please type your name): Sabiha Kalam-Polli

Date: 24.08.20

2



TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	[✓ YES]	NO

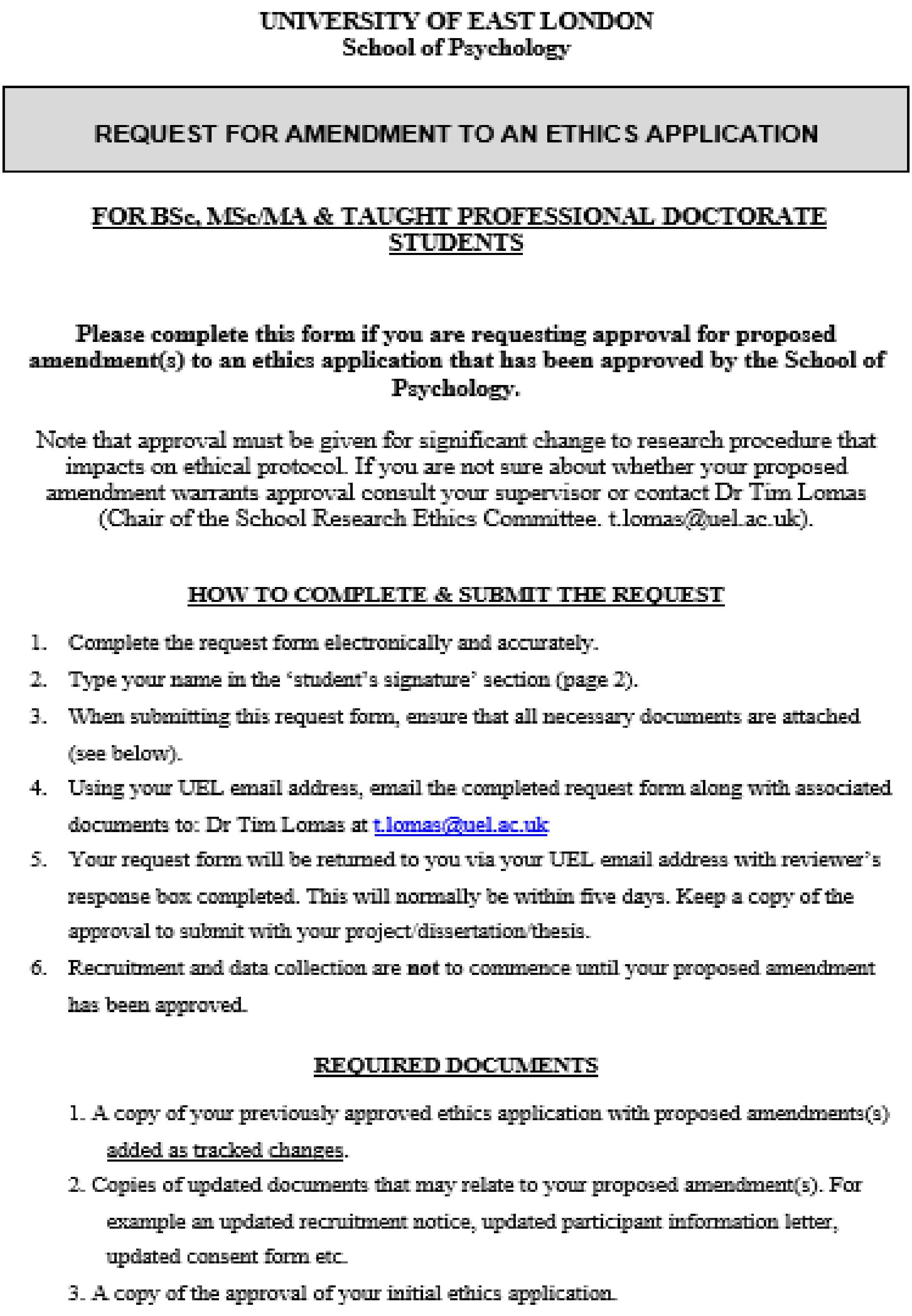
Comments

The amendment seems reasonable in order to reach more possible participants. The researcher is aware of contacting moderators for permission where appropriate and not to provide personal contact information (i.e. only using UEL email address).

Reviewer: Elley Wakui

Date: 01/09/2020

7.9 Appendix I: Second ethics amendment approval



UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

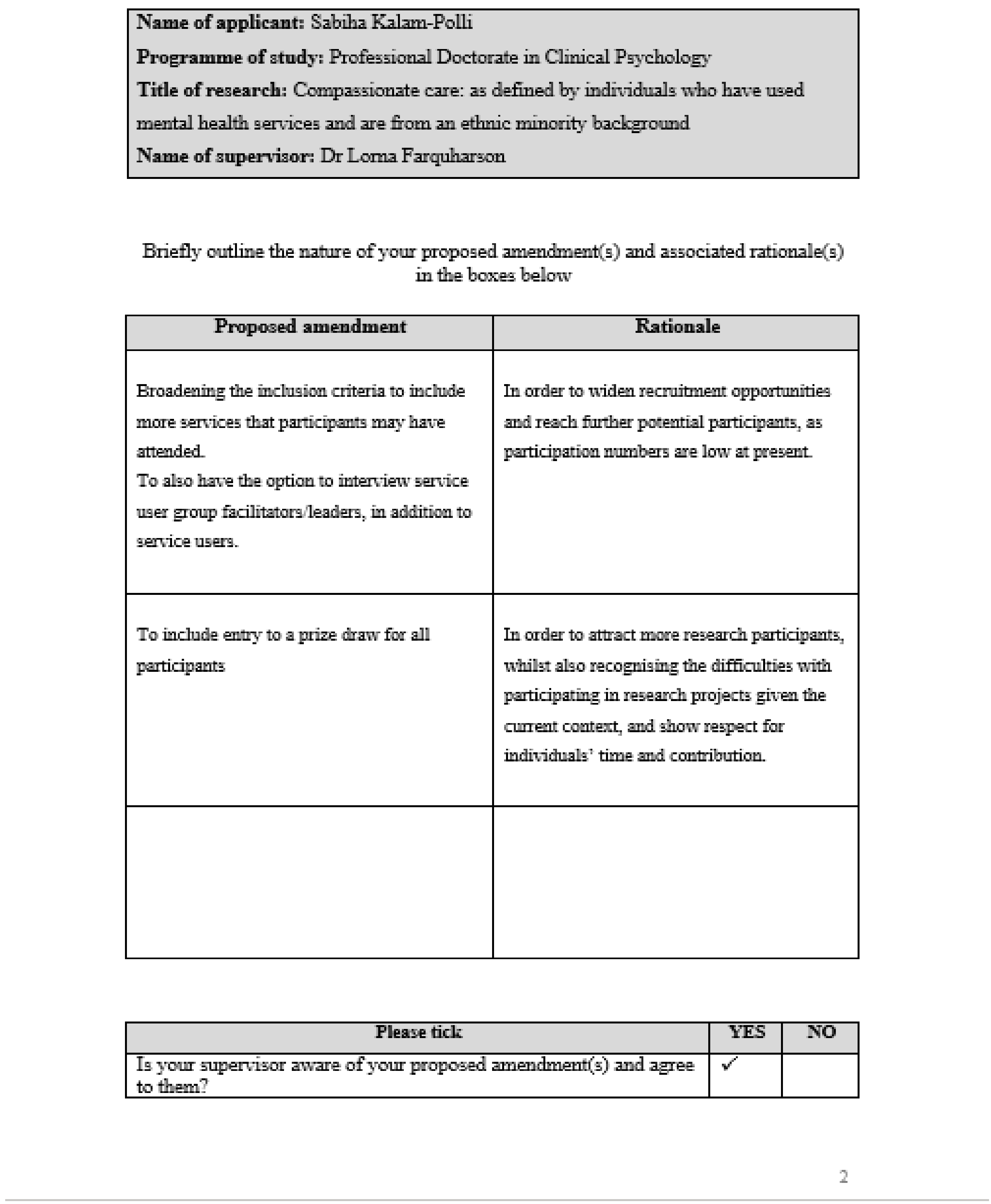
Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the ‘student’s signature’ section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.



Name of applicant: Sabiha Kalam-Polli
Programme of study: Professional Doctorate in Clinical Psychology
Title of research: Compassionate care: as defined by individuals who have used mental health services and are from an ethnic minority background
Name of supervisor: Dr Lorna Farquharson

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Broadening the inclusion criteria to include more services that participants may have attended. To also have the option to interview service user group facilitators/leaders, in addition to service users.	In order to widen recruitment opportunities and reach further potential participants, as participation numbers are low at present.
To include entry to a prize draw for all participants	In order to attract more research participants, whilst also recognising the difficulties with participating in research projects given the current context, and show respect for individuals' time and contribution.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	✓	

Student's signature (please type your name): Sabiha Kalam-Polli

Date: 23.11.20

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments Bear in mind that due to current COVID-19 guidelines at UEL, all research at present should take place online using Teams		

Reviewer: Tim Lomas

Date: 24.11.20

7.10 Appendix J: Debrief sheet

University of East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study, looking at the definition of compassionate care, from the view of individuals who have used mental health services and are from an ethnic minority background.

This letter offers information that may be relevant now you have taken part.

What will happen to the information that you have provided?
The following steps will be taken to ensure the confidentiality and integrity of the data you have provided:

- The audio recording will be transferred to the University of East London's secure computer network and will be deleted after the interview is transcribed.
- The interview will be transcribed word-for-word, and transcripts will be password-protected and stored securely.
- Consent forms and any other personal details collected will also be password-protected and stored securely.
- Only I will have access to the storage bases.

- Your name and contact details will not be linked to any responses you provide in the interview.
- No names will be used in the write-up of the study.
- Before starting the interview, you will be given a unique identifier number which will be linked to your data instead.

- The transcripts of the interview will be analysed to identify themes and help develop a theory around compassionate care, as experienced by members of an ethnic minority background.
- The anonymised data and full transcripts will be seen by myself and may also be seen by my supervisors and examiners at the University of East London.
- Direct anonymised quotes from your interview may be included in the write-up of the study.

- The final write-up will be available in the University of East London’s open-access research repository.
- The study may also be published in a research journal.

- After the study has been completed, your personal details will be deleted.
- The anonymised and password-protected transcripts will remain securely stored for 5 years. After this period all data will be deleted.

- 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 material that you provide, up until the point of my analysis of the data.
- Data analysis will begin one week after you have completed the interview.
- If you choose to withdraw from the study during this time, all your personal details and the interview recording will be deleted and not used for this study.
- After this time, data analysis is likely to begin and your anonymised data will form a part of the study.

What if you have been negatively affected by taking part?
All reasonable steps have been taken to minimise potential harm, but it is still possible that your participation may have been challenging, distressing or uncomfortable in some way.

If you have been affected in any of those ways you may wish to get in contact with available support systems. This may include your GP, a mental health team that you may be in contact with, local service user groups, as well as family and friends.

The following services provide helplines and further support information on their websites:

Samaritans
- *Helpline*: 116 123 (24 hours, Mon-Sun)
- *Email*: jo@samaritans.org (response time is 24 hours)
- *Website*: https://www.samaritans.org/

SANE
- *Helpline*: 0300 304 7000 (4.30pm-10.30pm, Mon-Sun)
- *Website*: http://www.sane.org.uk/home

C.A.L.M. (aimed at men)
- *Helpline*: 0808 802 58 58 (5pm-12am, Mon-Sun, London)
- *Website*: https://www.thecalmzone.net/

Silverline (aimed at people over 55)
- *Helpline*: 0800 4 70 80 90 (24 hours, Mon-Sun)

- *Website*: https://www.thesilverline.org.uk/

The Mix (aimed at people under 25)

- *Helpline*: 0808 808 4994 (4pm-11pm, Mon-Sun)
- *Crisis text line*: text THEMIX to 85258 (aims to connect in less than 5 minutes)
- *Website*: https://www.themix.org.uk/

The following services may also be helpful in obtaining information and support:

Mind

- *Website*: https://www.mind.org.uk/

Rethink Mental Illness

- *Website*: https://www.rethink.org/

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Sabiha Kalam-Polli
(Email: u1120061@uel.ac.uk)

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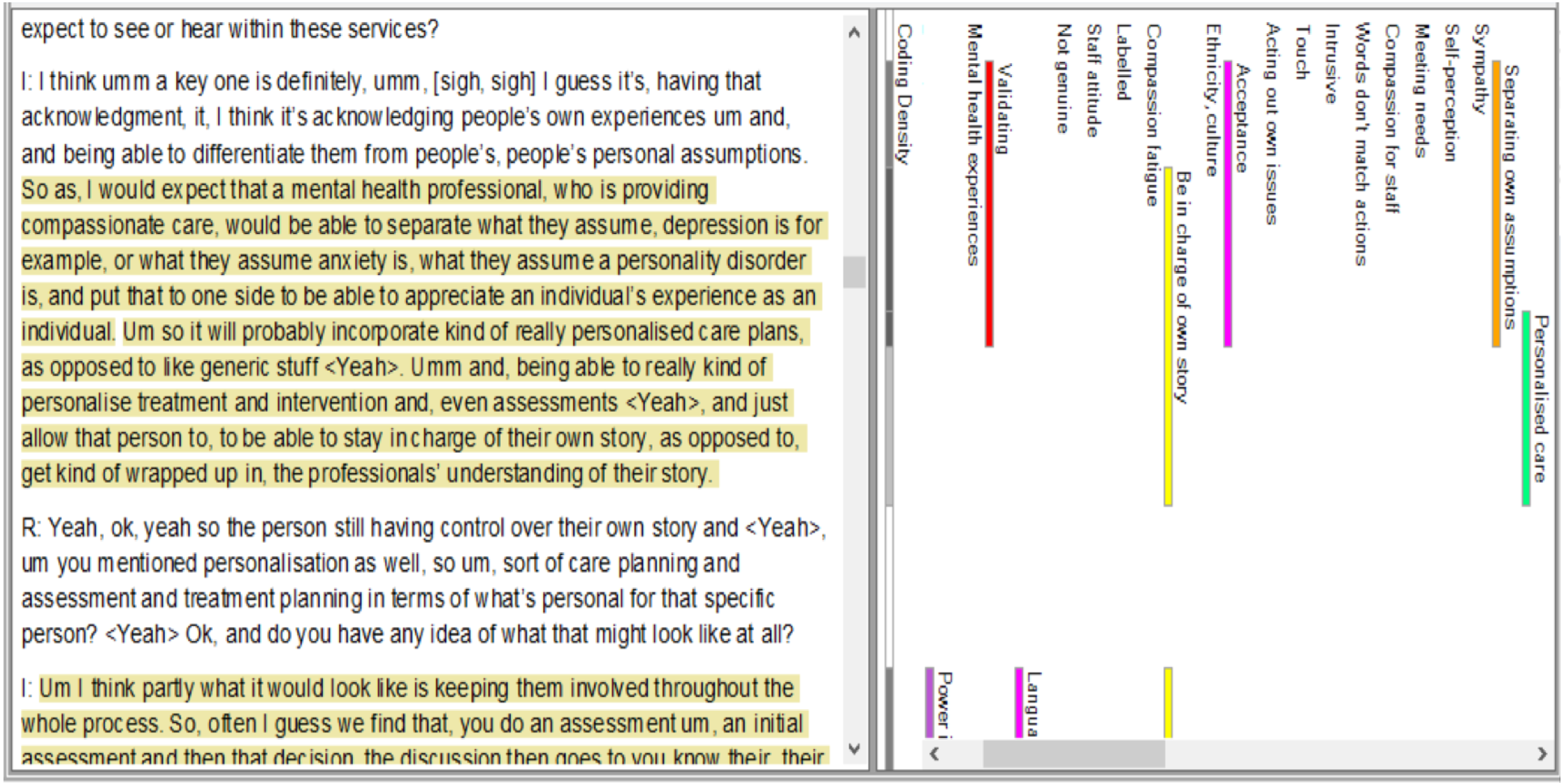
7.11 Appendix K: Coded extract example 1



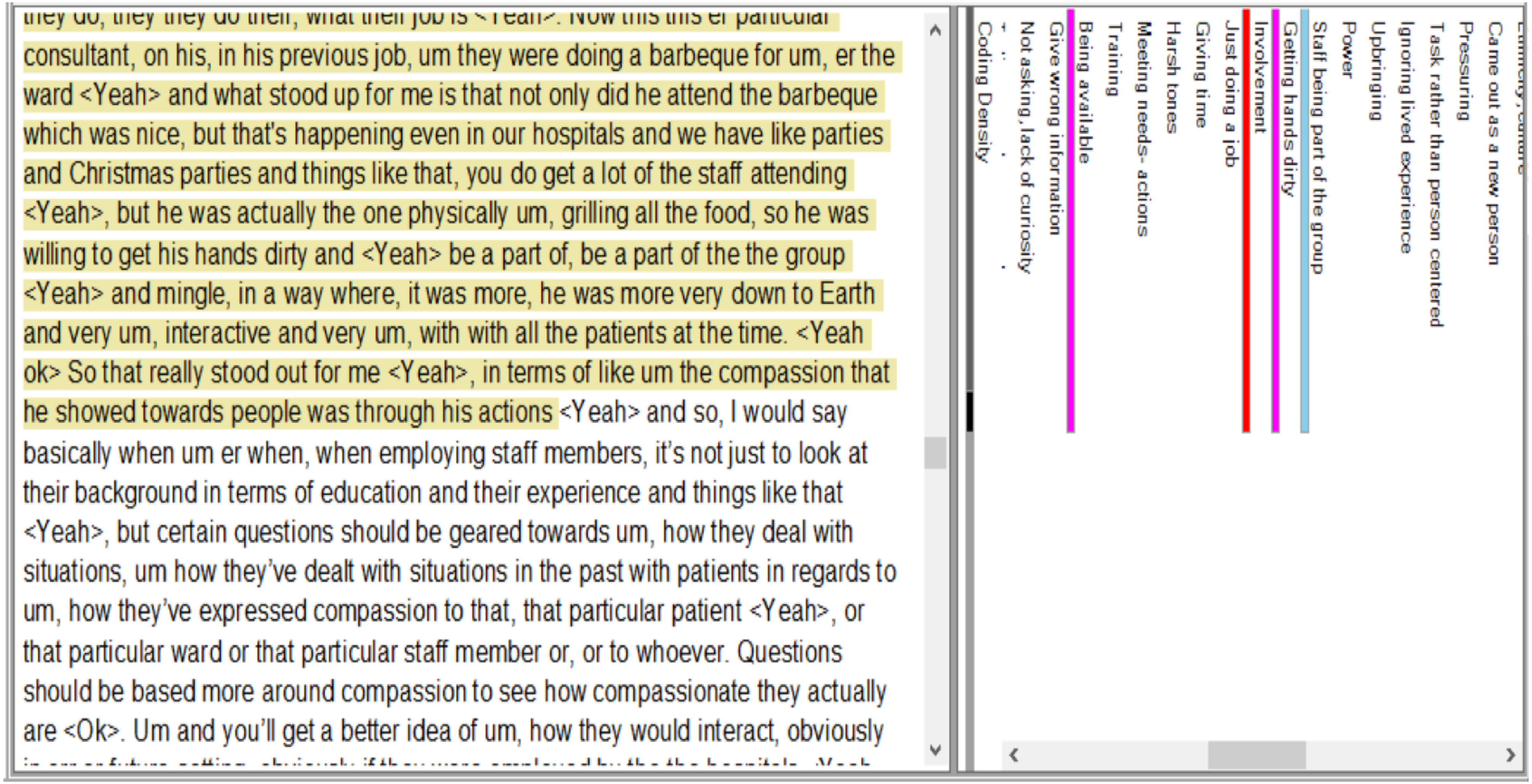
expect to see or hear within these services?

I: I think umm a key one is definitely, umm, [sigh, sigh] I guess it's, having that acknowledgment, it, I think it's acknowledging people's own experiences um and, and being able to differentiate them from people's, people's personal assumptions. So as, I would expect that a mental health professional, who is providing compassionate care, would be able to separate what they assume, depression is for example, or what they assume anxiety is, what they assume a personality disorder is, and put that to one side to be able to appreciate an individual's experience as an individual. Um so it will probably incorporate kind of really personalised care plans, as opposed to like generic stuff <Yeah>. Umm and, being able to really kind of personalise treatment and intervention and, even assessments <Yeah>, and just allow that person to, to be able to stay in charge of their own story, as opposed to, get kind of wrapped up in, the professionals' understanding of their story.

R: Yeah, ok, yeah so the person still having control over their own story and <Yeah>, um you mentioned personalisation as well, so um, sort of care planning and assessment and treatment planning in terms of what's personal for that specific person? <Yeah> Ok, and do you have any idea of what that might look like at all?

I: Um I think partly what it would look like is keeping them involved throughout the whole process. So, often I guess we find that, you do an assessment um, an initial assessment and then that decision, the discussion then goes to you know their, their

7.12 Appendix L: Coded extract example 2



they do, they they do their, what their job is <Yeah>. Now this this er particular consultant, on his, in his previous job, um they were doing a barbeque for um, er the ward <Yeah> and what stood up for me is that not only did he attend the barbeque which was nice, but that's happening even in our hospitals and we have like parties and Christmas parties and things like that, you do get a lot of the staff attending <Yeah>, but he was actually the one physically um, grilling all the food, so he was willing to get his hands dirty and <Yeah> be a part of, be a part of the the group <Yeah> and mingle, in a way where, it was more, he was more very down to Earth and very um, interactive and very um, with with all the patients at the time. <Yeah ok> So that really stood out for me <Yeah>, in terms of like um the compassion that he showed towards people was through his actions <Yeah> and so, I would say basically when um er when, when employing staff members, it's not just to look at their background in terms of education and their experience and things like that <Yeah>, but certain questions should be geared towards um, how they deal with situations, um how they've dealt with situations in the past with patients in regards to um, how they've expressed compassion to that, that particular patient <Yeah>, or that particular ward or that particular staff member or, or to whoever. Questions should be based more around compassion to see how compassionate they actually are <Ok>. Um and you'll get a better idea of um, how they would interact, obviously

7.13 Appendix M: Early thematic map

Sowing/growing the seeds of compassion

-“Internal”/“innate” factor

-Self-compassion

-Compassion grows

Looking at the individual/seeing the person

-“Putting yourself in somebody else’s shoes”

-Meeting needs

-“Treat me like a human being”

-Respecting differences/“don’t put us in one box”

-“Being in charge of own story”

-Recognising importance of religion/spirituality

-Personalised care

Specific service factors

-Power imbalance

-Making changes at an early stage

-Use of language

-Staff influences/attitude

Miscellaneous

-Relational/interpersonal factors

-Affects wellbeing

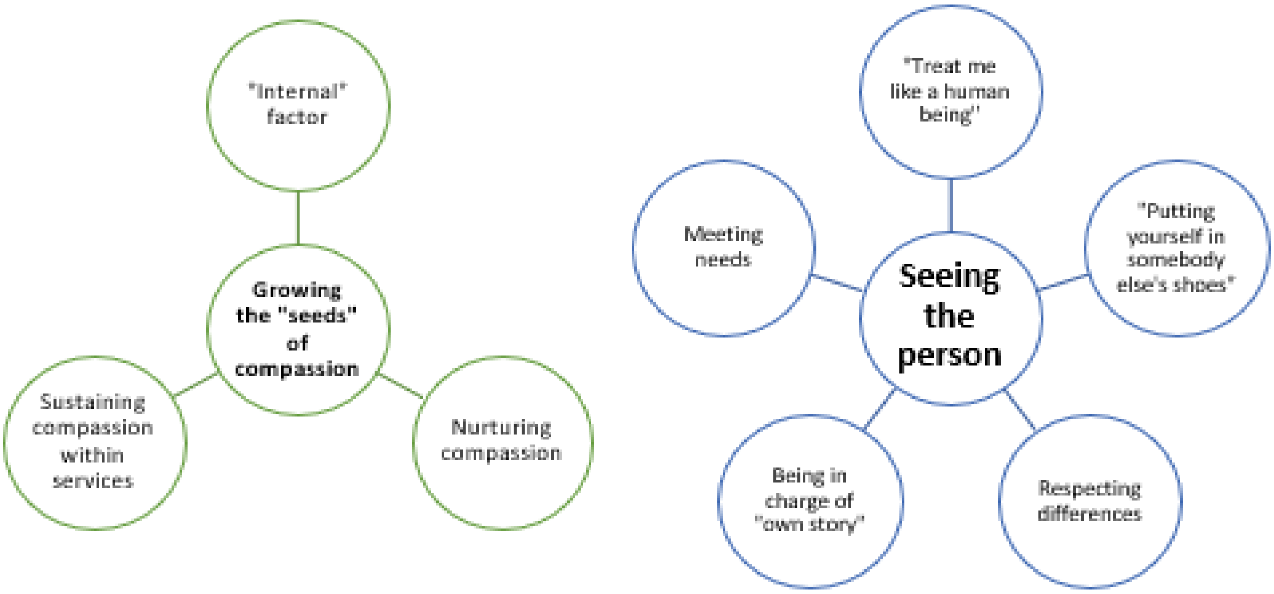
-Avoidance of services

-Better relationships with staff

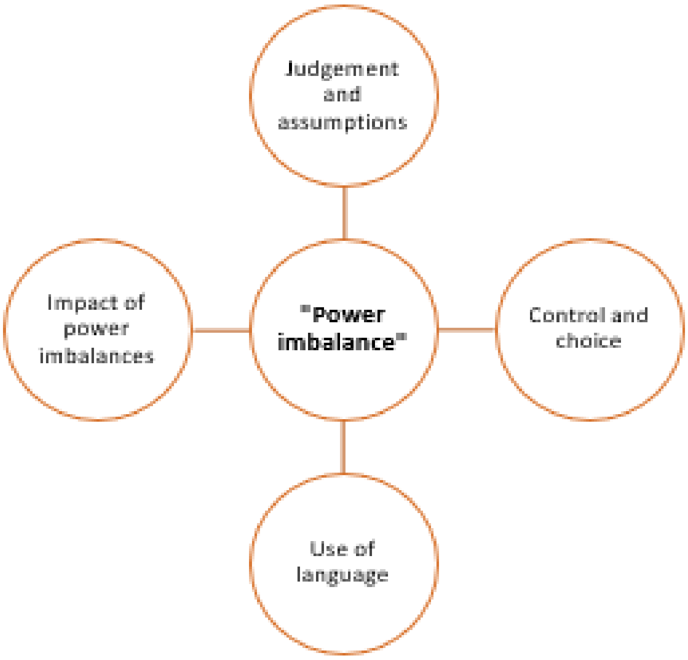
-Mental health experience

7.14 Appendix N: Final thematic map

Compassionate Care



Uncompassionate Care



7.15 Appendix O: Thematic table with participant contributions

Participants who contributed to each theme and sub-themes

Main themes	Sub-themes	Participants
Growing the “seeds” of compassion	“Internal” factor	Deborah Farah Nazia Nihal Sophea
	Nurturing compassion	Amira Deborah Farah Isaac Nazia Sophea
	Sustaining compassion within services	Amira Deborah Farah Isaac Nazia Nihal Sophea
Seeing the person	“Treat me like a human being”	Amira Deborah Farah Nazia Nihal Sophea
	“Putting yourself in somebody else’s shoes”	Amira Deborah Farah Isaac Nazia
	Respecting differences	Amira Farah Isaac Nazia Sophea
	Being in “charge of their own story”	Farah Nazia Sophea
	Meeting needs	Amira Deborah Farah Isaac Nazia Sophea

"Power imbalance"	Judgement and assumptions	Amira Deborah Farah Nazia Sophea
	Control and choice	Amira Deborah Farah Isaac Nazia Sophea
	Use of language	Amira Deborah Nazia Nihal Sophea
	Impact of power imbalances	Amira Deborah Farah Isaac Nazia Nihal Sophea

[1] Participants names are arranged alphabetically

7.16 Appendix P: Thematic map with summary sent to participants

Compassionate Care

Growing the "seeds" of compassion

1. **"Internal" factor**

-Innate- coming from within
-Need enough "seeds" for compassion to be felt
-Relies on trait like kindness, recognising suffering, desire to help
-Compassion can also be directed to the self

2. **Nurturing compassion**

-Compassion can grow
-Concept and understanding shaped by early life experiences, interactions with others
-Religious/spiritual ideas important
-Also overcoming difficulties, including in relation to mental health
-Receiving compassion increases compassion
-Comparing experiences to develop understanding

3. **Sustaining compassion within services**

-Recruiting compassionate staff
-Training to enhance, rather than create, compassion
-Needing enough staff
-Need supportive working environments for staff also

Seeing the person

1. **"Treat me like a human being"**

-Stigma and being seen differently as a result
-Right to be treated as human
-Different experiences in relation to this
-Seeing whole person and not a number
-Likely to positively remember staff who humanise

2. **"Putting yourself in somebody else's shoes"**

-Empathy and trying to understand
-Being non-judgmental and validating
-Queries about extent others can understand

3. **Respecting differences**

-Valuing individuals' diversity and intersecting identities
-Need open-mindedness and to set aside assumptions
-Religious/spiritual beliefs are important, help to cope and need to be recognised
-Also recognising wider differences- discrimination, oppression, cultural stigma of mental health

4. **Being in "charge of their own story"**

-Allowing own narratives including time to share story
-Involving people more in their care
-Recognising expert in self

5. **Meeting needs**

-Taking action -what needs doing, personalised care
-Going above and beyond
-But also small gestures
-Touch and continued support can be important
-Not just doing a task or ticking boxes – kindness as well as action

"Power imbalance"

1. **Judgement and assumptions**

-Staff views prioritised
-Being judged affects how treated
-Less willing to understand and lack of curiosity
-Difficulties challenge staff views
-Pathologizing
-Religious insensitivity

2. **Control and choice**

-Lack of control and choice, e.g., within inpatient care
-Decisions made on behalf of others, not being listened to
-Gatekeeping access to therapy
-Delays in receiving support
-Feeling forced/bullied

3. **Use of language**

-Mismatch between words and actions effects trust
-Labelling and stigmatisation
-Staff words can change/set narratives for a person

4. **Impact of power imbalances**

-Worsening outcomes
-Heightened fear and avoidance of services
-Taking alternative action
-Contrasts with compassionate care – better outcomes and relationships with services