

**UNDERLYING CONCEPTUAL FRAMEWORKS USED TO
UNDERSTAND MENTAL HEALTH BY DISABLED MEMBERS OF UK
GENERAL PUBLIC**

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ABSTRACT

This research explores how disabled members of the general public understand mental health and its causes, from the perspective of public mental health (PMH) and the social determinants (SDH). All participants self-identified as disabled based upon diagnosis received from healthcare professionals. Existing research into PMH and SDH does not distinguish mental from physical health. This qualitative research into health generally suggests the public have complex understandings of structural causes. Psychological research does examine mental health independently but does not incorporate structural explanations. It is therefore unclear as to how the public conceptualise mental health, its causes or what influences different frameworks being drawn upon. Within SDH research, lived experiences and many social locations have been excluded, including disability.

The current research utilised qualitative interview methodology and thematic analysis to examine how disabled members of the public conceptualise mental health, its causes, and what processes influence different models being drawn upon.

Four themes were constructed. The first regarded the impact of the language of health. The second identified that 'mental health' was conceptualised through social norm violation. The third incorporated the participants negotiation of labelling using psychiatric diagnosis and social categories. The final theme included different causal models of mental health, namely individualised, embodied causes relating to physical disabilities, oppressive ideologies and institutions.

There were many complexities to this research, including the multiple definitions and meanings of disability with their corresponding epistemological stance, multiple ideological frameworks that influence the SDH and difficulties with utilising an intersectional lens. Exploring these themes whilst conducting the research has raised more questions than answers, and as such it has been challenging to draw concrete conclusions. Despite this, I have suggested that future research considers the role of emotional processes in influencing which conceptual models are drawn upon at different times, and have I tentatively suggested potential priorities for PMH.

Firstly, to work with the public to develop a shared language for different conceptualisations of mental health, causal models and social locations. Secondly, before work can begin on primary prevention, I would suggest that PMH may work with public services including health and social care and the police to minimise iatrogenic harm that serves to perpetuate the unequal access to resources by marginalised groups who experience health inequalities.

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1.0 INTRODUCTION

This chapter begins with my relationship to and the development of the topic area. Challenges with interdisciplinary research will be addressed and my epistemological standpoint as well as clarifying linguistic choices. Subsequently, relevant concepts will be introduced, and contributions from relevant fields summarised. Critiques of what is 'known' alongside gaps will be interwoven and discussed throughout, culminating in the research questions.

1.1 Contextual Position

The development of this research project has been complex, due in part to my relationship to the topic area and to the Coronavirus-19 pandemic. It is essential to me that my work aligns with my core value of social justice. It is from this stance that I wanted to shape my contribution to public health. Due to the pandemic, my original research proposal had to be changed quickly, in a period of significant uncertainty and social isolation. My original project had planned to recruit staff of Clinical Commissioning Groups, and to explore their underlying conceptual frameworks used to understand mental health and their explanations of why services are structured in the way that they are. This was because I felt that current mental health services, reactive and under the umbrella of the NHS, are less aligned to an understanding of wellbeing as defined through the social determinants of health model (SDH), and I wanted to investigate whether this was due to systemic barriers, or the commissioner's own constructions of mental health. As the COVID-19 pandemic began to unfold, I realised it may be unlikely that I would be able to recruit commissioners to engage in interviews, which lead to me needing to revise my research proposal. I wanted to retain the focus on understanding conceptual frameworks but needed to consider who to recruit. The personal difficulties I experienced during the pandemic, exacerbated by having to change topic, served to strengthen my resolve because I could see the importance of the topic coming alive around me, the health inequalities I was researching so sharply exacerbated in the public health responses (Sisters of Frida, 2020). It felt like this period could be a

catalyst for change, for myself personally, to public mental health (PMH) and to a country arguably shaped by systemic discrimination, through structures and systems that privilege the needs of those who meet particular norms (Compton & Shim, 2014), one that needed to be capitalised upon. Because of these inequalities and my underlying values relating to social justice, I did not want to contribute to the phenomenon in which the majority of mainstream, western psychological research is conducted with norm-aligning participants, such as those who can be classed as White, Educated, Industrialised, Rich and Developed (WEIRD) (Henrich, Heine and Norenzayan, 2010). I therefore began the research the impact of the pandemic, both of the virus itself and of the governments response, which is where I came across the abovementioned Sisters of Frida research, alongside attended as many remote workshops as possible that related to this area. I was repeatedly struck by unequal impact upon disabled people, something I felt was silent in mainstream news. Not only did I find this appalling, I was also shocked at the extent of my own ignorance. I therefore decided to use the thesis as a learning opportunity, where I could dedicate substantial time to researching this area, to better myself both personally and professionally. The pressures involved in this led to the re-imagining the project was time consuming, which inevitably, when deadlines are to be adhered to, has led to some limitations, of which I have attempted to be reflexive of throughout. These will be discussed in detail section 4.5.

1.1.1 Epistemic Reflexivity

Public health is a multi-disciplinary area of practice (Jarvis et al., 2020) and as such, research from a number of disciplines is relevant. It is beyond the scope of this research to explore all of the relevant ideas in depth, and as such pertinent information will inevitably have been excluded. My philosophical stance is used to reflexively explore the selection of material deemed relevant. I ascribe to Critical Realism (CR) as set forth by Pilgrim (2017), of which he proposes there are three components. Firstly, CR takes a realist ontological stance which acknowledges the existence of a mind independent reality. This is an imperative stance within public health, as it acknowledges the very real and potentially distressing impact of material circumstances. A wholly realist position would mean that there are 'facts' or 'truth' that can be discovered. However, as the epistemological position is relativist, CR

recognises that all knowledge is value laden. The ways reality is related to and made sense of is construed through language in social interactions and so is influenced by available discourses in the cultural and socio-political context. Therefore, we can transform reality, through our understanding upon which actions are based, but these possibilities are constrained by the real material conditions in which we are positioned. Pilgrim (2017) defines the final component of CR as judgemental rationalism. This means that because of the realist ontology, there is a reality upon which we can evaluate the different accounts of reality which arise through relativist epistemology. There is no value free knowledge, or way of knowing, and so whilst all perspectives contribute to the knowledge base, not all perspectives are deemed to be of equal weighting. It has been explicitly called upon for public health research to combine what is deemed 'credible' evidence with attention to the values embedded within this (Smith, 2013) which I use in support of my decision to take this position.

I used the principle of judgemental rationalism to consider which disciplines and their corresponding account of reality to privilege and which to subjugate here. I am weighing these up based upon two assumptions. Firstly, each discipline itself will take a philosophical stance, and subsequently be based upon different assumptions about what there is to be known, ways of knowing and who can know them, rather than representing a more or less accurate depiction of reality. These assumptions can lead to the devaluing or exclusion of certain knowledges (Harper, et al., 2020), known as epistemic exclusion (Dotson, 2014). Because of these exclusions, different disciplines and methods are useful for providing different information, and all of these have some limitations. Because of these epistemological differences and limitations of the multiple contributing fields the field of public health is unlikely to ever be cohesive (Garthwaite et al., 2016). Its main aim is arguably to create a more just society, and in order to do this we need to value these epistemological and contextual differences between disciplines and what they claim to know, because this can open a new space for understanding that is not hegemonical (Josewitz, 2016) and that can utilise and combine, with critical awareness, the helpful contributions from each perspective. I believe it is only within a space such as this that we can hope to understand holistically the complexity and diversity of a heterogenous population. This is important because interventions and ways of acting

are designed based upon understandings, so without this complex understanding, we cannot develop similarly complex, appropriate interventions.

Secondly, in line with CR, I comprehend the different disciplines to simply represent different accounts of reality. From the judgemental rationalism position, the perspectives I have privileged here are those that I believe best contribute to a social justice aim and/or the capture the necessary complexity for public health. These decisions reflect my experience, self, and understanding of the world, and so I am writing in the first person to take ownership of this, positioning it as just one of many ways in which to construct an understanding of PMH but one that is inherently mine. Inevitably, there are conceptual and epistemological challenges to independently integrating multi-disciplinary perspectives, and I may make theoretical or practical mistakes in the neighbouring fields (Wilkinson & Pickett, 2017). On balance, it is felt that these mistakes are justifiable in the context of the necessity to move towards a conceptualisation of public health that resides in space between disciplines, equally valuing the contribution of each.

1.2 Language, Definitions and Conceptual Frameworks

In order to locate the research within its context and make explicit how I have used judgemental rationalism to privilege certain perspectives, I will highlight the values underpinning my selection of material through reflecting on and providing rationale for the language used.

1.2.1 Public Health

Public health refers to any organised societal measures, implemented at the population level, to prevent illness and disease and to promote wellbeing, especially those that are under government provision and regulation. Wellbeing refers to living a satisfying, meaningful and contributing life, more than the absence of ill health (World Health Organisation [WHO], 2014), and as encompassing cultural, spiritual, economic, political, social and biomedical aspects (Josewski, 2017).

1.2.2 Public Mental Health

Historically, public health research has not explicitly distinguished what it means by 'health' but most often addressed physical health problems, frequently infectious diseases (Berridge, 2009). Contributors in the field have expanded their thinking to consider social factors but is still implicitly associated with physical health, for example in a study asking experts to explain what they mean by health in this context, they refer to disease and mortality rates, rather than mental health or wellbeing (L'Hôte et al., 2018). Only recently, these social factors have been explicitly addressed regarding mental health (Compton & Shim, 2015; Larsson, 2015; WHO, 2014). PMH has often been discussed without an explicit deconstruction of what is meant by mental health. Examination of relevant documents suggest that this continues to be underpinned by a physical health framework, which, in the context of mental health, constitutes psychiatric diagnoses. Therefore, PMH then can be seen as an extension of public health, rather than conceptually distinct. When I refer to PMH, I am referring to this extension, where mental health is implicitly understood via a physical health framework.

1.2.3 Different Conceptualisations of Mental Health

Within the mental health professions there remains an ongoing debate as to what constitutes mental health (Hinshaw & Stier, 2008). This complicates the question as to what causes mental health problems and promotes mental wellbeing. This problem is bi-directional, because different assumptions are made about the nature of mental health depending on the believed cause (Schomerus et al., 2013). In professional debates, conceptualisations of mental health vary and are dependent on philosophical stance and theoretical alignment. There are many different conceptualisations, and it is beyond the scope of this thesis to cover them all. The philosophical position of mainstream research, theorising and policy appears to be realist both ontologically and epistemologically (Rapley, 2011). Even within this is a plethora of alternative ways to conceptualise mental health. The dominant is the medical model, as in PMH, with psychologists traditionally reacting to what they conceptualise as 'illness' rather than promoting wellness (Hinshaw & Stier, 2008). This model assumes there is actual organic underlying biological abnormalities that lead to actual conditions, which can be identified so long as the symptoms are

correctly observed (Bentall, 2004). Criticisms of this model are due to concerns with validity and reliability of diagnostic categories (Pilgrim, 2017). Critics, from a relativist epistemology, instead understand mental health to be situated within its social, cultural and historical context, and so encapsulates a judgement about what is distressing and/or deviates from social norms at any given time, in any given place (Johnstone & Dallos, 2013). There is similarly a multitude of conceptualisations of mental health under this umbrella. For example, liberation approaches conceptualise mental health as an enactment of social oppression in social structures, relationships and discourses (Afuape & Hughes, 2015). As the psychiatric conceptualisation is that which is implicitly assumed in the majority of public health discourse, this is the meaning I will be denoting throughout this chapter.

1.2.4 The Social Determinants of Health

Population level epidemiological data indicates that certain social demographic groups experience poorer health outcomes than others (Albee, 1999). The social determinants of health (SDH) is an explanatory model that attempts to explain these health inequalities, through conceptualising the ways in which social and structural factors at the population level shape health. This is opposed to attributing this to inherent factors associated to the group. It was historically developed around physical health but have recently been broadened out to address mental health explicitly (Compton & Shim, 2015, p.420; WHO, 2014).

The WHO (2014) define the SDH as the conditions in which people are born, grow up, work and live, conceptualising the main SDH as unemployment, poor education, poor housing, food insecurity and neighbourhood deprivation. Compton and Shim (2015) explain that these environmental factors are influenced by the unequal distribution of opportunities, resources and power amongst different social groups. This itself is a result of public policy, the rules and legislation of society, and social norms, the values and attitudes held at a societal level. These social norms subjugate and discriminate against individuals from certain groups, which seep into and influence public and political will, leading to public policy also marginalising the needs of certain groups. These norms are influenced by overarching ideologies and therefore determine which groups' needs are privileged and hence, which are

afforded more opportunities to access the adequate physical and mental resources that shape wellbeing, named the SDH. Compton and Shim (2015) explain that it is within these conditions that create stress and restrict options that lead to individuals making what health professionals can judge as unhealthy and risky choices. To provide an illustrative, albeit linear and simplistic, example, the subjugating social norms against people from lower socio-economic backgrounds is influential in UK conservative economic policy such as to minimise state welfare support which perpetuates unequal financial opportunities, itself leading to SDH such as poor social housing, poor education and food insecurity. The experience of this is inherently stressful and restricts options to, for example, ways to relieve stress. This may lead to individuals making unhealthy decisions that quickly and temporarily relieve stress, such as to smoke, because healthier, longer term options are not easily accessible within an individual's material constraints. Currently, public health intervention and campaigns target these downstream health-related decisions (Smith et al., 2015).

Due to the overarching influence of ideologies constructed into public policy and social norms, health inequalities are recognised to be actively produced by society and therefore unjust and avoidable (Whitehead, 2007). Using judgemental rationalism, I believe it ethical to privilege these structural conceptualisations that understand individuals within their complex contextual position, over more simplistic individualised understandings which blame individuals, contributing to shame and stigma and so are harmful (Smith, 2013). The SDH does not claim that a 'healthy' society would be one in which physical illness or mental distress would be eradicated, but rather that a 'healthy' society would be an equal society, in that the distribution of mental and physical health problems would equally affect all social groups (L'Hôte et al., 2018). It is argued that this cannot be achieved through individual, reactive treatment of mental health problems (Albee, 1999).

1.2.5 Epidemiological Underpinnings

The population level epidemiological research that forms the majority of the evidence base for the SDH indicates that particular groups are more likely to face poorer health outcomes because of the unequal distribution of opportunities afforded to them. In the UK context, these groups include minority ethnic communities, disabled

communities, those with minority sexual orientation and gender identities and those from deprived socio-economic backgrounds (L'Hôte et al., 2018). The contribution of being able to map structural inequality at a societal level is clearly valuable contribution, offering an important starting point, however there are also significant limitations to epidemiological research. It is based on the assumption of a positivist epistemology despite the lack of explicit naming or reflexivity regarding this (Raphael, 2006). Positivism incorporates realist ontology and epistemology, meaning that all things that can be known must be directly observed (Pilgrim, 2017). This therefore aligns with an interpretation of reality that is static and individualistic, because complex structures and the values embedded within them and enacted by them are arguably not directly observable. Accordingly, this acknowledgment of 'social' in the SDH theorising does not mitigate that this understanding is still based on research that assumes linear causal mechanisms between structural factors and an individual's health (Josewski, 2017). Arguably then, attempting to understand the SDH through this paradigm alone surmounts to nothing more than reducing mental health inequalities to internal properties of individual minds (Bolam et al., 2006). Furthermore, in order to identify these widescale trends individuals are reduced to quantifiable categories, which does not afford rich, nuanced understandings upon which a complex preventative measure could be designed. These qualitative methodologies have typically been marginalised in mainstream PMH research (Rose-Clarke, 2020). Psychiatry and psychology have traditionally reinforced these individualised understandings and interventions of mental health outcomes and have been late in contributing to PMH and population level understandings (Orford, 2008). Psychologists are well placed to contribute more in-depth, qualitative research regarding the complex lived experience of multiple SDH. In order to develop appropriate, acceptable and effective prevention of the health inequalities experienced by particular groups, we need to be able to identify and integrate the multiple different ways of understanding the SDH and health inequalities (Josewski, 2017).

1.2.6 Social Locations

When using qualitative data, we have the space to afford complexity to the categories used to group people in large scale epidemiological research. It is from

this position that we can begin to deconstruct the implicit conceptualisation of health as an individual phenomenon through drawing attention to society's role in the creation and sustenance of structural inequality (Hankivsky & Christoffersen, 2008). Throughout this thesis I attempt to do this by referring to the social groups that experience health inequalities as 'social locations'. This is to clarify that I am not referring to an internal characteristic belonging to, or on control of, the individual, but rather the active structural minoritisation of groups through a process of restricting access to resources, so are representative of actual power differentials and can be used to reflect those experiencing injustice (Roberts, 2009). Categories are constructed by those with power, and therefore the norm is assumed from a place of privilege, which in the UK is presently characterised by ideologies of Whiteness, Maleness, Heteronormativity and non-disability (Hankivsky & Christoffersen, 2008). Those outside of these norms experience the unequal distribution of opportunity and resources (Compton & Shim, 2015), as explained in section 1.2.4. The term location reflects that these categories do not represent distinct groups but are spectrums in which an individual can be positioned in a more or less powerful location (Crenshaw, 2006). Diversity is situated in the margins of society, with homogeneity at centre, meaning that those minoritised individuals have the 'widest view' of society, arguably meaning they are best situated to understand society as a whole and its fundamental truths (Afuape & Hughes, 2015). This wide understanding is necessary to conceptualise and prevent the health inequalities ultimately caused by public policy and social norms (Compton & Shim, 2015) and design PMH interventions appropriate for the whole population.

1.2.7 The Different Constructions of 'Disability'

The language I use at different times denotes different conceptualisations of disability, of which I intend to address and explain here. When I am discussing the findings of mainstream research, such as throughout the introduction, I am using what I believe is the same definition as this literature. Namely, utilising a realist epistemology and referring to a diagnostic construct, with 'disability' therefore being a medical or psychiatric condition that an individual does or does not have. My personal conceptualisation of disability, referred to mainly throughout the method and the critical review and recommendations parts of the discussion chapter, is that of a social location (as above in 1.2.6). I conceptualise this location as socially

constructed, in the sense of some ways of being as being constructed as problematically outside the norm, for example, having a learning disability or hyperactivity been framed as a deficit rather than a different way of being. Within this construct I believe are multiple, overlapping spectrums as opposed to categories. These include severity, visibility, support needs and impact on daily life. Different participants within their interviews appear to use disability to denote different meanings. When I am referring to a specific participants definition, mainly during the results chapter, I have attempted to reflect the meaning I have interpreted them to have used. These different conceptualisations are also therefore interweaved throughout the discussion chapter at points where I refer to participants constructions. When referring to the disabled community, I intend to reflect all those who would classify themselves as disabled, by whatever definition they choose. Understandably, these different conceptualisations all being utilised may lead to confusion on behalf of the reader, as adding this complexity certainly did for myself. I believe it is important to attempt to hold and work with this complexity, as different disciplines relevant to PMH will all hold different conceptualisations within themselves. I believe our debates cannot be complex enough if we reduce disability to only a limited portion of its meanings.

1.2.8 The Relationship Between the Social Determinants, Social Policy and Ideology

As explained in section 1.2.4, the literature regarding the SDH often examines social factors at the population level, assuming that a combination of social factors lead to mental health problems (WHO, 2014) implying a rather linear causal model, such as outlined in 1.2.4. However, this linearity is overly reductionist. It has been argued that social policy itself can worsen social factors, such as poverty and racism, rather than simply reflecting the norms valued by society (Cairney, 2019; Hankivsky & Christoffersen, 2008). It can be argued that many of the social policies with these negative consequences to social factors are neoliberal in nature. This is an economic framework that prioritises market deregulation, individual responsibility and a corresponding reduction of state support (Hankivsky & Christoffersen, 2008; Mackenzie et al., 2017).

It is important to consider the political nature of the process of structural minoritisation addressed in 1.2.6. This is because the process of upholding these

inequalities through policymaking is intensely ideological, enacted by those in power in ways that consolidate their power (Roberts, 2009; Stevens, 2011). This process, however, is not through individuals and their intentional actions but rather that systems are designed in such a way that the default position is to maintain the status quo (Cairney, 2019). We therefore need to name the systems in which PMH is situated and enacted in order to understand the unequal relationships of power that serve to uphold privilege to certain groups and subjugate others. Neoliberal ideology in the UK can be seen enacted in the policy. This sets a stage for a conceptualisation of justice based upon individual meritocracy, independence and competition (Mackenzie et al., 2017). This is because essentially the individual is seen as solely responsible for their own circumstances, and it is therefore hard work, will, strength of character or other internal characteristics that, through lifestyle choices rather than access to resources, shape the individual's environment (Smith, 2013). Health inequalities then, are seen as the responsibility and fault of the individual, rather than systems, which impacts how we conceptualise and attempt to produce a just society (Josewitz, 2017). This ideology serves to protect discriminatory systems from critique, and so does not align neatly with an SDH perspective through obscuring conceptual frameworks that would enable disruption of this dominant hegemony.

It can be argued that neoliberalism shapes the public policies and social norms that lead to SDH and health inequalities. For example, the neoliberal moral preference towards efficiency and hard work is a social norm that devalues less economically productive individuals, for example those with disabilities, which then creates an inequality in opportunity, or structural barrier, for individuals diagnoses as disabled to access employment (Josewski, 2017). This SDH has a financial and psychological impact (Mcgrath et al., 2016).

Research into the SDH are carried out within this wider context of neoliberalism and researchers have identified the significant impact this has upon their work. Smith (2013) interviewed public health researchers and found that whilst they were personally critical of government policies, such as 'austerity' policies seeking to reduce government spending on the public sector and welfare, due to the negative public health impact, they felt unable to be so professionally. This was because their

career was dependent upon receiving funding for their proposed research, which comes from the powerful institutions who benefit from neoliberal ideology. Clearly and concerningly then, structures with power and financial resources can shape the knowledge that is generated and therefore influence our understanding about health inequalities, and this process occurs within the systems that prioritise the individualisation of these inequalities through the focus on individual determination to choose a healthy lifestyle (Cairney, 2019; Smith, 2013).

An example of this is the way in which public health interventions focus on individual responsibility to engage in healthy behaviours and lifestyle choices (Mackenzie et al., 2017), such as the Every Mind Matters campaign (Public Health England [PHE], 2019). These interventions further consolidate neoliberal ideology amongst the public through the representation of state sanctioned discourse of individualised mental health. These are continually implemented in spite of growing recognition that these individualist interventions actually widen health inequalities, through having a greater financial impact on poorer communities and increasing stigma and thus discrimination by shaming people for their poor mental health outcomes (Smith, 2013). This gap between research and policy has been referred to as 'behaviour and lifestyle drift' (Mackenzie et al., 2017). Ethnographic research has identified that policymakers actively subjugate research regarding social inequalities (Stevens, 2011), as this understanding leads to interventions that do not neatly fit with neoliberal systems that perpetuate these individualised understandings of health inequalities.

Despite this, there are problems with only utilising the ideological framework of neoliberalism to consider the impact upon the SDH. Bell and Green (2016) critique the way in which neoliberalism is used in public health research, identifying that it is used in many different ways but researchers are rarely explicit about the ways in which they use this. They say that this leads to neoliberalism as an ideology being used monolithically, and with the implication that it itself is a causal force. Bell and Green (2016) advocate against reifying neoliberalism in this way, as it leads to an overly reductionist causal model of the SDH, ignoring many other important, contributing ideologies, such as Whiteness, Heteronormativity and the Patriarchy, all of which shape the SDH, inequality and access to resources in different ways. Bell

and Green (2016) suggest researchers reflect and clarify how they use neoliberalism, whilst calling for more specificity and nuance in accounts. I would argue that one way in which this aim can be achieved would be to attend to intersectionality.

1.2.9 Intersectionality

Raphael (2006) argues that a critical perspective is necessary in order to incorporate and illuminate the multiple forces that influence the structure of society and shape the political, economic and social processes that in turn shape the SDH. An intersectional framework has been argued as perfectly situated to address this criticism of attending to just one ideological framework and incorporate the full extent of these macro-level structures and the power relations that uphold them (Bowleg, 2012). Whereas the SDH frameworks points to moral concerns and practical solutions around the equitable distribution of downstream resources and opportunities, an intersectional lens looks further upstream, placing the primary ethical focus on the forces determining *why* resources have been unequally distributed in the first place, and *how* this disparity is maintained (Josewski, 2017). Arguably, policy change that may lead to more equitable opportunity distribution cannot be achieved or maintained without addressing this how and why.

Intersectionality is an explanatory theoretical framework that aims to understand structural discrimination in all its multiple and overlapping complexity (Bowleg, 2012). Clearly, this can also be applied to understand the health inequalities particular groups face as identified by epidemiological data (Bowleg, 2012). It emphasises each social location is not seen as unidimensional, meaning that particular positions within each social location are not homogenous (Bowleg, 2012). It further highlights that social locations are not independent categories (Hankivsky & Christoffersen, 2008), we each occupy multiple social locations at any one time, and therefore are both simultaneously privileged and oppressed (Crenshaw, 2006). This means that any experience relating to a social location cannot be understood in isolation from others, for example, that gender cannot be related to mental health outcomes in the absence of also considering ethnicity, sexual orientation, socio-economic status etc.

Health inequalities are shown to be widening in the UK (Smith et al., 2015). This may be impacted by the fact that we do not fully understand the ways in which the determinants of health intersect and mutually reinforce each other (Hankivsky & Christoffersen, 2008). Most public health research that examines the SDH rarely incorporates an intersectional lens, instead examining at one oppressive social location individually (Bowleg, 2012). Specifically within the UK context socio-economic status has been the focus, positioned as the 'primary' social determinant of health, in that it explains the causes of health inequalities above and beyond other social locations (Smith et al., 2015). This has been explicitly problematised because it draws focus away, as described above, from considering the active, political, stratification of society (Raphael, 2006), and does not consider social locations as heterogenous, for example that within a socio-economically deprived social locations, other marginalised social locations are more likely to then be situated within this, such as disabled and ethnic minority communities.

It is widely acknowledged that to use an intersectional lens is to complicate matters (Hankivsky & Christoffersen, 2008), and that this has likely contributed to its lack of adoption within public health discourse more broadly and research specifically. Intersectionality highlights a plethora of different ideologies that influence the construction and reinforcement of social norms, public policy and therefore the SDH. Intersectionality reminds us that at the individual level, these different aspects of identity and privilege intersect and influence each other in ways that are difficult to study within a linear social determinants perspective, in part as the privileged and subjugated positions are continuums rather than dichotomies. For example, the ideology of Whiteness privileges Western ideologies, the ideology of Heteronormativity privileges a nuclear construction of family, and a Patriarchal ideology privileges masculinity over femininity. While these are interrelated, they all shape social norms, social policy and SDH in different ways.

I have found this complexity challenging to incorporate into every aspects of the research. Despite this, using public health aim to achieve a more just society, from a judgemental rationalism standpoint, we should endeavour to incorporate intersectionality despite this complexity. It should be appreciated that health inequalities result from alignment to multiple, intersecting discriminatory structures

(Bowleg, 2012). We need the focus on the most upstream determinants in order to intervene in the appropriate places, without locating blame or responsibility upon those situated within these oppressive structures.

1.3 Public Understanding

Public health is now dominated by an SDH understanding (Smith et al., 2015; WHO, 2014) rather than individualised or intersectional. Still, there remains amongst professionals debate as to the public understanding regarding mental health, its causes, and mental health inequalities. The lived experience contribution is notably absent from this debate (Rose & McAuley, 2019; Smith et al., 2015). It is necessary to understand public opinion as it is within this context that public policies are advocated for and generated, and that social norms are enacted (Compton & Shim, 2015; Wilkinson & Pickett, 2010). However, the debate often takes the form of whether the public understand what the SDH are and how they lead to health outcomes (Smith et al., 2017). There are ethical and pragmatic reasons as to why this simplified debate is problematic. Ethically, positioning non-professional understanding as non-expert, and considering whether the public 'have' the 'correct' understanding or not, devalues embodied and lived experiences and knowledge. This reinforces the elitism in the field, by positioning people without certain types of expert training as not possessing the right knowledge and therefore unable to contribute to the knowledge production (Smith, 2013). This paternalism is further reinforced through developing in a top-down manner applying inaccessible theoretical models to people, removing their agency to take control of factors influencing their health inequalities (Kagan et al., 2019). This directly contributes to Fricker's (2007) epistemic injustice, whereby the public are assumed not to understand the SDH because of their lack of professional status, which constitutes testimonial injustice because their opinions are deemed less credible because of the 'lay' categorisation. This then excludes the public from debates that develop understandings further, constituting hermeneutical injustice because the public are not afforded opportunities to learn the professional concepts necessary to contribute in these debates. Given this, public health has understandably been critiqued for being elitist, paternalistic and for its rare consideration of public viewpoints (Smith,

2013). There is a clear tension here as I will be drawing upon expert theoretical conceptualisations to make sense of my findings, which risks reproducing the power relations I have been critiquing. I will return to address this more fully in section 4.5.2. Here, I will use judgemental rationalism to attempt to ameliorate this tension by privileging non-hegemonical qualitative literature that positions the public as experienced and embodied experiences in understanding health inequalities (Grace et al., 2008; Mackenzie et al., 2017) (see section 1.4.5).

This debate also has pragmatic implications, through indicating how resources should be allocated within PMH research, policy and intervention. For those who think the public do not understand the SDH and the way in which they cause health inequalities, there are education campaigns (Smith & Anderson, 2018) and those focusing on an individual's responsibility to change their behaviour (Garthwaite et al., 2016). For those who believe the public do understand the SDH and how they lead to health inequalities, these campaigns are unnecessary and are thought to widen these inequalities (Smith, 2013). As well as causing this harm, these campaigns are ineffective in relation to reducing health damaging behaviours, because individuals have been shown to resist identification with a stigmatised role (Wilson et al., 2013) and therefore would not apply the information to themselves or change their behaviour as a result.

1.4 Overview of Research into Public Conceptualisations of Mental Health

As noted above, research into the SDH often uses 'health' to refer to both physical and mental health. Therefore, it is unclear whether the public conceptualises mental health differently to physical health, particularly in the context of the social determinants.

1.4.1 Public Conceptualisation of what Constitutes 'Mental Health'

Mental health can be conceptualised in many different ways. The SDH as an explanatory causal framework does not posit what mental health actually is. For example, 'mental health' could correspond to experiences that reside in the individual body, brain or mind or alternatively this experience could reside

relationally, in the interface between individuals and others, or within the interface between individuals and power structures, replicating oppressive/privileged dynamics (Afuape & Hughes, 2015). Research methodology and epistemology impacts how mental health is constructed (Larsson, 2013) and the majority of research approaches it from an intrapsychic standpoint (Rapley, 2011).

Quantitative psychological research has asked participants whether they would classify unusual or distressed behaviour, thoughts and feelings as 'mental illness'. For example, Link et al., (1999) distributed a survey to 1444 members of the US public who were randomly allocated one of five vignettes, depicting symptoms of psychiatric diagnoses including Depression and Schizophrenia and a subclinical 'troubled person'. Participants conceptualised the first four vignettes as describing 'mental illnesses', indicating a biomedical conceptualisation of mental health problems that is categorically different from 'normal' distress that the used to conceptualise the fifth vignette. This has changed substantially over time. Star (1955) conducted a survey with over 3000 members of the US public incorporating six vignettes of symptoms that corresponded to psychiatric diagnoses. Only one vignette, described to depict the symptoms of Paranoid Schizophrenia, was identified as a 'mental illness' by the majority of participants. This change is likely to be related to concerted efforts to promote illness understandings in Western countries in recent decades (Read et al., 2006), and that more funding has been given to studies exploring biology, partly because the profit-producing psychopharmological industry can afford to fund this and subsequently further profits from the findings, which are then published in high impact journals due to a more rigorous methodology and consequently regarded as the most established evidence-base (Lebowitz & Appelbaum, 2019).

Qualitative research into health generally, rather than physical or mental specifically, has identified that is a complex concept, and that people struggle establishing what they believe it actually is before they can consider its causes (Blaxter, 1983; Glover et al., 2020). This research body similarly concludes the public predominantly conceptualise mental health as a biomedical phenomenon. L'Hôte et al (2018) interviewed 36 individuals who were described to be demographically representative of the UK population. Health was understood by the participants to constitute the

absence of illness and the presence of happiness, which itself was defined as the absence of problems. Structures that react to ill-health, both physically and mentally, were foregrounded (i.e. the NHS), which resulted in participants struggling to conceptualise what could prevent poor health. Health was attributed a clear moral dimension, in that good health was to be independent from direct reliance upon social or state support, which aligns with current neoliberal social norms and public policies.

While these findings are helpful, neither psychological research into mental health or in-depth, SDH research into health generally with the public explicitly determines how mental health is conceptualised.

1.4.2 Public Conceptualisation of the Causes of Mental Health

Angermeyer and Dietrich (2006) conducted a review of research regarding the public causal beliefs of 'mental illness' from 1999-2004, incorporating 33 national and 29 regional studies from America and Europe, and concluded that the public's causal beliefs vary. L'Hôte et al (2018) summarise that the public hold a range of different understandings that are differentially drawn upon depending on context. As noted elsewhere, the dearth of literature regarding SDH (Parry et al., 2007) is reflected here, in that this literature does not include the SDH and so does not contribute to understandings of public perspectives regarding structural causes. The common causal beliefs and influencing factors illustrated in this research body will be outlined below.

1.4.2.1 Common Causal Beliefs

When presented vignettes denoting experiences that depicted symptoms in the diagnostic categories of Schizophrenia and Depression, in the absence of labelling these with the psychiatric diagnosis, the public identify primarily social causal factors, namely stress as the primary causal factor, and individual biological causes as the secondary (Angermeyer & Dietrich, 2006; Link et al., 1999). Link et al (1999) found that participants blended the psychosocial with biological factors. Bignall et al (2015) presented 34 participants in focus groups with 19 vignettes that correspond to symptoms of DSM psychiatric diagnoses. Using grounded theory, they identified 12

different casual beliefs used by participants. Overall, the most endorsed causal belief was individual characteristics such as laziness. This was followed by family (not elaborated further), normalisation (rather than pathologisation), spiritual and then biological causes.

1.4.2.2 Impact of Diagnostic Label

Whether a psychiatric diagnostic label is provided alongside or instead of the description of behaviours influences the causal beliefs the public draw upon to understand each mental health problem. Reviews have concluded that the majority of this research is conducted with the labels Schizophrenia and Depression (Angermeyer & Dietrich, 2006). This review identified that contradicting to when presented without the label, the presence of the diagnostic label of Schizophrenia lead to the public endorsing biological causal mechanisms as primary. For Depression however, psychosocial causes remained most endorsed when the label was introduced to the vignette. Pescosolido et al (2010) provided vignettes depicting symptoms of psychiatric labels to members of the public in 1996 and 2006. They identified that for Depression, in 1996 life stress was endorsed almost frequently as the causal belief, whereas in 2006 chemical imbalance became the most endorsed. For Schizophrenia, biological causal beliefs were the most endorsed at both points. Schoermus et al (2014) identified multiple causal beliefs were endorsed including biological, stress and childhood adversity for both Depression and Schizophrenia.

1.4.2.3 Historical Socio-Cultural Context

In their comparison study Pescosolido et al (2010) identified that overall, the publics endorsement of a biological cause increased over time, alongside the adoption of psychiatric labels to denote these experiences. Over this period, psychosocial and moral causal beliefs were found to decrease. Schomerus et al (2012) conducted a review of 16 studies globally that themselves conducted time trend analyses, collectively covering 16 years, and also conclude that the publics belief in biological causes of mental health problems increased by approximately 20%. However, they conclude that psychosocial beliefs, namely stress, remained at high levels and did not decrease for either Schizophrenia or Depression, suggesting that the public draw upon both biological and psychosocial causes for mental health problems.

1.4.2.4 Impact of Participants Social Locations

Reviews of this research have found that participant socio-demographic characteristics influence which causal beliefs they draw upon (Angermeyer & Dietrich, 2006). Bignall et al., (2015) examine frequency of causal beliefs of 19 vignettes in relation to participants ethnicity. They conclude that Hispanic participants endorse spiritual causal beliefs most, whereas Hispanic and Asian American participants were the most likely to normalise the vignettes. The white participants were the most likely to draw upon a history of trauma as a casual belief. Ventevogel et al (2013) similarly identified that culture influences how one conceptualises unusual, distressed and distressing thoughts, feelings and behaviours, and subsequently what causes these. They conducted focus groups with participants they selected to be representative of their local communities in four different regions in three African countries (South Sudan, Democratic Republic of the Congo and Burundi). They asked their participants to ‘talk about problems and illnesses that manifest through problems in thinking, feeling or behaving’. Participants did not use Western psychiatric diagnostic terminology to denote these experiences, but did classify certain groups of experiences thoughts, feelings and behaviours that differed from normal. The causal belief differed for each experience. All four regions endorsed what the authors call supernatural causes, including disturbed ancestral spirits, and natural causes, including psychoactive substances and infectious diseases, for experiences characterised by aggression, suspicion and/or talking nonsensically. Experiences characterised by sadness or social withdrawal were most commonly thought to be caused by psychosocial causes, such as bereavement, or structural causes, such as experiencing poverty.

1.4.3 Methodological Limitations

This research into the public’s causal beliefs of mental health problems indicates that multiple causal frameworks are drawn upon by different people in different contexts. These are influenced by the inclusion of a psychiatric diagnostic label and change according to time and place. The validity of these findings are strengthened as they take into account the social context of the individual depicted in vignettes, by changing gender, ethnicity and education level, and randomly allocating participants different vignettes (Bignall et al., 2015; Link et al., 1999; Ventevogel et al., 2013).

However, there are significant issues with this research that impacts the conclusions that can be drawn. This causal belief literature is not situated within a structural, macro-level conceptual framework, and I believe it is not fit for purpose to transpose from its original intention to PMH. This is largely due to methodological constraints. The majority of this research utilises questionnaires or surveys where participants are presented with statements and asked to rate agreement on a Likert scale. The statements on these are mostly predetermined by either the authors directly or indirectly through their selection of a standardised questionnaire (see Bignall et al., 2015; Ventevogel et al., 2013 for notable exceptions). As these are often not framed from a structural standpoint, they do not include structural statements such as institutional discrimination, and so the public endorsement of structural causes such as SDH cannot be interpreted. Therefore, we cannot conclude that these are the only frameworks that the public use, or that the public would use these frameworks if asked openly, as they have been primed and constrained by the causal statements provided.

These predetermined statements are reductionist, complex and distressing social, structural and relational factors are minimised statements such as 'workplace stress', 'traumatic experience' and 'adverse childhood experiences' which can actually be understood to obscure an individual's causal understanding. For example, 'workplace stress' could be conceptualised from the dominant Stress-Vulnerability model (Harper et al., 2020; Zubin & Spring, 1977) whereby the experience of this personal adversity triggers an underlying, predisposed individual pathology, leading the development of a mental health condition. Alternatively, 'workplace stress' could also be understood from a structural causal lens, leading to difficulties conceptualised as relational that re-enact discriminatory institutions on the micro level (Afuape & Hughes, 2015). Thus, it is difficult to conclude from this research alone what conceptual frameworks the public are drawing upon, let alone what influences different frameworks being used at different points.

Similarly, the studies that use psychiatric diagnostic labels to depict of unusual or distressed experiences, without space to deconstruct this, further restricts the conceptual frameworks that can be drawn upon. For example, as demonstrated

above, participants are more likely to attribute biological causal mechanisms when the label Schizophrenia is provided rather than a description of the associated unusual behaviours and thoughts (Angermeyer & Dietrich, 2006). As argued, targeted campaigns have aimed to increase these association (Read, 2005). However, this contrived/arbitrary scenario may not reflect anything that relates to actual experience. For example, a participant who ascribes to the Muslim faith may conceptualise the unusual perceptual experiences that they may come across in daily life as Jinn possession and may never use the term Schizophrenia or biological causal mechanisms to make sense of this in a naturalistic setting but may select this when presented with a limited list of causal options.

1.4.4 Epistemological Limitations

The research appears to, uncritically and without reflection or acknowledgement, hold a realist ontological and epistemological position, thereby implicitly assuming the psychiatric conceptualisation of mental health represents a real, underlying entity existing within individuals that can be correctly identified (Bentall, 2004). This narrows and constraints the research, which can be understood as investigating whether the public understand or agree with the authors pre-existing assumptions, narrowing space for the public to share their own ideas spontaneously. Realist ontological positioning further reinforces elitist and expert models, through assessing whether the public have 'mental health literacy' which essentially means to conceptualise mental health to be a 'disease like any other' (Jorm, 2000). By positioning any conceptualisation that does not align with the psychiatric model as 'incorrect', this may be contributing to testimonial injustice (Fricker, 2007) through reinforcing the narrative that the 'lay' person, those without socialisation to the medical model through formal training, does not possess the correct knowledge. This serves to silence any alternative conceptualisations and so can only reinforce the psychiatric as correct. This is additionally problematised when using the label Schizophrenia from this realist position, which even amongst professionals who adhere to medicalising conceptual model of 'psychosis' is one of the most contested diagnoses, having been argued as invalid and unreliable as a categorisation (Boyle, 1990). We cannot draw conclusions as to whether the public correctly understand

what a construct is and what causes it when this correct understanding is not agreed upon.

1.4.5 How the Public Conceptualise the Causes of Health

To address some of these issues, we can draw upon in-depth, qualitative, sociological literature that examines how the public understand the causes of health inequalities. In order to include this methodology, I had to widen my literature search to incorporate health generally, as majority of these studies refer to both physical and mental health. These studies therefore implicitly frame mental health from a psychiatric diagnostic standpoint. Whereas the above research is international, these studies are from a UK context and are explicitly conducted from an SDH lens, allowing space for a structural causal interpretation. This research similarly illustrates that the public draw upon multiple causal conceptual frameworks, albeit including structural.

L'Hôte et al (2018) identified the public predominantly draw upon an individualistic understanding, which was conceptualised to include both psychosocial and biological factors. They utilised interview methodology and grounded theory to conclude that the individualistic conceptual framework comprised several main models. Health was mainly understood to be caused by lifestyle and behavioural choices made by the individual, which were determined due to individual discipline and willpower. This included mental health problems, in that with the right mindset people could be happy and so good mental health was conceptualised as the outward manifestation of strength of character. This indicates the moral dimension to health, as poor health and subsequent burdensome use of resources was understood as the result of an individual failing, in line with neoliberal ideology. Any exceptions that appeared to violate these assumptions were explained as a result of genetics or fate. Through their exploratory questions, L'Hôte et al (2018) conclude that the public also draw upon a structural causal conceptual framework. They identified that it was less often drawn upon, was more unstable in response to questioning and so utilised in a simplistic manner. For example, they interpret that while participants articulated how stress led to mental health outcomes, and that stress could be caused by structural inequalities such as poor housing, participants

would revert to an individualistic health narrative to conceptualise health promotion and prevention, in that individuals should simply remove themselves from stressful situations and otherwise will themselves to make healthier choices in order to become well. Discrimination was conceptualised by participants as a consequence of health inequalities, such as the stigma associated to being diagnosed with a psychiatric condition, rather than a cause.

There are ethical implications these conclusions. Suggesting that the lay public do not have adequate understanding of the SDH, from the benchmark of a professional understanding, simultaneously serves to privilege the expert position as 'correct', and devalue the public knowledge, which contributes to epistemic injustice (Fricker, 2007), as above described. Rather than a lack of knowledge, these findings may indicate that the public hold complex and multiple narratives to conceptualise the causes of health, and that certain social processes may have led to these participants privileging an individualistic health narrative at this time. Other qualitative research provides evidence for this premise. This research in the UK is typically carried out with people who experience socio-economic deprivation (Ridley et al., 2020). There appear to be complex and nuanced processes occurring that constrain or facilitate the narratives that individuals draw upon to understand the causes of health inequalities. This research typically asks people who reside in a deprived area how living there impacts their health, or, presents participants with evidence of health inequalities, therefore providing a structural causal explanation, and asks them to discuss this (Smith & Anderson, 2018). These represent key differences from the psychological literature, by asking people about their own experience rather than hypothetical others, and presenting predetermined causal statements that are structural rather than individualised. Taken overall, this research body largely highlights the public's understanding corresponds with academic understandings, that structural causes, such as unequal access to good quality housing and education, are mediated to health outcomes through interpersonal psychosocial processes, for example the impact of poverty leading to feelings of stress, fear, isolation, powerlessness, hopelessness and low self-esteem (Smith & Anderson, 2018). These, in turn, impact upon behavioural and lifestyle choices, such as smoking and consuming alcohol at the end of a complex causal chain, through providing survival strategies such as short term de-stressing and escapism

(Davidson et al., 2006; Mackenzie et al., 2017). This complex causal conceptualisation is evident across multiple studies assessing 'health' generally (Backett-Milburn et al., 2003; Bolam et al., 2006; Cattell, 2001; Dolan, 2007a, 2007b; Garthwaite & Bambra, 2017a; Grace et al., 2008; MacDonald & Shildrick, 2013; Mackenzie et al., 2017; McGarrol, 2020; Morrow, 2000; Parry et al., 2007) and mental health problems specifically (Barnes et al., 2016; Mattheys et al., 2018; McDermott et al., 2018; Sah et al., 2019; Watson & Douglas, 2012).

These findings conclude that there are also multiple influencing factors as to which causal frameworks the public draw upon at different times. One influencing factor I found notable was emotions. For example, some studies identified that when confronted with a health inequality they may experience, participants could deny a structural cause in favour for individualist explanations that foreground choice, which was concluded to this afford the individual control which may manage fatalistic anxiety (Airey, 2003; Backett-Milburn et al., 2006; Bolam et al., 2004; Macintyre et al., 2005; Peacock et al., 2014; Popay, et al., 2003). In other studies, individuals discussed structural causes in reference to hypothetical others from the same area rather than to themselves directly (Airey, 2003; Backett-Milburn et al., 2003; Bolam et al., 2004; Peacock et al., 2014; Popay et al., 2003). Peacock (2014) labels this process 'othering' and explains this allows the self to be positioned in the non-judgemental, safe place of not experiencing an inevitable and fatalistic inequality, while also affording space to make sense of their own painful experiences that are safely projected onto the 'other'. When confronted with health inequalities in focus groups, participants did discuss rather than deny structural causes (Davidson et al., 2006, 2008; Hodgins et al., 2006; Parry et al., 2007; Rind & Jones, 2015). Whilst not highlighted directly by the authors themselves, I interpret this in the context of the other findings as collective solidarity that may act as partial protection against the strong, negative affect that Davidson et al (2006) note the participants displayed.

In summary, research presents a complex picture as to how the public understand mental health, health inequalities and their causes, which appears related to the research methodology, epistemology and discipline (Garthwaite & Bambra, 2017; Mackenzie et al., 2017; Popay et al., 2003; Smith, 2017). Quantitative psychological research suggests the public conceptualise individualised spiritual, psychosocial and

biological causal factors and which they draw upon is dependent upon time, place and whether a health framework is introduced through the provision of psychiatric diagnostic labels. Qualitative sociological research suggests the public primarily utilise a structural understanding in line with the SDH when considering their own health, but that affective defences can detract focus to individualised causes which are in the individual's control. However, both methodologies imply that participants may acquiesce to predetermined causal statements.

1.4.6 Intersectional Critique

This qualitative literature also has limitations. Namely, intersectionality and different social locations are overlooked, conclusions are drawn in relation to economically disadvantaged groups in the UK context or to the public generally which problematically centres privileged locations as the norm, by not explicitly reflecting whether participants conform to these norms and the impact of this. Therefore, the production of knowledge continues to be perpetuated from a White, Patriarchal, Heteronormative, non-disabled context in the UK (Cole, 2009; Hankivsky & Christoffersen, 2008). Disability particularly has been overlooked within research which largely does not address the disability status, in diagnostic terms, of the participants (Cole, 2009). L'Hôte et al (2018) is an example of this, recruiting a sample representative of the UK context but without mentioning disability status which should have constituted 20-25% of their sample in order to be representative in this respect (DWP, 2018). Public health interventions that are researched on the general population are assumed to apply to people with impairments (Berghs et al., 2016). This represents a historical pattern of structural violence whereby disabled individuals are silenced and treated as an afterthought, for example as seen that there has been a limited literature that incorporates both public health and disability rights frameworks (Berghs et al., 2016). The above research then inadvertently replicates the dynamics of the structural oppression through the silencing of disabled voices.

1.4.7 Disabled Social Location

The above could be argued for many different subjugated groups. It was during the beginning of the COVID-19 pandemic that I had to re-design the research. I wanted

to be aware of how the pandemic and public health responses were impacting health and social inequalities and so spent time researching this. The significant exacerbation of inequalities faced by the disabled community as a combined result of both the necessity to 'shield' and the disproportionate impact of public health responses (Sisters of Frida, 2020; ONS, 2021) disturbed me and led to deep reflections on my own internalised ableism and subsequent role in upholding these narratives in seemingly innocuous, everyday interactions (Afuape, 2011). Further investigations highlighted there is a dearth of public health literature that focuses on the experience of disabled individuals (Berghs et al., 2016), and what is available discusses the unequal impact of structural interventions, such as welfare cuts (Duffy, 2013). Hence, I decided privilege the lived expertise of disabled members of the general public in this research. All members of the general public are situated within multiple intersecting social locations. While not the focal point of this research, I aim to normalise research with the general public that highlights without focusing primarily upon marginalised social locations they may be positioned upon. It is unfortunately beyond the scope of this research to fully examine the how structural discrimination impacts people with disabilities and their lived experience. This is a powerful, important and moving body of literature. However, in the aim of normalising disabled people as 'members of the general public', this is seen as justifiable.

In the SDH literature, disability, here the presence of a diagnosis, is conceptualised as both a health inequality and a cause of health inequalities (L'Hôte et al., 2018). I have conceptualised disability as a social location here (Oliver, 1983), a group that experience health inequalities. This conceptualisation is in line with a critical realist epistemology and originates from a social model conceptualisation. These frameworks distinguish the notion of 'disability' from that of 'impairment'. An impairment refers to an organic problem or functional limitation of a body, but the 'problem' is situated as within a society that dis-ables people through restricting their ability to function within a normal range due to social barriers (Oliver, 1983; WHO, 2011). This distinction is made so that these biological and social difficulties can be disentangled and approached separately (Josewski, 2017). I therefore use this term as a social location to understand that individuals with physical impairments are structurally marginalised through the processes outlined in section 1.2.4, and that it is this process that leads to the additional health inequalities faced by the disabled

community. In line with intersectionality, I am not conceptualising disability as a binary category in which one is either disabled or abled, but rather than this represents a spectrum of power and privilege (Hankivsky & Christoffersen, 2008).

1.5 Summary of Research Justification

I have outlined some of the limitations to existing research, of which I aim to address here. All of us live mental health, we all have expert knowledge on the subject, contrary to professional colonisation. There is a call for research that assesses the public causal beliefs of mental health difficulties specifically, rather than health generally, utilising a methodology that allows for open ended exploration (Hinshaw & Stier, 2008), which is lacking in current literature. This methodology can create space for a live understanding of multiple causal frameworks that each individual may use to understand mental health, alongside using psychological understandings of process to consider what may influence different conceptualisations being drawn upon at different times. I will both allow space for participants to spontaneously bring and explore different conceptual frameworks in the absence of predetermined statements to explore what is drawn upon initially and naturally, as in L'Hôte et al., (2018). I will then provide predetermined causal frameworks in order to provide adequate opportunity to demonstrate their opinions, ensuring I do not conclude individuals do not possess knowledge that they have not been provided adequate opportunity to consider without constraint.

I did not want to replicate exclusionary research that reifies white, heteronormative, patriarchal, non-disabled hegemonical understandings, as I aim to use the power afforded to me through my professional training and status to disrupt these hegemonical systems. There is a dearth of public health research that utilises the perspectives of the disabled community (Berghs et al., 2016), a group who have experienced sharply exacerbated health inequalities as a result of the COVID-19 pandemic and the public health responses to this (Sisters of Frida, 2020; ONS, 2021). Diversity is situated at the margins of society, with homogeneity at the centre, meaning minoritised individuals have the 'widest view' of society and are therefore best situated to understand society as a whole (Afuape, 2020). Given the unequal

impact of the pandemic, I believe it is a key moment in history to listen to the expertise of the marginalised disabled community to progress PHM because, as we have seen, inventions designed solely by professionals can be problematic (Sisters of Frida, 2020). It is only through liberation of the most marginalised that we can liberate everyone (Kagan et al., 2019), a philosophy that applies well to public health interventions.

1.6 Research Question

The study aims to explore how disabled adults in the UK understand mental health and it's causes alongside what processes influence which causal frameworks are utilised at different points. The main research question is:

how do disabled members of the general public understand mental health, and what processes influence this?

2.0 METHODOLOGY

This chapter outlines the construction and position of the research, along with the procedures utilised.

2.1 Epistemological Approach

As defined in section 1.1.1 ontological realism allows me to approach the data from the assumption that there is a material reality and the participants' talk reflects this (Pilgrim, 2017). I explicitly position myself as actively constructing the research conceptualisation, design and analysis, so that I own how my assumptions and social position interact with the research process (Malterud, 2001), and will be modest about any claims made. There is the risk that I could analyse the findings inconsistently through selective relativism, meaning to choose to question some claims whilst ignoring others (Harper, 2004) which could perpetuate oppressive ideologies by negating to critically appraise them and therefore presenting them as factual. I have attempted to manage this conflict through positioning 'real' and constructed' neither as a mutually exclusive dichotomy or as homogenous categories (Burr, 2002), but that both material reality and the influence of power structures can simultaneously constrain and facilitate participants understanding of mental health and its causes. This dual emphasis that incorporates an explicit critique of the awareness of how political power relations and structures maintain and constrain different forms of understanding allows space to disrupt these systems (Sullivan & Forrester, 2018). For this purpose, the political context has been explicitly introduced in section 1.2.7. As in section 1.1.1, I am using judgement rationalism to justify privileging the interpretations that allow space for subverting oppressive discourses as I believe this best meets the PMH aim of social justice.

I selected Thematic Analysis (TA) as it has no embedded theoretical or epistemological alignment and so can be utilised from a CR position. I utilised Braun and Clarke's (2006) TA conceptualisation, detailed in section 2.3.6. This can allow explicit consideration of the constructed politicised as well as lived reality of social

locations and mental health to be explored. I have utilised an inductive approach in attempt to identify freely the conceptual frameworks the participants use, rather than through the lens of particular professional-guiding theories or frameworks such as the SDH. Foucauldian Discourse Analysis and Narrative Analysis may have addressed the research question, however on balance I decided neither allowed enough upon material reality than is appropriate for subjugated groups or the experience of health inequality (Willig & Rogers, 2017). Grounded Theory could also be considered an appropriate method to address my research question, however, when attempting to utilise an intersectional lens, the generation of a model is not the most appropriate aim.

2.2 Intersectionality in Research

There is a dearth of guidelines regarding incorporating intersectionality into research (Bowleg, 2012; Smith et al., 2015). Intersectionality rejects the assumption of homogeneity of categories, instead positioning them as fluid, heterogenous and because we all occupy multiple simultaneously, inappropriate to separate and analyse independently (Bowleg, 2012). Understandably, this poses challenges when combining with methods that assume within category homogeneity. I therefore had to manage the conflict of conducting good quality TA whilst ensuring I do not assume these individuals, positioned upon the social location of disability, represent a normative experience (Cole, 2009). One way that has been suggested to manage this is to seek and value maximum variation across participants, in relation to other social locations, in order to incorporate intersectionality's assumption of heterogeneity within categories (Dean et al., 2017). Fortunately, this was able to be achieved with the current sample, representing diversity across social locations such as age, gender, ethnicity, sexuality and geographical location. Through positioning the social location of disability as a gradient and not a binary (Smith et al., 2015), large within category variation was also achieved through diversity of conditions, including visible and invisible disabilities, a spectrum of severity including life-limiting conditions, daily support needs and independently manageable conditions, physical and mental diagnoses (see table one).

Relativist epistemologies assumes 'language' to denote a form of social action through which reality is constructed in interactions, and therefore is used as a tool to deconstruct reified concepts (Pilgrim, 2019). The act of naming can be understood as violent in itself, through reifying a category which involves imposing a hierarchy, identifying an 'other', and restricting available constructions of lived experience through creating the binary of being assigned to the group or not (Spivak & Derrida, 1998). Uncritically applying well-established binary categories to classify participants and to interpret their experience fails to challenge structural and interpersonal power dynamics (Hankivsky & Christoffersen, 2008). When considering how best to incorporate intersectionality, I considered whether to recruit a specific intersection of multiple social locations as has been suggested elsewhere (Bowleg, 2012; Quinn et al., 2019). However, mindful of the oppression that binary categories can impose, I decided to constrain inclusion criteria to the one social location of disability.

Public health researchers have been called to incorporate intersectionality into their analysis to better understand the complex, cumulative and converging experiences that shape health (Hankivsky & Christoffersen, 2008). They recommend doing this by continually asking "who has power and control over whom in this interaction?", which I have incorporated into the both the semantic (what the participants explicitly communicated) and latent (ideologies and assumptions underlying the participants speech) levels of analysis (Braun & Clarke, 2006). To answer these required I continually reflect upon my own 'institutionalised cultural patterns of interpretation and evaluation' to attempt to minimise the influence of my own assumptions, which have the risk of actively subjugating through exploitative and tokenistic use of participants talk (Khanom et al., 2015). See Appendix A as an example extract from my reflexive accounts.

2.3 Method

2.3.1 Ethical Considerations

Ethical approval was received from the UEL Ethics Committee (Appendix B). Multiple complex ethical issues arose in the consideration of conducting research with a

marginalised community of which I am not a part of. These are explored in-depth in section 4.5.2. Participants confidentiality was protected by anonymising transcripts through removing identifiable information included names, places and institutions, and allocating pseudonyms. The risk of conducting online interviews was managed using an encrypted, university approval software, Microsoft Teams. Risk was managed through asking participants abstract and general questions rather than about their personal experiences or mental health, allowing participants the non-coerced option as to whether to disclose. Further support resources were included in the Debrief Letter to manage risk (Appendix C).

2.3.2 Data Collection

I utilised semi-structured interviews due to the balance of targeted questioning, flexible follow-up and in-depth exploration. This ensured I could consider participants spontaneous causal frameworks, processes influencing the negotiation of multiple frameworks, alongside ensuring the structured opportunity to discuss all the causes arose from my literature search. Focus groups may have been appropriate to address the research question. However, given that some areas of the disabled community are small, for example online communities of those with rarer conditions, I felt this might risk participants confidentiality and potentially restrict what they felt comfortable to share. I produced an interview schedule following the early literature reviews and discussions in supervision (Appendix D). Inevitably, my skill, refinement and focus with follow-up questions developed as the interviews progressed, particularly in relation to the complex, abstract conceptual questioning. I decided not to complete a pilot interview with a participant who identified as disabled, given the time constraints imposed by the pandemic and changing topic, and possibility that recruitment could take substantial time. I instead piloted the interview with friends and colleagues as practice to refine my questioning.

Microsoft Teams software has a function that transcribes recorded meetings. These transcripts were saved to my confidential, password-protected University Microsoft account, downloaded through a VTT cleaner and opened using Microsoft Word. I then checked the transcription against the recordings to ensure accuracy. I added punctuation to increase readability and to attempt to represent participants talk as I

heard it. Recordings will be erased when the thesis has been completed and examined. Transcripts will be stored on a private, password-protected computer and will be erased after 5 years. My supervisor and the researcher examiners can request access to the anonymised transcriptions.

2.3.3 Recruitment

A flyer was developed to advertise the research, identifying the inclusion criteria. The first criteria was for those who identify as disabled. This request for self-identification had two reasons; that it would not be necessary to 'evidence' one's disability, for example through receipt of any related benefits, and as my write up would position participants as disabled it was vital to ensure participants were comfortable being labelled as such. This aimed to minimise the harm of imposing violent binaries within the researcher-participant relationship. The broad inclusion criteria of 'disability' was selected in line with the United Nations Convention for the Rights of People with Disabilities, this meant that individuals with both physical and mental health diagnoses participated. I allowed for this in order to prevent imposing my personal conceptual framework of mental health upon participants. The second inclusion criteria was for adults residing in the UK. The age was to minimise risk as children are considered vulnerable and the topic is potentially distressing, and UK residence for some homogeneity of socio-political context. The final inclusion criteria was for participants to be members of the general public rather than health-allied professionals, which I established upon screening.

Eight to twelve participants is suggested as the minimum required to reach theoretical saturation in qualitative analysis (Guest et al., 2006). A range of recruitment strategies were adopted to ensure this was possible, particularly given that I am not personally connected to the disabled community. The flyer was disseminated through the social media platforms Twitter and Instagram using hashtags linked to the disabled community and PMH. I contacted three national third sector organisations and requested they disseminate to their mailing lists, two of which kindly supported with this. Finally, I contacted non-health, Non-Governmental Organisations that friends are employed by and disseminated through their

employee disability networks. At least one participant was recruited through each outlet.

2.3.4 Procedure

The disseminated flyer invited interested individuals to contact me for further information. Everyone that contacted me to inquire about the research was sent an Information Sheet (Appendix E). Once participants had consented to participate and I had established whether they met inclusion criteria, they were emailed a Consent Form (Appendix F). Interviews were held virtually using Microsoft Teams. I conducted all interviews from my home in a quiet, private room. All interviews were recorded on Microsoft Teams, for which consent was gained at the beginning. I offered participants a space to ask questions about the research and put into place some accessibility needs (for example, turning off cameras, arranging a time point at which cease, one interview took place over 2 30-minute sessions for this purpose). The total duration of each interviews was between 66 and 123 minutes. Following the interviews, participants were emailed debrief information, a gift voucher and a voucher claim form.

2.3.5 Participants

Ten individuals participated, their self-defined demographics are summarised in Table One. As illustrated, the participants represent diversity across multiple social locations. The participants ages ranged from 22-74. Five participants identified as female, three as non-binary and two as male. Five participants were in paid employment at the time of their interview, five were not. All participants had received physical health diagnosis. Six participants also shared lived experience of mental distress or mental health conditions. Participants represented a range of ethnicities. Five participants identified as White British, one as White European. One participant identified as Pakistani, one as Chinese, one as British Asian and one as Arab mixed race.

Table 1

Participant demographics

Pseudonym	Age	Gender	Ethnicity	Employment Status	Disability
Maggie	N/K	Non-Binary	White British	Self-employed	Muscle Wasting Disease
Jules	44	Female	White British	Retired due to long term health condition	Myalgic Encephalomyelitis (ME)
Sukhi	22	Non-Binary	Arab mixed race	Full time student	Disability/learning difficulty and mental health
Agnes	74	Female	White British	Part time employed	Sensory disability and mental distress
Misha	27	Female	British Asian	0-hour contract	Cerebral Palsy
Liena	26	Female	Chinese	Student and in receipt of disability benefits	Physical and previous mental health diagnosis
Jamie	28	Non-Binary	White European	Employed	Irritable Bowel Syndrome and Borderline Personality Disorder
John	58	Male	White British	Student and volunteer	Long term physical and mental health conditions
Kimberly	29	Female	White British	Employed and student	Life-limiting genetic syndrome
Zahir	43	Male	Pakistani	Full time carer	Heart condition and historical psychosis

2.3.6 Data Analysis

Analysis of the ten interviews followed Braun and Clarke's (2006) six step approach, highlighted below.

- a) Familiarisation with the data. I checked the transcripts back to the recording to make corrections which required close examination of each interview. During this phase I kept a reflective log of themes and issues that stood out to me non-systematically. This was helpful to highlight my own biases, including my initial privileged of oppressive causes over health-related processes.
- b) Generating initial codes. I initially read the transcripts, summarising the smallest units of meaning. In line with inductive analysis, these codes were closely linked to the content of the text.
- c) Searching for initial themes. I began with organising the codes into meaningful groups within and across transcripts. This process allowed the condensing of codes. I then returned to the transcripts in NVIVO software with the reduced codes to allow more efficient re-organisation. I also utilised various colour coded maps using post-it notes to allow visual conceptualisation and experimental reorganisation of the themes and subthemes (Appendix G).
- d) Reviewing themes. I then revised the themes in order to check that they were appropriately distinct and internally consistent (Patton, 1990), which involved merging of themes and the generation of subthemes.
- e) Defining and naming themes. I defined the themes ensuring the broad categories could be succulently summarised and that each was representative of the whole data set. This is an iterative rather than a staged process and I cycled through the steps multiple times in order to refine the themes.

- f) Producing the report. I attempted to select key extracts that were fairly distributed across participants and that demonstrated the narrative of the findings within and across themes.

2.3.7 Evaluative Criteria

In line with Braun and Clarke (2006)'s guidelines for good quality research, I engaged in personal and epistemological reflexivity throughout the research process. Consideration of my own social locations and the impact on the participants and research process is addressed in section 4.5.2 and Appendix A. I will return to appraise the quality of the research in section 4.5.4 utilising Spencer and Ritchie's (2012) criteria of contribution, rigour and credibility.

3.0 ANALYSIS

3.1 Introduction and Overview

This section presents the constructed themes. Table Two outlines the four superordinate themes and corresponding subthemes. Whilst I have actively constructed the themes and therefore my own assumptions are deeply embedded, I have attempted to ground these in the participants own words and have utilised extracts from their interviews to illustrate how I interpreted how they made sense of mental health. This will be explored in more depth in chapter 4.

The first theme focuses on the process of utilising health language, how this influenced the participants conceptual models drawn upon. The second theme incorporates the ways the participants made sense of experiences that indicated a problem in comparison to 'normal' distressing experiences. The third theme includes the process of critical exploration of categorising, both into psychiatric diagnoses and into social locations. The final theme explores the multiple and complex causal explanations the participants drew upon. A key for the presentation of extracts can be found in Appendix H.

Table Two

Themes

Superordinate Theme	Subordinate Themes
“Mental Health’ Makes You Think Medical”	
“When Does a Normal Condition Become an Illness?”: Social Norm Violation	
“Walking on Dangerous Ground”: The Impact of Categorising	“The Labels Helped” Criticisms The Dangers of Questioning: “Not Being Heard”
Causal Explanations	Explanations for Everyone Embodied Explanations Oppressive Impact of Social Norms Institutional Explanations

3.2 Theme 1 – “Mental Health’ Makes You Think Medical”

This theme explores the process initiated through the terminology ‘mental health’ to introducing the interview. Eight participants are included in this theme, which incorporates both an implicit utilising of health frameworks and an explicit, critical analysis of the assumptions underlying this term. Four participants primarily used this framework implicitly, drawing upon assumptions as facts. One participant entirely discussed health frameworks explicitly, naming the taken-for-granted assumptions. Three participants drew upon health frameworks both implicitly and explicitly. These participants initially illustrated taken-for-granting thinking which progressed to an explicit analysis as the interview proceeded. I have constructed these variations under one overarching theme to demonstrate this overlap is normal because the everyday available language used to understand emotional wellbeing and distress utilises a health framework (L’Hôte et al., 2018; Link et al., 1999).

The below extract represents conceptualisation using a taken-for-granted health assumption. With the example of a broken leg, it is implicitly thought as fact that internal damage exists that can be made visible through medical scans that a medical professional can interpret. Without explicitly naming this, Misha is drawing upon the same framework to understand mental health. She appears to conceptualise low mood as originating internally, that could similarly be evidenced through a specialist scan. The conceptual model that mental health is akin to physical health, caused by internal, biological, deficit is treated here as fact.

There is a frustration as well like with physical health, you go to the doctor if you've broken your leg, you can see it, we don't all have access to MRI scans when we're feeling crap, to be able to have that scan to then show a doctor "Look, I am down". (Misha)

Of the four participants who drew upon the health model implicitly, doing so appeared to restrict the resources available to reason and explore mental health conceptually. This is likely because the assumptions are so deeply taken-for-granted that they are held unquestionably as fact which is therefore difficult to identify within oneself. One such example was that distressing or unusual experiences are illnesses which are made up of symptoms, an assumption that participants used to delineate psychiatric diagnoses from non-diagnostic experiences of distress. Below, Jamie represents a culturally prevailing example, whereby the identification of a physiological processes in association with mental health and its embodied experience is implicitly assumed to be both its cause and constitution.

I think where there is just this like much more physical feeling of something about it [Borderline Personality Disorder]. I self-medicated with abusing substances in the past that has helped my symptoms go away, so maybe there would be a medication out there that like does the same thing but in a better way[...] Which makes me feel like it is a bit more of this like physical thing as well, I think with mental health it is, I think no matter what you have, I think it is always physiological though. (Jamie)

Four participants were conscious the language of health restricted their thinking to notions of illnesses, problems and reactive treatments, whilst other terminology, such as “wellbeing”, is conceptualised more straightforwardly as different to psychiatric health.

‘Mental health’, I probably initially jump straight to mental health conditions, so I’d probably start thinking about Depression or Anxiety or things like that. When I think of it deeper, I think ‘why?’. Mental health is actually a really broad term, it means your psychological health, and that doesn’t actually mean an illness.[...] The term mental health makes you think of medical[...] I think it’s it kind of pushes you down a certain road and I don’t think it is....It’s such a different combination of factors but I think like the word ‘health’ actually trips you little bit. If someone said ‘mental wellbeing’, that’s positive to me[...] It’s another term for mental health, but I feel I wouldn’t have even thought about like diagnosis or doctors or hospitals. (Kimberly)

The three participants who used both implicit and explicit health talk, began to question their earlier taken-for-granted assumptions as the interview created space for deconstruction. An example explored by all three was the term “inherited” used to explain how difficulties “run in families”. Through critical exploration they subsequently made explicit the assumption that this denotes genetic causality but how in itself the idea of familial similarities elucidates very little about the cause of distress. It was identified that this assumption is deeply held due to the power of the pervasive health narrative and those who uphold for it.

I think you can see these things going through families as well, whether or not consciously or unconsciously they’re discussed as genetic and whether that’s environment or not, we don’t know. It’s just kind of fixed in my mind that maybe there is a genetic component. But genetics don’t have to define you [...] Part of the reason I believe part of it is like genetic is partly because medical professionals have told me this probably is an element and you can see it in families if they’ve got... but also that could just be environment,

families are more likely to have the same environment. Then you don't really know if it is the nature or is it nurture. (Sukhi)

These latter, more detailed explorations indicate that overall, participants did not hold a strong health model for mental health but more likely are influenced by everyday, dominant language for conceptualising mental distress.

3.3 Theme 2 – “When Does a Normal Condition Become an Illness?”: Social Norm Violation

Nine participants are included in this theme which is similarly constructed of contrasting conceptualisations. The four participants who utilised implicit health frameworks drew upon the idea of norm violations to explore when a normal distressing experience becomes a problem that warrants specialist understanding. These social norms are framed to include a clear, causal relationship that is implicitly understood by others. Five participants critically explored this, establishing that experiences are not abnormal but instead social norms are too narrow to clearly make sense of experiences. Violating these norms means others cannot implicitly reach this understanding, because they rely upon observable proximal rather unobservable distal causes, and literal rather than metaphorical language. These variations are included under one superordinate theme to illustrate the constant negotiation of social norms, represented in the extracts below.

When we mean psychiatric diagnosis, do you mean something more serious like Schizophrenia or do you just mean a normal experience like Depression? (Sukhi)

And because people, I think, are often afraid of something that seems different or unusual, then it's seen as abnormal.[...] We're all just people, and some people are fortunate enough not to be experiencing distress or trauma. But those who are, we're not abnormal. (Agnes)

I think 'normal' is societally defined and things that are considered irrational by people who are not subject to the same pressures as one culture would be 'normal' to people of another culture. (Liena)

The assumption that an experience warranted a psychiatric diagnosis when it breached normal societal expectations was taken-for-granted and not explicitly named. This abnormality was constructed of when a responding experience was classified as 'irrational'. This appeared to mean disproportionate to its cause, and when the cause was unobservable. Unexpectedly, this model was equally applied to more noticeably unusual experiences, such as those that could be diagnosed as Psychotic, and those more common diagnoses such as Anxiety and Depression, as well as non-pathologised, distressing experiences such as stress and loneliness. When an experience complies with social norms it implicitly aligns with a shared understanding without need for further exploration. This is illustrated below, where Jamie explains the distinction between normal and psychiatric Anxiety. They use the causal example of hospitalised parents, identifying that others would understand as normal to worry for their welfare. This enables a third party to implicitly draw a linear, causal relationship between the distressing event and the distressed response. Where the social norms have been violated, and thus the experience is abnormal for Jamie, is when the emotion of anxiety is coupled with a thought pattern and behavioural response that does not appear directly linked or proportionate to the causal event, in this example, an obsessive-compulsive response. Because an implicit, direct relationship can no longer be made by others, the experience is signalled as abnormal.

Anxiety. That's where you have so many irrational thoughts about the thing you're anxious about, like "my parents are gonna die if I don't do XYZ". That is not extreme worry. That's the way of thinking that is not your fault, obviously, and that will create a barrier to you doing things, day-to-day tasks for example, and that is a disability[...]. Someone who's really, really worried about that, yes, you could say that if someone who's mum's in hospital and is really worried all day that they might not be able to get things done that they would usually. But that to me is different, because they could explain that to someone who would get it whereas someone with Anxiety saying "if I don't do something

in this order, my parents are going to die” and it's just so much harder to say that to someone and then get someone to understand you and talk it through with you. (Jamie)

Participants talked about their own experiences of mental distress as understandable. These experiences were also discussed in relation to an identifiable, proximal adversity in the immediate environment, in which a direct, linear relationship could be drawn that was observable and therefore understandable to others. This is what constituted a socially normal response. Kimberly illustrates this with her explanation that delineates her own understandable anxiety, that she names 'situational' because the cause observable to others, from a diagnostic Anxiety which she names 'Chronic' because the cause is unclear and so the response disproportionate, violating an expected social norm. This abnormal Anxiety is implicitly associated with the presence of experiences conceptualised as “symptoms”.

I would never say I'm bad enough to say I've got Anxiety because I have it in a moment, and yeah I might not be able to sleep the night before, but that's not my whole life. I can step away from that.[...] I think the main difference is 'situational' [anxiety] is around certain situations. It's not a constant thing, whereas when I think of Chronic [diagnostic] Anxiety I do think of the symptoms that people put with that. Obviously you get anxious in a certain situation but if you have Anxiety that isn't actually part of the situation, that's just part of your everyday. (Kimberly)

The second group of five participants explained that even experiences that appear to violate social norms most significantly are also rational and understandable responses to adversities. These participants used the example of distal adversities, such as institutional racism, that are prolonged and not always directly observable to others in the immediate environment. Liena illustrates this, explaining that while it may not be clear to others, repeatedly being targeted by the police clearly and proportionately leads to paranoia, which she frames as rational due to the necessity of this for survival. This therefore frames the social norm as inadequate at

capturing distressing experiences because it only understands relationships to proximal causes, rather than the experience itself as inherently abnormal. Participants identified that individuals who fall outside social norms who are more at risk of experiencing these distal adversities, generating a double violation.

For people who perhaps are categorised as paranoid about, for example, the police coming to get them, I would see that as partially or mostly societally produced in the sense that people who are particularly targeted by the police or disempowered in society are more likely to be categorised as paranoid[...]And it's sort of a spectrum of things where if people have experienced something a lot, then I believe it's rational for them to make certain conclusions and make certain inferences from things that happen. (Liena)

Other participants explicitly explained how we have shared understandings through social norms, but these socially approved ways of understanding and communicating experiences of trauma are too narrow. As Agnes highlights, if we looked beyond the literal explanations of experiences that appear to violate shared understandings and the assumption of clear, linear, causality towards a more metaphorical causal relationship, others can also understand the unusual experience. She clearly frames this as normal, and the problem lies within prescriptive social norms.

You're re-experiencing that through things like voices or unusual experiences, but if that's just supposed to be an illness that you can treat with two, three drugs, it's just such a basic misunderstanding[...]I think it's because there's such a narrow idea of what's normal and how you express trauma and you give people sort of descriptions where people, for example, see themselves as the Queen that's immediately supposed to be abnormal, but what isn't looked at is, what is someone trying to express through that that they can't express in ordinary everyday language? Because the trauma is too deep, so ordinary words just fail you. (Agnes)

3.4 Theme 3 – ‘Walking on Dangerous Ground’: The Impact of Categorising

All ten participants negotiated how they understood and used categories, both in terms of psychiatric diagnostic labels and social locations, discussing benefits, criticisms and conflicts that appeared to generate anxiety for six participants.

3.4.1 “The Label’s Helped”

Eight participants identified benefits in relation to diagnoses, particularly for identifying and accessing appropriate support from services, facilitating an understanding for oneself and in communication with others. The necessity for a labelling system to meet these needs was agreed, but some challenged the type of category that is used.

They can be helpful to get access to certain services, so I see them as a means to an end. (Misha)

As Kimberly demonstrates, her anxieties were eased through being able to understand all her seemingly disparate health conditions under one, broad, unifying label. This one name, rather than a list of symptoms, appeared to serve an affective purpose through being containing and reducing anxiety, seeming more manageable than the idea of having many conditions.

I know sometimes it [diagnosis] can be good, because you’ve got a name for what you’re experiencing and that’s quite nice, not to just be experiencing ‘stuff’.[...]Before there were lots of little things and I thought, why I am someone so unlucky to get all of these little things? And then when I realised it was one big thing I thought, okay, one big thing is fine. (Kimberly)

The participants were clear that resources do need to be distributed in a systematic, justifiable way, and that a categorisation system is necessary to do this. Some agreed with the current categorisation system to allocate resources, the psychiatric diagnostic system. Others felt it would be more appropriate for the labels to be

grounded in constructs that locate the problem in social adversities and not individual's responses.

Because the people are not the problem. It's more how they've been treated is the problem[...]It depends on, in some sense, the point of the categorisation and who's designing the categorisation. [...] I also believe that we cannot abolish categorisation without replacing it with something that will actually allow people access to resources. Like I don't believe in getting rid of Depression and Anxiety and PTSD and all sorts of categories without replacing them with social model mechanisms of oppression that will still be just as validly seen as credible when it comes to accessing resources[...]Things that actually had happened to those people and not being seen as a problem with their heads then still being allowed to access support. (Liena)

3.4.2 Criticisms

All ten participants addressed issues with categorisation. Some explained the medical model, under which they identified psychiatric diagnoses to be conceptualised, as only one way of making sense of unusual and distressed experiences. It was problematic to participants that this is presented as fact without alternative options. As Agnes illustrates, there are not equivalent models available within systems to conceptualise mental distress in a shared manner and gain access to support for those who disagree with psychiatric diagnosis.

The problem is it shouldn't be the only model. Again, you need to meet everyone's ways of conceptualising themselves and their difficulties. That's the problem with it, it's not that it shouldn't be there for people find it helpful. [...]. Someone has the right to make their own choices. But for some of the rest of us, we don't have parallel choices to have a different model, to have different support system, to refuse to take psychiatric drugs. (Agnes)

Sukhi criticises psychiatric diagnosis for their inherent comparison to a productive norm, which implies individuals who receive diagnoses are deficient through their inability to achieve to 'normal' levels. They outline that the needs of the capitalist

system that requires productivity to sustain itself are upheld over the needs of individuals, who should be afforded an environment that allows them to be valued no matter their productivity.

I just think a lot of the reason they [psychiatric diagnoses] are quantified the way they are is because of capitalism. So humans are categorised by how well they can be productive[...]it's only until you start applying people to environments that aren't suited to them do they become classified as disabled or mentally ill. And therefore it's not about the person, it's about society not being suited to them. (Sukhi)

Another criticism of labels was that the shared understanding unpinning labels is actually only shared amongst certain groups, such as those with Western medical training and those who grew up with Western culture. As Zahir demonstrates, this can lead to misunderstandings. Jules takes this further, identifying the problem lies in the social norms used to define unhealthy experience. As Jules identified, anyone who does not align with the majority in the context of where the norms were developed, such as anyone not White in the UK, can automatically but inappropriately be labelled as abnormal. As she alludes, this can risk stigmatisation through pathologising groups of people and certain experiences.

These are because the words in the Asian language when you translate them... So if you met me and I was going through some sadness, I would say to you, "my heart is hurting" and you will understand what I mean. But if I said that in English, you're thinking I'm saying "I'm getting chest pains". So you're automatically thinking I'm saying I've got chest pain, so, culture plays a big part in terms of how we define illnesses and health. (Zahir)

It's because immediately I was thinking about kids in school. Particularly black boys, because it's always like "they're so naughty and loud" and subconsciously judged differently. And then you get labels such as Attention Deficit Disorder or whatever and I presume prescriptions are made. I don't know much about it but that's impression I get is that kind of labelling from young age so there's something wrong with them. (Jules)

As each interview unfolded, participants began to recognise the process of pathologisation and instead draw upon a plethora of non-dominant models to conceptualise unusual or distressing experiences, recognising that the power afforded to the explanation provided by the medical model is a taken-for-granted assumption that is rarely challenged in the mainstream.

How do we know it's an illness, just because the medical terms define it? Just because the world of psychiatry has said it. What if it's not an illness, but if it is that people are born with certain, let's call it powers, what if that's the power he's got that he can go into the universe and the stars in the space world, that me and you can't reach out to? What if, you know in the Muslim community we believe in Jinns and possession by the Jinn. What if there is such thing as ghosts and you know it could be spirits and things like that? [...] And we say under the mental health condition she was classed as having split personalities as the medical term, but the Hindu religion or the culture would say she had 15 souls in her. [...] So we need to further explore when someone has mental illness. Why do we always just assume it's only one medical approach to defining it? (Zahir)

3.4.3 'Not Being Heard': The Dangers of Questioning

This theme included six participants and had three main variants. Firstly, participants felt questioning diagnoses equated to invalidating the reality of distress, secondly, participants struggled to hold both that adversities can happen to anyone alongside the greater probability of specific adversities impacting specific groups, and finally that understanding someone through the lens of a label would obscure their individuality.

Participant's anxieties appeared to be elicited through the act of questioning an individual's diagnosis. It seemed to participants that this would invalidate an individual's distress because it could be understood alongside normal experiences which would not validate them as extraordinarily distressing. Moreover, participants appeared to equate questioning the reality of the label to questioning the reality of

the distress, which they felt would be harmful by denying its existence and would constitute gaslighting.

[How people are treated] does cause difficulties that are real, for example, if you get really depressed and you really, really find it hard to get out of bed, which I've been getting, that is a real problem. (Liena)

Participants also appeared concerned about categorising people into social locations, as this may lead to assuming experiences and risk excluding the distress of those located upon a more privileged position. This was mostly discussed in relation to those from more advantaged socio-economic backgrounds. Participants felt this understanding was reductionist.

That doesn't mean obviously that there aren't problems with people where there is money, and I think we need to be cautious. Yeah, there's an assumption that these things happen to lower class people and that means that people who grow up in middle class households and face abuse and whatever can fall through the gaps because no one's looking. (Maggie)

Participants appeared to experience an internal conflict when negotiating a balance between acknowledging that mental health problems can happen to any individual, compared with the higher probability at a population level that they can happen to individuals located within marginalised groups.

Mental health happens regardless of social class, income and resources. But if you were to ask me on a very personal level without a balance, I would say the most people that are most likely statistically to experience that and be more experiencing more adverse effects of mental health due to the lack of the resources, I would say are people with vulnerabilities, are disabled people with comorbidities[...]it is the minorities, black people, Asian people. (Misha)

Participants explained the problematic consequence of society's over simplistic conceptualisations of social categories, where the privileged and

subjugated positions are dichotomised. As Sukhi demonstrates, the social location of ethnicity is understood as a binary in which individuals are either grouped into White or not, referred to here as Black and Minority Ethnic (BAME). Sukhi frames this assumption that all individuals who are not categorised as White could be represented by one person to be harmful, hugely reductionist and devaluing of individuals experiences.

I'm the BAME student officer in the Student Union and they are constantly asking me what the [BAME] experience is like and I'm like "I don't know, have you heard my accent? I'm European passing. I definitely do not experience the same stigma as a black person, you can't ask me what that experience is like". It's very frustrating. (Sukhi)

Misha's account illustrates that this anxiety about causing harm to people through understanding them through the lens of a label originates from her experience of the healthcare system. She explains below that herself and the disabled community have experienced doctors to assume individuals' health presentation will align with the expected symptoms of a diagnosis, and different experiences are disregarded. This results in silencing of different disability experiences, a lack of trusts in one's own bodily perception of reality and in the medical professional as benign.

[to try and understand the difference between someone who described their experience as "extreme worry" and someone with a psychiatric diagnosis of Anxiety] I think you would be walking on dangerous ground and it's lumping people... You got the danger, you're at risk of generalising an experience, generalising an impairment, so I'd be very mindful not to do that because extreme worry for one person could be completely different to somebody else's experience [...] Without more information it's hard to set parameters and, really, although the profession tries to be objective and scientific, how does anybody other than the person really know how it affects them truly? And I'm not sure how much you're linking this to lived, experiences of disabled people in general, but there is a big feeling out in the community with not being heard or believed. And when we express concern over physical health they're often minimised [...] If you take one wrong footing that person's not gonna open

up again because they're gonna feel like you already know everything that there is to know[...] so that they've got the fear of being turned away, it's a very, very fine line. (Misha)

Kimberly's personal experience of her disability similarly alludes to the harm that can be caused through assuming someone's experiences based upon a diagnosis or social location. She discussed how being located within the subjugated social location of disability felt all-consuming, reductive and eradicating of her individuality and how subsequently she found it liberating to explicitly acknowledge that one label is not enough to encapsulate an understanding of a whole person. There was a repeated desire for medical systems to be able to holistically view individuals, which participants experienced to be jeopardised by categorisation.

It's maybe easier to be like "you got all this all the disabilities and stuff, but you're not your disability you're separate you're..." You know, like something else, not just disabled. Whereas now I'm like "well I am disabled yes, but I'm so many other things as well as that". (Kimberly)

3.5 Theme 4 – Causal Explanations

3.5.1 Explanations for Everyone

All ten participants drew upon causal explanations that could be equally applied to all social groups, including constitutional factors and personal adversity. Some drew upon the culturally prevailing Stress-Vulnerability model (Harper et al., 2020), that a combination of internal, biological factors precipitated by personal adversity cause mental health problems. Whether the individual could manage in a healthy way, characterised by socially expected 'coping', was afforded by their strength of character, a trait which arose internally and existed regardless of external circumstances. However, four participants explicitly discussed the problematic nature of this individualising of wider social processes.

It can be triggered by events, and it can be caused by events but sometimes it can also be genetics where it's part of who you are. (Zahir)

These accounts demonstrate multiple implicit assumptions, including that biological vulnerability and environmental stressors are distinct rather than integrated (Rose, 2001) and the prevailing privilege of biological accounts that arguably colonises and precedes psychosocial factors (Read, 2005), as can be seen above in the statement that genetics constitute “who you are”. This serves to simultaneously reinforce biological explanations as primary and negate societal causes by locating the problem within the persons ‘oversensitivity’ to harmful environment, rather than the social harm itself (Boyle, 2006).

Nine participants referenced inherent causal mechanisms such as genetics. These were mainly addressed in taken-for-granted passing and not explicitly explained. The pervasiveness of this model may be because it appears to provide language to conceptualise embodied psychological experience but actually is only superficially available, used as cultural shorthand to make something ‘unknowable’ known. The chemical imbalance hypothesis was a key example because it is utilised despite not having an in-depth understanding or direct experience of it, and was used to causally explain differences in perception.

If you're deficient in certain chemicals, for example, you know because I've seen in my family, one of my brothers just really suffers with Anxiety. We've all had the same exact upbringing, but it's his perception and how he perceives it. But then I think, well, it's maybe deeper than that. Maybe chemically he's [...] deficient in certain chemicals and that's impacted. (Kimberly).

Seven participants referenced a strength of character that enables one to cope with personal adversity. The cause of mental health problems was individualised as a failure of this. John described the responsibility for people experiencing poverty to maintain their mental wellbeing is ultimately upon themselves to actively seek help. Kimberly initially describes the responsibly and ability everyone has to decide to focus upon certainties rather than dwell upon uncertainties that can lead to mental distress. She goes on to acknowledge however that this skill was not developed in isolation, but through the support of long-term counselling.

[What would prevent poverty from leading to distress?] By making an effort to change your lifestyle. "I need to self-help" or reaching out to people (John).

It's almost like recycling out all these uncertainties and pulling out, actually, what can we be certain about? [...] And I think for me, anyone can strip away that uncertainty. There's certainties everywhere, and it's actually sometimes about focusing on them [...] For me it's easier because I have had a few forms of counselling so it wouldn't have happened overnight... It wouldn't have been like that 10 years ago. (Kimberly)

Some participants challenged the notion of individualising social processes, by re-contextualising their examples and highlighting power dynamics as more relevant to mental distress than constitutional factors. Below, Liena describes how it is an individual's context that shapes both their character and their ability to live in accord with this. She describes how those with greater autonomy and access to power resources have to face less material consequence as a result of their decisions, which may shape their personality. Using the intersectional example of minoritised ethnicity and low socio-economic status, Liena contrasts this to those who have less access to power resources which forces people to make decisions for survival. She highlights this relegates their character irrelevant when understanding their circumstances.

It's also a power dynamic, like personality plays a bigger role in people who are socially more empowered, societally and politically more empowered, and a smaller role in people who have so much less choice over their circumstances. So a billionaire has so many more choices over what they do with their money and what they choose to work on than someone who is in a job where they cannot find another one and are afraid of, for example, being deported if they're going to lose their job as well. There's currently a visa program where people have to stick with their original employer and therefore a lot of particularly women Au Pairs and people who migrated to work in the UK are abused and exploited by their employers, but they can't do anything about that because if they do, they'll be kicked out of the country. And I don't think what they do then, even if it involves having to submit to whatever the employer

says, is their personality as much as the employer's choice, is the employer's personality because whoever's got the power has the personal power, and therefore their personality is more manifest. (Liena)

3.5.2 Embodied Explanations

Six participants discussed embodied causal explanations through the psychosocial mechanism of bodily insecurity, including extracts where participants referred to the impact of embodied problems on mental health. In line with dominant models, they distinguished between the body and mind in their language, although seemingly attempting to convey an understanding of the mind and body as a unified whole, as can be seen in Jules' account below. Her body's experience of pain and sensory discomfort was inseparably intertwined with her corresponding mental distress. As such, this theme well represents the struggle we experience to convey non-dominant conceptual models in the absence of access to linguistic alternatives by which to conceive them.

You cannot have insomnia and pain without it affecting your mental health and even just discomfort like for me and being really sensitive to temperature and noise and light levels and things like that, things that cause discomfort. It's almost like torture. Those unwanted sensory inputs or things your brain can't cope with or process and you know, there is going to be a mental health impact around that kind of experience. (Jules)

The notion of rationality was discussed in relation to these embodied experiences, with participants explaining that conceptual models of social norm violations are inappropriate for understanding the disabled experience. As Maggie explains, fear is a normal and understandable response to their physical condition, in which their blood pressure can drop suddenly, resulting in falls. However, to others this is seen to violate social norms. This may be because fluctuations in blood pressure is an adverse event that is not directly visible to others, who may then interpret Maggie's fear as disproportionate, and therefore irrational, violating social norms and constituting an abnormal experience.

Being insecure about one's physical health can also be a factor in that for me, for instance, I had problems where part of the issue I have with my blood pressure dropping sometimes is if something causes me acute stress, my blood pressure could drop, and obviously my blood pressure dropping is acutely stressful, so it's one of those kind of being afraid of fear itself situations, and no matter how rational I am about it, it's difficult to manage that. (Maggie)

Participants discussed a plethora of psychosocial mechanisms via which these embodied experiences could lead to mental distress. In Jules' example below, she describes restricting communication and social interaction as a necessary requirement to manage bodily exhaustion and sustain physical health, but that this can have detrimental impact on mental health through limiting access to social support. This extract of self-restriction appears to separate the mind and the body and position their needs as opposing.

I was thinking about disability, like myself with ME, I have a friend who is just too exhausted to communicate, you just can't communicate as much as you would like and it's very isolating, I barely ever get to talk to my mum on the phone because it's just so exhausting, even if you can do it because you have that rush of adrenaline it's just so exhausting afterwards it just isn't worth it. [...] You have to hold yourself back and it's so difficult, sometimes you really want to keep going because you have this rush of adrenaline or whatever but you just can't. It's constantly restricting yourself. (Jules)

Kimberly's account strikingly described the impact of a separation of the mind and body and how this leads to mental distress. She described her physical health conditions including heart failure and the resulting distressing relationship to herself where her mind wanted to punish her body for failing. She alludes to the instability and insecurity caused by missing this grounding connection of one's mind to their actual body, as well as anger and fear resulting from this disconnection.

I had a big problem for a long time of separating me and my body, I saw us as two different things and I'd do things to my body to punish it for doing things to me. But now I've had therapy I'm like 'why?'. If I had a bad day, if I was feeling

really upset, I'd self-harm because that's what you deserve, what your body deserves for putting me through that[...] For so long I had that split between... my physical body and my mental self. I felt like I don't wanna go blind or I don't want heart failure that's the body that's decided this, I haven't and we had that disconnect... I mean I had that disconnect for such a long time. (Kimberly)

3.5.3 Oppressive Impact of Social Norms

This includes all participants and was a significant focus of the interviews. Participants addressed social norms which centres the privileged social location and how being considered to violate this causes mental distress. This occurred through two main pathways. Firstly, participants described denying or hiding parts of themselves in order to be experienced by others as more closely aligned with social norms. Secondly, violating these norms could lead to social exclusion, which risked isolation and discriminatory attacks. This theme was constructed of complex descriptions of the cumulative impact of multiple disadvantages and discriminatory experiences.

A particularly harmful oppressive discourse addressed was social norm of independence. The taken-for-granted assumption of being able to look after oneself is in the immediate sense, by having no one physically around to care for personal needs. This ignores the normal proximal emotional dependence, such as through relationships and normal distal dependence upon others, such as services that build houses, generate electricity and water. This related to visibility. Participants with disabilities were especially constrained by the need for productivity that defines neoliberal society, that further defines independence as the ability to work to financially support oneself. To violate this social norm meant one's worth was devalued by society.

What we value in terms of thinking of what gives us a sense of achievement and what gives us a sense of being valuable within society. Often that comes with a very sort of internalised ableism of "I haven't achieved anything today, therefore I'm worthless. I haven't helped anybody or I haven't made any money for myself or I'm dependent or I'm useless". Without that ableist construct,

because we all exist and therefore it's OK that we exist and there's value and worth in that you don't have to do anything to prove that you're worth existing.
(Jules)

Misha takes this further, highlighting the dangerous impact of dualistic social narratives on mental health, describing the independence narrative as a dichotomy between being seen as either superhuman, for which she would have to achieve over and above what is classed as normal, or otherwise be treated as a 'scrounger', a burdensome person that needs the others support. Both the pressure this leads to, and this dehumanisation are understandably distressing and are related in a vicious cycle. As Misha describes, working hard to achieve and being seen as 'superhuman' was a powerful, proud experience, but when this was lost, through no circumstance of her own, the depth of the fall into the polarised 'scrounger' was devastating.

I couldn't get the support in work so also fell apart because then it was like I'm failing, I'm gonna lose my job and as a disabled person that was a big part of my identity because we fight so hard against traditional, well I do, I fight so hard against the traditional narratives of disabled people either being superhuman because they're in athletics, or benefit scroungers. And I was so proud of myself when I got my first job because I was able to say I'm not completely relying on support. (Misha)

The cumulative impact of being positioned within intersecting subjugated social locations was drawn upon by participants as key to understanding the multiple fronts from which they had to deny parts of their self that are not societally accepted in order to feel fundamentally safe and valued. As Misha and Zahir describe, the impact of being positioned to violate multiple social norms is cumulative and distressing. This was because these are internalised and lead to inner conflicts, as Misha describes between the two parts of herself. This also leads to multiple parts of the self being minimised in order to try present a self that is more aligned with culturally prevailing norms. As Misha describes, she was 'condemned' for both her female sex and her disability, she perhaps felt a need to distance herself from vulnerable and feminine traits. Perhaps correspondingly Misha describes her Indian culture taught

her that to seek help, that could be seen as vulnerable and feminine, was seen as a 'failure', support that she earlier described as vital. Misha alludes to feeling a pressure or responsibility for the condemnation her family experienced. Understandably, this may have distanced Misha from valuing herself and living peacefully and authentically as her female, disabled self.

It's like 2 parts of me and I have, because it very much in India, Asian culture and particularly Indian you're socialised to not share your mental health. You do not share your dirty laundry. You do not seek support outside. If you do, you failed. It shows the community and those around you that you can't cope. There's a deficit in your family[...]. One of the downsides of how I was socialised about Hinduism is that you must have done something wrong in your previous life and about reincarnation and karma to be experiencing what you are experiencing. So not only did I have medical model attitudinal barriers of individual deficit but also religion had the same, a condemning effect on me as well. Not just me, but my family as well because they had a disabled daughter and also the pressures of having a daughter as well just in Asian communities, but also disabled daughter and I believe that I'm impacted my parents' mental health. (Misha)

Because of oppression, not because of who you are, but the oppression and discrimination that you face[...]. If you don't feel accepted by society is it's very hard to accept yourself. (Zahir)

Jamie similarly describes the need to perform a public self in line with social norms as a protective strategy against violating them. They reflect how the constant struggle of this alongside the distress the private/authentic self feels results in the individual having experienced without really living, a life. As this performed life progresses, the individual may feel they have more to lose, such as the family described in Jamie's extract and the pressure of sustaining this performance may then prevent individuals from feeling able to seek or receive support.

I was just existing. I always thought about killing myself, but I was always just like "I just didn't feel like person". But you do the things you need to do for

people think you're a person and...you're just constantly acting and you know exactly what they want to see and you will do it and you have that crazy skill to do that. It's like a whole performance. But it's not really living and it's really, really bad for you, and I think there are a lot of people out there that will live...they'll be like 45, will have kids and they'll have this performance of a life and then they'll kill themselves suddenly and people have no idea why. (Jamie)

Jamie's description demonstrates how binary, dualist social locations lead to harmful societal narratives through the teaching that the privileged binary position, men in their example, are owed and can exploit those in the subjugated position, which establishes and consolidates power. Understandably as Jamie indicates, this can lead to mental distress through dehumanisation, abuse and the removal of bodily autonomy.

I know anyone could abuse anyone no matter what gender, but the end of the day I happen to live in a time society-wise where men do have more power, and they're told that they are owed power and that they owed the ownership of bodies, particularly like female bodies as well. (Jamie)

The extension of these subjugated narratives led to the second pathway by which participants conceptualised violating social norms as harmful, through social exclusion. Maggie demonstrated that when resources are scarce or demands on privileged, normalised groups are high, the subjugated, norm-violating group are seen and treated as disposable, stripping individuals of the inherent value of their lives. This has been acutely visible in the context of Brexit, as described in Maggie's account, where they describe the distress of being consistently confronted with the imposed narrative of burdensome and worthlessness.

It has been very clear that disabled people are seen as disposable by a huge number of people[...]Now after these things have happened and much more acute awareness that people don't care if we die, a lot of the time and having that present in one's life again and again, encountering that sentiment or being told, sometimes aggressively, we don't care if you die, why should we care? (Maggie)

This social exclusion was impacted by being positioned upon multiple, intersecting marginalised social locations and was powerfully demonstrated by Zahir. His experiences of racism, whilst painful and undoubtedly detrimental for his wellbeing, were more tolerable than his experiences of homophobia because of the protective nature of a sense of belonging and solidarity to the Pakistani and Muslim communities. The restriction of access to these community resources was discussed as exposing individuals to risk of physical attack and as such, a constant sense of unsafety.

I'm a gay Muslim man and I had a lot of, as a teenager, a lot of mental health issues, and I know that was because, a major part was because of my sexuality. Not that being gay was an issue, the fact that not being accepted and being around positive role models and growing up in an environment which was saying being gay is wrong and you choose to be and God hates you and you can't be a Muslim.[...] You know, just sort of just having one person say it's OK. You know we love you no matter what. It makes a big difference. (Zahir).

3.5.4 Institutional Explanations

The construction of this theme was also substantial, incorporating a significant proportion of transcripts. It addresses how institutional harm, through the restricted access to needed services and resources, and the policies that uphold institutions, lead to mental distress. The participants mainly drew upon the examples of health and social care. This theme therefore incorporates a double tyranny in that institutions designed to support those already in mental distress reproduce it.

Participants discussed the deeply held societal assumption that medical knowledge equate to facts. As Maggie illustrates, this professional knowledge is continually privileged and upheld against lived experience knowledge when they contradict. Maggie demonstrates the need for bodily autonomy and consent, which can be forcibly removed in line with medical knowledges interpretation of best interest.

As an intersex person, you know, I know the difference between what doctors say and how a lot of people would prefer to be living their lives, in the number of people I know who've had their genitals cut as infants who really, really didn't want to be in that situation, never had the chance to consent, and doctors still say it's the best thing that could have happened to them and they feel very differently about that. (Maggie).

Participants described how institutions resist hearing from people with mental distress or disabilities regarding the ways in which they are harmful and increase distress. Agnes explains how the recent Mental Health Act public consultation, developed by professionals and policymakers to supposedly be accessible, is not. She describes how this further exacerbates mental distress by interlocking people in vicious cycles of powerlessness, through causing distress through inviting distressed individuals to work hard to contribute to feedback but setting up people to fail through the length of the procedures that are inaccessible during acute distress. Ultimately, harmful, distress causing systems and policies remain the same, and the experience of contributing to this reinforces people's devalued position and sense of powerlessness, further exacerbating distress.

The consultation is also very unsuitable. For example, there are I think 35 questions, all of which you're invited to comment further on. For someone who's feeling acutely distressed and those are the people whose voice most need hearing, you can't spend hours on it. Also it means that you have to had read the whole of 180 page white paper. There is an executive summary, but it's very glowing and it doesn't actually give you a real sense of what the white paper actually means. And similarly for people with learning difficulties[...]. Understandably, with everything that can be difficult, when you've got a learning disability and also experience mental distress, that accessible document is over 50 pages long. And again, with the same number of questions. And the other concern about it is again, it doesn't seem to give a fair view of what the White paper really is about. It still gives a glowing impression of it, so that's what I mean about powerlessness. (Agnes)

Liena's extract expands this point made above, further demonstrating how institutions cause mental distress through instilling powerlessness. She explains how often, people's choice of understanding and managing their distress is restricted, because the current institutions gatekeep access to resources through diagnoses. She described how people are required to accept that they are in some way deficient in their ability to cope with homelessness in order to be supported with managing the distress this understandably causes.

It's often the only way to access services and necessary material support [...]if someone's homeless and poor and they need to have disability diagnosis to gain their disability social security then they have to, to some extent, conform or allow oppressive structures to categorise them so that they can access what they need to survive. (Liena)

Systems are further constructed so that the default position is disbelief of the accessing individual, and as such the burden of proof falls upon them to demonstrate why they are deserving of a limited resource. This was understood to devalue individual's realities, positioning their intentions and morals as questionable and subject to punitive investigation. The repeated need to prove oneself as both physically deficient and incapable as well as worthy was understood to lead to mental distress through replication of trauma and coercion.

It's dehumanising, they try to foster a hostile environment and it's so dehumanising[...]It's not like you go in and they give you stuff, you have to prove that a million times and you have to go over your trauma a million times to get any sort of semblance of support. (Sukhi).

Misha further describes the harm caused by professionals denying her need, despite her condition and subsequent needs being clearly visible. This is invalidating her suffering, doubly harmful as positioned from a system that is supposed to ameliorate this suffering. This serves to uphold the narrative of disabled individuals as 'less than' the norm, through treating her as unworthy of support she clearly, visibly, needs.

You know it's very much visible a lot of what I suffer from, and even me, I have to spend half my life defending why I need support even to my everyday care support. The only people that really, truly understand me or people who have lived with me. So my partner who's able bodied, my best friend who I lived with for a bit, but it's really, really small, the people that we can trust in, the people that we diverge our insecurities. (Misha)

Services were also understood to cause mental distress through making accessing individuals feel like they need to compete with each other in order to access the resource. This was described by Liena to further isolate individuals from communities with similar diagnoses, who may have been an invaluable source of social support. Leina also implies this to lead to mental distress through reinforcing the narrative of the self as undeserving, which sustains social norms that blame struggling individuals for needing of support.

It's sort of a way of gatekeeping I guess. Pits against each other because then you get the narrative of... For example, if you're anorexic, you're not underweight enough to be treated in eating disorder service and that sort of thing where people are compared against each other and seeing this undeserving because other people are more deserving. [It's] generally neoliberalism and trying to pit people against each other so that the people who are withholding resources get to point the blame at other people. [...] And like the idea of people who already experience some sort of shared oppression with other people in the sort of community that they have been segregated into in some way[...] So you sort of get put into an outside group and then you develop understandings from being in an outside group. (Leina)

Participants also addressed the ways in which society can contribute to mental wellbeing. As Maggie succinctly summarises, being protected from adverse social events maintains wellbeing. Leina's extract expands upon this, highlighting that it is the lived experience of discrimination that comes from being located within a marginalised group that allows for in-depth understanding into structural oppression leading to mental distress. Taken together, these suggest that those located within

more privileged positions are more likely to conceptualised mental distress as caused by internal factors.

I think some people are mentally well because nothing has ever really gone wrong for them, in which case they stayed mentally well. (Maggie)

Life experience and the more marginalised you are, the more well this is statistically backed up in research. The more you believe that external environment really affects your life choices in life and life outcomes and it makes sense because, for example, I have found as a rule, even though there are other people who seem like they're exceptions, but I think on a sort of spectrum sense, people who are cis, white, male, straight and rich are most likely to believe in individual control and individual mental health, even though they could also experience oppression in some ways. People who are on the very other end most likely to believe in life experience and there not being a mind problem[...]in a society where there's sexism and that women have had to experience one form of structural oppression, so on average, understand more about structural oppression than cis men. (Liena)

4.0 DISCUSSION

This chapter considers the findings in relation to the research questions and existing literature, whilst considering their implications followed by a critical appraisal. To remind the reader, the research question is: how do disabled members of the general public understand mental health and what social processes influence this. I have organised the findings here by topic area rather than theme name, in order to allow me to address overlapping and interrelated aspects from multiple themes.

4.1 The Impact of Health Language

It appeared that the everyday available language for participants to construct an understanding of mental distress is health (L'Hôte et al., 2018; Pescosolido et al., 2010). My positioning of distress of 'mental health' was described by some participants to result in these health assumptions being drawn upon. These health models appear to contain numerous implicit, taken-for-granted assumptions about the nature of distressing experiences (L'Hôte et al., 2018). Namely, that medical systems provide diagnoses when patterns of observable symptoms are reliably associated with an underlying, measurable, biological pathology (Boyle, 1990). Psychiatric diagnosing is assumed to be the same, therefore culturally positioned as an act of discovering of a pre-existing, underlying entity within a distressed individual that manifests in symptoms (Boyle, 1990; Georgaca, 2013). For some participants, the act of diagnosing was sometimes positioned to reify the existence of this entity. However, in psychiatric systems, the relationship of symptom patterns to underlying measurable pathology has not been identified nor has reliability between symptom patterns (Bentall, 2004). Some of the participants seemed to draw upon assumptions of genetic essentialism, the underlying belief that biological 'essences' define categories in a deterministic manner (Haslam, 2005; Lebowitz & Appelbaum, 2019). These assumptions did not appear explicitly available knowledge for participants who implicitly used a health framework. It also appeared that the health language could lead to constraining of prevention, which was framed as idealistic and impossible by these participants (L'Hôte et al., 2018).

Participants also drew upon other conceptual frameworks in depth. It has been argued we all hold multiple causal frameworks that we move between depending upon context (L'Hôte et al., 2018). When asked to make explicit the underlying health assumptions participants were drawing upon, some struggled to do so, sometimes utilising the assumption as evidence in a circular manner. An example was that the identification of a biological process was implicitly assumed to precede causally, rather than follow, distress (Harrop et al., 1996). Whereas, as the interview progressed and space was made for questioning, most participants began to draw upon other models, aligning with the SDH (Compton & Shim, 2015). This process of moving from an individualistic health conceptualisation to critically appraising these assumptions is also noted elsewhere (Peacock et al., 2014). This may suggest the process of using health language that leads to health assumptions being drawn upon is a weakly held model that constrains structural understandings. This contrasts other research that concludes the public do not understand the SDH (Raphael, 2006), and that the health model is the most strongly held conceptual framework because when underlying assumptions of other frameworks are explored participants revert to the individualist health model of understanding (L'Hôte et al., 2018).

This difference could be explained by multiple reasons. It may be due to the social location of these participants as disabled. L'Hôte et al's (2018) sample was described as representative of the UK population in terms of demographics, who may arguably be norm-conforming as they represent the majority, and so may have less experience of structural oppression. Alternatively, it may be due to the apparent realist epistemological position of L'Hôte et al (2018), who seem to present professionals as in possession of the 'correct' knowledge regarding health causes, to which public understanding is compared. This may have led to a different engagement with the material to myself from a relativist epistemological position, whereby neither professional nor public knowledge were framed as 'correct'.

4.2 The Limits of Social Norms

Some participants appeared to implicitly draw upon social norms to conceptualise what constitutes a mental health problem, appearing to make sense of unusual or distressing behaviours as abnormal (Haslam, 2005; Pilgrim & Rogers, 1993). For some participants, these norms seemed to be incorporate an unusual or distressing response to which a clear, linear relationship could be drawn in a proportionate relationship to an observable cause in the immediate environment. Breaching these rules appeared to result in the response being labelled irrational, which was implicitly assumed to constitute abnormality and therefore a mental health problem.

It appeared that other participants felt norm violation models were inappropriate to conceptualise mental health (Boyle, 1990). This appeared to be because current social norms cannot incorporate structural causes or metaphorical ways of making sense of experiences because these cannot be directly observed by others. This appears a different focus to the construct of norms as seen elsewhere (Haslam, 2005).

Negotiation of norms as a conceptual model of what constitutes mental health did not arise in L'Hôte et al's (2018) interviews. This could be taken as evidence for the assertion that when considering 'health' generally mental health is implicitly conceptualised in the same way as physical health, because when these terms are separated people spend time negotiating what constitutes mental health.

Unexpectedly and contradicting existing research (Boyle, 1990; Haslam, 2005), participants used more common diagnoses, such as Anxiety, to explain social norm violations equally as frequently as more obviously unusual diagnoses, such as Psychosis. Within this participant group I understood this as potentially related to ableism due to a neoliberal society that defines value by productivity and autonomy (Greener et al., 2010; Watermeyer, 2013). This group may experience shame/discrimination due to the societal assumption of violating this norm, and so it may be more accessible due to direct experience and emotional salience.

4.3 Impact of Emotional Processes

The findings outlined in theme three suggest that the process of negotiating using both social locations and psychiatric diagnostic categories is emotional (Carter et al., 2018; Garthwaite & Bamba, 2017; Smith & Anderson, 2018). This emotionality is not addressed in other literature that examines the negotiation of multiple frameworks (L'Hôte et al., 2018).

For psychiatric diagnostic labels, these conflicting emotions appeared to arise because participants thought that questioning the reality of a diagnosis equated to denying an individual's experience of distress (Boyle, 1990). Participants also discussed the institutionally embedded nature of diagnoses (Harper, 2013). This may explain why this participant group, who have perhaps greater interface with state systems of support, may have reacted emotionally to the notion of challenging the diagnosis, because in material reality this could impact one's ability to access necessary support. Simultaneously, for other participants these labels were framed as themselves representing oppression, because people are forced to conceptualise their distress as an individualised deficit to obtain access this necessary support, (Hagan & Smail, 1997). This indicates the conflicting, complex and emotional nature of this argument.

For social locations, participants seemed anxious to convey the differences of individuals positioned within social locations by resisting naming health inequalities (Popay et al., 2003; Smith & Anderson, 2018). This has been argued to be a process through which to resist stigma and shame and reassert control to minimise fatalistic anxiety and/or hopelessness (Garthwaite & Bamba, 2017; Smith & Anderson, 2018). These participants resisted this categorisation for themselves and for others. One participant explained that this anxiety originated from the personal and collective harm caused by medical professionals' denial, questioning and minimising of individual illness experiences when they violated expectations based upon diagnoses. This suggests that participants lived experiences of institutional oppression and harm evoke desire to minimise this harm in others through the

resistance of labelling. This has important implications for PMH that I will return to address in section 4.6.2.

4.4 Causal Conceptual Frameworks

Multiple causal conceptual frameworks were drawn upon to understand mental health (Carter et al., 2018; L'Hôte et al., 2018). It was explained that lived experience of marginalised social positions was facilitative to utilising this understanding over a more individualised understanding (Garthwaite & Bamba, 2017; Mackenzie et al., 2017).

4.4.1 Explanations that Individualise Social Processes

All participants addressed causal models in line with the dominant Stress-Vulnerability model (Harper et al., 2020; Larsson, 2013). This theme included the idea of strength of character that affords individuals control, where a failure of this personal willpower is seen as a cause of mental health problems (Bolam et al., 2004; L'Hôte et al., 2018; Popay et al., 2003). This can be understood as an example of the individualisation of social processes (Hagan & Smail, 1997). This has been argued to occur in neoliberal and unequal societies because these lead to a hierarchical stratification of society in which an individual's sense of internal worth and external value is attributed depending upon social status (Wilkinson & Pickett, 2017). This need to upwardly, favourably compare to others is therefore positioned as a survival strategy (Wilkinson & Pickett, 2017). Alternatively, this can be framed as a defence against unbearable emotions, whereby individuals need to construct a favourable identity even when they are positioned to violate social norms, which can occur through the attribution of a strong sense of character to the self (Popay et al., 2003).

4.4.2 Disability and Embodiment

In line with dominant models, participants appeared to draw upon Cartesian Dualism to conceptualise the self. This distinguishes the mind and the body as distinct entities (Abrams, 2016). To my knowledge, this has not been identified in the context of PMH research. These findings can be argued to provide insight about how social norms

lead to health inequalities (Compton & Shim, 2015) for the disabled community. The impact of this potential separation of the body and mind is important to consider when conceptualising public health and PMH.

Social norms can be communicated in dichotomies, as participants referenced here (i.e. the disabled superhero or scrounger). Dichotomous thinking can lead to harmful consequences (Karban, 2016). It could be argued that some of these were addressed here, including the needs of the body and mind being positioned as separate and sometimes conflicting. For example, the need to restrict one's communication and therefore social interaction, itself framed as a psychological care need, was a necessity in order to care for the body's needs. The body was therefore sustained at the expense of the mind and mental health, which again, is important when conceptualising public health and PMH.

Participants referenced neoliberal and western social norms about productive, autonomous bodies being valued (Greener et al., 2010; Watermeyer, 2013). It has been argued from a critical psychoanalytic perspective that it is damaging to individual's wellbeing to live in a society that positions them as deficient (Watermeyer, 2013). These social norms appeared to interact with dominant models of Cartesian Dualism in harmful ways in that it may have generated propensity for splitting (Marks, 2002) and have been argued to contribute to oppression (Marks, 1999). This refers to a Kleinian defensive psychological process whereby individuals attempt to clearly separate the 'good' and the 'bad' in themselves, others and/or the world, attempting to eliminate the 'bad' and leave only goodness (Gomez, 1997). This could lead to the unequal access of resources/healthcare, as described by participants, through the potential internalisation of the neoliberal social norm that positions the disabled body as 'bad' (Marks, 2002) and so people may see themselves as undeserving of resources. At the extreme end, one participant described how this separation lead to the mind, potentially positioned as the good object, attempting to annihilate the 'bad' body through punishing it for failing.

Alternatively, the dichotomy here may have been drawn upon for a beneficial purpose, ensuring professionals do not conflate physical conditions with mental distress or deny the reality of their physical conditions through explaining it

psychosomatic (Marks, 2002). This was referenced by participants as a form of iatrogenic harm, against which this splitting could be conceptualised as resistance. Further understanding of the function and impact of Cartesian Dualism for the disabled community may be an important precursor to developing acceptable and accessible PMH interventions.

4.4.3 Oppression

Participants demonstrated complex understanding of the SDH as described by Compton & Shim (2015) through identifying the oppressive impacts of social norms and institutions. Elsewhere it is concluded that the public do not understand the SDH (L'Hôte et al., 2018; Raphael, 2006). While L'Hôte et al., (2018) identify the public to understand governmental responsibility, they conclude the public do not understand the role of power relations or discrimination in causing mental health problems. This was not the case here.

The psychiatric diagnostic system is understood to be the culturally dominant model for making sense of unusual or distressing mental experiences in the UK (Burr, 2003). The findings here suggest that it may be difficult to align a causal understanding of oppression with this dominant model, which may be due to oppressive macro-structural causes not being directly observable, and because the experiences resulting from oppression were understood as normal, contradicting the norm violating models that the language of health could lead people to draw upon.

4.4.3.1 Oppressive Impact of Social Norms

It was indicated that those with lived experience inequality know the widespread extent of its impact (Peacock, 2012) and have shared implicit understandings of this. Participants implicitly appeared to discuss social norms as shaped by those with power. To be positioned outside of these norms lead to the risk of being discriminated against. The discussion of discrimination as a causal framework appeared to draw upon an implicit understanding of mental distress as an understandable, not abnormal, response, as the cause was knowable to others who experienced this discrimination, even if not directly observable. Furthermore, the resulting distress was not discussed using health language that draw upon

intrapsychic assumptions but appeared to implicitly draw upon a relational understanding of distress. For example, it appeared a taken-for-granted fact that mental distress existed within the interface of needing independence from burdening others, in the loneliness that was located in the absence of others through social rejection and in the paranoia towards being targeted by the police. These emotions did not appear to be discussed intrapsychically in the oppressive causal model.

A plethora of oppressive social norms were drawn upon by participants as causal of mental health problems. These were drawn upon differently than previous research, which concluded the public discuss cultural norms only insofar as to what health related choices they facilitate and constrain, therefore obscuring structural causal frameworks (L'Hôte et al., 2018). Here, participants described that negative psychological impact of being positioned to violate social norms.

One social normal frequently referenced was of independence and if violated, feeling burdensome which damages self-worth (Vassilev et al., 2014; Watermeyer, 2013). The type of independence described by the participants as desirable by society was narrow, in that it was immediate and visible whereby one should be able to manage their physical and financial needs, rather than acknowledging the ways in which we are all interdependent (Reindal, 1999; Wendell, 1996; White et al., 2010). This finding dovetails with previous research, whereby independence is conceptualised as a constituting factor of good health (L'Hôte et al., 2018). The difference in valence, of these findings describing this as harmful, may be due to the participant group, who are more likely to violate this norm through physical health conditions.

The harmful impact of not aligning with social norms was discussed through inauthenticity. Participants described a need to be seen to live in line with socially acceptable norms through constructing a protective but inauthentic self, in order to prevent social exclusion. To achieve this sometimes meant to deny the parts of the self that violated these norms. To not do this was to risk social exclusion, which could lead to isolation or physical attack. The causal impact of social norms did not arise in other research (L'Hôte et al., 2018) nor did the psychosocial mechanism of inauthenticity (Smith & Anderson, 2018). There are numerous possible ways this

impact of inauthenticity could be made sense of. One example is that, in line with the abovementioned, the development of a protective but inauthentic self may serve as a form of resistance against painful emotions. This could alternatively be interpreted to allow individuals to reassert control (Smith & Anderson, 2018).

Some participants drew upon intersectional frameworks to explain understand the multiple fronts from which they had to deny parts of their self that are not societally accepted to feel safe and valued. They appeared to feel dominant understandings, that address only singular positions, were incompatible with understanding the whole self holistically. They appeared to bring in intersectionality to address the interlocking impact of the cumulative social norms of which they violated on their sense of self, but also to conceptualise from which community supportive resources were accessible. Quinn et al (2019) label this as intersectional stigma. Different shared language utilised by the public and by professionals can lead to communication at the societal level breaking down (L'Hôte et al., 2018). As most participants here seemed to bring multiple social locations, including gender, disability, ethnicity, minority religions and culture, alongside structural determinants, perhaps their language of “holistic selves” reflected what professionals mean by “intersectionality”.

4.4.3.2 Oppressive Institutions

Participants highlighted a multitude of structural discrimination against disabled communities in line with SDH (Gartrell et al., 2018). It was addressed how health and social care systems re-enact oppression based upon social norms, which in turn restrict individuals from marginalised groups access to care (Mattheys et al., 2018; Parry et al., 2007). This then appeared to lead to distrust of services that were positioned as a risk to wellbeing (Canvin et al., 2007). Participants appeared to relate this to mental distress through the psychosocial mechanisms of powerlessness, a sense of injustice, being blamed, gaslighted and ignored (Smith & Anderson, 2018).

4.5 Critical Review

There are important limitations to this research that have ethical considerations. These were carefully considered in the design and implementation with the aim to

minimise harm but are presented here to normalise a culture of accountability. I do not intend this to diminish the findings, of which I evaluate in line with guidelines of good quality qualitative research (Spencer & Ritchie, 2012).

4.5.1 Generalisability

Methodological limitations of the research impact the extent to which conclusions can be drawn and applied to other individuals who identify as disabled. These include the small sample size and the large heterogeneity of the sample. Part of aligning intersectionality with TA requires acknowledgement that conclusions drawn from this specific group are socially, historically and contextually bound, and may not continue to be fair conclusions for the same group over time. The current UK socio-political context is polarised, presumably influencing the findings, including Brexit and the Coronavirus-19 pandemic, which were described by participants to bring into acute awareness ableist societal narratives. Furthermore, the language of health during the pandemic is arguably more acutely available to the public. All of these factors limit the generalisability of the findings. However, as I earlier argue, using an intersectional lens means the value of generalisability is limited given that the assumption of within category homogeneity is rejected.

4.5.2 Appropriateness of Thematic Analysis and Intersectionality

I found it challenging to align TA with intersectionality due to their divergent underlying assumptions. As outlined, intersectionality rejects the assumption of within category similarities, whilst TA is based upon this assumption to allow a researcher to draw conclusions from their sample based upon a shared characteristic. It has been widely acknowledged that it is challenging to conduct qualitative research from an intersectional lens, which is similarly reflected in the lack of explicit guidelines for how to do so (Bowleg, 2012). Bowleg (2012) states that trying to understand health disparities using only one location obscures understandings of the complexities in which multiple experiences of discrimination interact to produce health inequalities, which has inevitably occurred here as I only used the social locational of disability. I have outlined in section 2.2 how I attempted to align these differences, for example drawing upon intersectionality's assumption of within category variance by recruiting a diverse sample. As explained, I utilised this

method rather than recruiting participants from specified, multiple, social locations in order to reduce the imposition of categories that can restrict experience. My aim was that, by focusing on one social location, I could use an intersectional lens to explore the within category differences within this social location, which is different from how the literature I identified had operationalised the intersectional lens. However, a huge array of different conceptualisations drawn upon between participants. This made it difficult to construct overarching themes representative of the whole dataset and as a result, a large amount of nuance felt lost. I also found it difficult to interpret participants responses based on their social location when they did not explicitly name the influencing location. Therefore, this may not have been the most appropriate solution. TA also meant I was unable to examine within participant variance in depth, for example the nuances of the processes that lead to initial implicit health frameworks being recognised and critically examined as the interview progressed.

I also endeavoured to manage this conflict by bringing intersectionality into the themes. However, this was also difficult as only some of the participants brought this explicitly, and each participant's social locations and experiences were different. Other intersectional qualitative research has managed this dilemma by explicitly recruiting participants from multiple intersecting social locations in order to draw conclusions from this intersection (Quinn et al., 2019). However, this continues to violate the assumption of within category homogeneity and involves the researcher's imposition regarding which intersecting positions may be relevant. This is difficult to justify from a PMH perspective, in which the entire population should be considered.

4.5.3 Personal/Professional Reflexivity

I struggled with the ethical dilemma of conducting research with participants located within a subjugated social position that I am not a part of. There have rightly been criticisms of this as it can be experienced as exploitative (Kagan et al., 2019). This reinforces the relational power dynamic as unequal, inadvertently and indirectly upholding epistemic injustice (Fricker, 2007) and positioning communities as worthy of being studied but unable to actively contribute to this. It has been suggested that researchers should embed themselves in the community of interest prior to

commencing research (Kagan et al., 2019). Research could then be truly collaboratively developed, centring the actual need of the community, rather than the researcher imposing their beliefs as to what would be helpful. As I am not disabled, I am unable to fully immerse in the community. In the absence of this it is suggested that research should be co-produced (Kagan et al., 2019). This would involve people who identify with the location of 'disabled' being involved collaboratively at each stage, through developing the research questions, designing the method and interview questions, recruitment and analysis. This level of co-production takes time and I believe it would be unethical to request this without the ability to adequately pay those involved for their work. Neither option could occur in the available timeframe with the available resources. Ultimately, I concluded that while the research is problematic in these ways, I could mediate this harm with transparency with participants, allowing people to decide for themselves given this context whether to participate, and by gifting vouchers to thank participants for their time. Furthermore, I firmly believe there is need for those who benefit from discrimination and current power inequalities in society to do the work to challenge and disrupt this process.

Problematically, research in the field of health prevention is still expert driven (Garthwaite et al., 2016; Smith, 2013). Due to the requirements of the thesis, to contribute psychological knowledge, I have inevitably taken the expert position through interpretation of the participants semantic and latent talk and linking this with existing theory (Willig & Rogers, 2017). There are clear limitations to me positioning lived experience as valuable expertise, and then superimposing my knowledge and interpretation onto this. This can contribute further to hermetical injustice (Fricker, 2007) by shaping available information through an inaccessible, academic lens. Given the historical systemic ableism described by participants and the impact of this on relationship with the disabled community this had the potential of being harmful. I aimed to manage this dilemma in several ways. Firstly, my intention was to equally value the opinions of the participants with my psychological understanding of processes, positioning both types of knowledge as equally 'true' and helpful, enabled through the relativist epistemology (Pilgrim, 2017). Despite this intention, a sense of obligation was evoked within me in response to participants who expressed a sense of responsibility to engage in the research due to its work with an under-represented

population in order to ultimately benefit others. Through a desire to respect their accounts, I may have at times been too realist in my interpretations in order to represent exactly what they wished, and at other times too interpretative, for example to justify aspects that were not evidence based or in line with my personal values. I recognise that my privileged position enables me to take an ideological, value-based stance at times when the participants may need to take more pragmatic position, for example, accepting individualised deficit models in order to access services.

These differences in social location between myself and the participants may have influenced the research process. Some participants discussed the harm caused by the health and social care system. The project was advertised as a part of my training to qualify as a Clinical Psychologist, naming my position within this system. This may therefore have influenced who came forward to participate. This may have subsequently influenced what the participants felt able to share potentially skewing answers towards the psychologically-socialised, dominant model of individualising distress. This may explain some of the contradictory findings, of those that focused more on the individualised conceptual frameworks than structural ones. This has implications for my conclusions, which need to be held tentatively, of the impact of health frameworks obscuring access to structural conceptual frameworks, as this may have been a considered and conscious decision.

4.5.4 Managing Resulting Complexity

There is substantial complexity within the topics of PMH, disability and intersectionality. A huge number of different disciplines, models and ideas are relevant, all of which use similar terminology in largely different ways (such as addressed in 1.2.7). Upon reflection, it appears I have attempted to manage this complexity through attempting to be more certain, for example in my conclusions. This was particularly impacted by the personal uncertainty facing all of us during the pandemic and by the fact that the thesis was an assessed piece of work. I was unsure of how it would be received to be uncertain and to leave some questions unanswered. I had hoped to reach some clear conclusions but the process of conducting the research has made me aware of a range of complexities and

ultimately has left me with more questions than answers. I have not managed to illuminate with any clarity how intersectionality might best be addressed within research, or how inter-category heterogeneity might be investigated, recruited, asked about or interpreted. Although I had attempted to reduce some of the complexity when designing the study by focusing on only one social location, disability, the constructions of mental health were hugely variable. This meant that I cannot conclude with any certainty or clarity which social locations or influencing social norms and ideologies related to different constructions of mental health. I have also found it difficult to shed light on how best to discuss even one social location, given that there are so many different definitions and meanings of disability and a range of explanatory frameworks and epistemological standpoints. Given this uncertainty, it is difficult to consider what may be helpful next steps for the field of PMH

4.5.5 Evaluation

I have evaluated the research in line with Spencer and Ritchie's (2012) three criteria for good quality qualitative research, as outlined below.

4.5.5.1 Credibility

I hope to have demonstrated credibility, referring to the plausibility of the conclusions drawn. Given that an array of difference was demonstrated by the participants, which I hope to have highlighted through explicitly naming how many participants are incorporated in each theme, I have intended to draw only tentative conclusions that themselves are grounded in the findings of previous research. Furthermore, through my deliberate consideration of a relativist epistemological position (Pilgrim, 2017) coupled with first person language, I have intended to demonstrate ownership over my role in actively constructing the conclusions.

4.5.5.2 Rigour

Rigour refers to the documentation and demonstration of the research process in order to highlight how the method and design allow the research to meet its aim (Spencer & Ritchie, 2012). I hope to have demonstrated this through transparency of the thoughtful decision-making processes which are detailed in Chapter 2, section 4.5.2 and the inclusion of a reflexive account (Appendix A). Furthermore, I have

endeavoured through the inclusion of extracts in Chapter 3 to illustrate my claims as grounded in the participants talk. I have included examples of early thematic maps (Appendix G) and an early coded transcript (Appendix I) to further evidence how I constructed the themes in line with TA guidelines (Braun & Clarke, 2006).

4.5.5.3 Contribution and Implications

I have also considered Spencer and Ritchie's (2012) third guideline, contribution, which refers to the value and relevance of the research. I believe the contribution of the research is valuable for multiple reasons. Firstly, this is the first psychological research to my knowledge that investigates PMH explicitly, rather than public health generally, through in-depth qualitative analysis. From previous public health research, it is unclear how mental health is conceptualised and from this we can assume it is conceptualised, uncritically, in line with physical health. These findings suggest there are additional nuances to mental health that are obscured by investigating only 'health'. Namely, the negotiation of social norms in defining which experiences are identified as abnormal. This is in addition to the harmful impact of social norms that contribute to the unequal distribution of opportunity and resources within Compton and Shim's (2015) conceptualisation of the SDH, which, as outlined in section 1.2.4 contributes to the determination of which social groups needs are privileged. If replicated, this finding has implications for PMH and models of the SD of mental health, through a potential need to consider the complex interaction of both usages of social norms. This is unlike physical health needs, which are not identified based upon norm violations.

A second nuance regarding mental health that investigating only health obscures is the different, non-dominant conceptualisations of what mental distress is (section 1.2.3). As these findings could suggest, mental distress may be implicitly conceptualised differently depending upon the causal model being discussed. It appeared that participants may have drawn upon psychiatric conceptualisations of mental distress and these assumptions when the language of health was utilised, whereas when using structural frameworks to discuss macro- and micro-level discrimination participants may have implicitly drawn upon a relational conceptualisation and underlying assumptions. These assumptions appeared to be

regarding the normality of the experience, a shared 'knowing' that was not based upon visibility, and the framing of the mental distress as located within relational interactions rather than an intrapsychic deficit. Furthermore, structural causes were related to understandable distress, which may be able to be considered as preventable, whereas psychiatric diagnoses were not seen as preventable. These potentially have implications for PMH. This could be because communication related to health, for example through the NHS or PHE, may constrain an understanding of mental distress to the health model and obscure structural understandings. This may therefore impact how the public understand and relate to health services engaging in macro-structural interventions.

Furthermore, this research contributed to psychological literature by addressing some methodological and epistemological limitations outlined as in section 1.4.3 and 1.4.4, which has allowed me to consider two processes which may have influenced which causal models were drawn upon at different times. Firstly, the in-depth interview methodology utilised here allowed the potential impact of the language of health to be illustrated, as well as the non-dominant conceptualisations this may initially obscure to be highlighted. Whilst there are multiple interpretations regarding which conceptual framework is held most strongly and the contextual factors that influence when various are drawn upon (L'Hôte et al., 2018), I have endeavoured to justify my different interpretation (section 4.1). I believe it an important one for consideration, as if replicated, may have multiple implications. Firstly, this may suggest why some research has identified the public not to understand the SDH (L'Hôte et al., 2018) by reframing this as a methodological issue and not related to public knowledge. Secondly, this may have implications for the ways in which PMH communicates as a public facing system. As suggested, opening space to recognise and critically explore assumptions may allow the health framework to be recognised as just one explanatory framework, facilitating discussion of non-dominant (Peacock, 2014). This may not align with the current PMH model of quickly consumable awareness raising campaigns (PHE, 2019; Smith, 2017).

The second process I have considered here that may influence which causal model is drawn upon at which time is the process of defending against painful emotions. I believe is an important contribution to both PMH and psychiatric diagnostic debates

and may not yet have been considered in enough depth. This may go some way to explaining why the health framework is upheld against logical and evidenced critique (Harper, 2013). Furthermore, this has implications for PMH and understanding the SDH. These findings suggest, along with others, that the public understand health inequalities but can sometimes resist naming them (Smith & Anderson, 2018). If a preventative strategy is designed based upon this evidence, it may need careful consideration of the language used to communicate and justify it, because those who do not face the inequality may deny it in favour of personal strength of character explanations for their healthiness (Garthwaite & Bambra, 2017; Mackenzie et al., 2017) while people who do experience the inequality may challenge naming this to resist fatalistic anxiety (Popay et al., 2003). It has been argued that a limitation of qualitative research is that it does not adequately address emotional process. I have since become aware of psychosocial methodology which claims to consider emotional defences that may arise during research (Hollway & Jefferson, 2013). Further research could be undertaken from this methodology. There is a danger that this could lead to the expert voice predominating and I would therefore advocate for this to be undertaken using co-production approaches.

Finally, the contribution of this research to how upstream social norms impact disabled individuals' mental distress and the ways in which the healthcare systems can cause iatrogenic harm can be useful to practising clinical psychologists. For example, this may suggest ways to include social context in formulations, locating problems within restrictive social norms rather than in individualised deficits. This may also suggest a focus for the work of clinical psychologists working with medical teams and/or long-term health conditions could be around mending the systems relationship with the disabled community, through supporting discussions of managing individual illness experiences that do not align with diagnostic expectations.

4.6 Recommendations

4.6.1 For Research

These findings may suggest we need to further investigate, using in-depth qualitative methodology, the different ways in which the public conceptualise what constitutes mental distress and what contextual factors influence these different models. One of the influencing contextual factors may be the causal model being drawn upon. The different causal models and what contextual factors influence these being differentially drawn upon could also be elucidated further. Moving forward with PMH may be difficult without an understanding of these models, influencing processes and whether these differ for different groups in society. The outcomes of these further findings may be additionally investigated using wider scale quantitative methodology to elucidate population level group differences.

More broadly, I think this research demonstrates both the value of and limitations with in-depth qualitative research. As outlined in section 1.2.5, PMH research and academia should work to position multi-paradigm method as gold standard rather than RCT's alone which have been argued to be inappropriate for the investigation of the impacts of upstream structural causes (Larson, 2013). This multi-disciplinary collaboration could be an aim of future PMH research. Further work towards generating guidelines for producing intersectional qualitative work would also be beneficial.

There is a growing body of literature in the UK shows those from lower socio-economic backgrounds have complex understandings of SDH (Smith & Anderson, 2018). These findings suggest that disabled individuals may also draw upon complex understandings of the mental health impacts of structural factors. In regards to PMH, further investigation with both the disabled community and other marginalised groups is warranted to establish whether this finding is replicated in the UK socio-political context. I believe this should be positioned within research of the lay public as a way of bringing in intersectionality, acknowledging that we all are positioned within multiple privileged and oppressed social locations simultaneously (Bowleg, 2012).

The initial pervasiveness of the health framework in research into public discourse could be seen as a demonstration of Fricker's (2007) hermeneutical injustice. People, especially those with lived experience of personal marginalisation and structural discrimination, may have an implicit understanding of SDH, but these are obscured in research findings by the deeply embedded culturally dominant health frameworks that are more readily available. This is perpetuated by the elitist, institutional blocking of access to shared academic language developed to conceptualise other understandings of mental distress, which is actively hid behind paywalls and expensive higher education courses means that it is difficult to move away from the language of health in everyday discourse. This hermeneutical injustice upholds testimonial injustice, through the positioning of the general public as lacking knowledge in how they conceptualise health (Fricker, 2007). In order to not perpetuate health inequalities and epistemic injustice, I recommend the system of PMH academia to prioritise the sharing of knowledge with the public that is co-produced and free at the point of access.

4.6.2 For PMH Policy and Prevention

I have separated PMH from research for the purpose of clarity, although recognise that policy and prevention in PMH cannot be implemented without further research into the suggested areas. It has been argued that academic work regarding the SDH has had little effect on the actual process of policymaking due to individualistic approaches fitting with neoliberal government structures and not easily aligning to structural (Raphael, 2006). From these findings I have two main, tentative recommendations for PMH priorities that may contribute facilitate policymaking: developing shared language and working with public services to minimise iatrogenic harm.

Policy documents that state they are addressing structural causal factors have been argued to quickly revert to individualised language (Larrson, 2013). As identified by L'Hôte et al (2018) gaps in shared language can lead to communication breakdown. I have considered here whether these participants may have been referring to what professionals name as intersectionality through a language of being holistic. Furthermore, mental distress appears to be conceptualised using different language

at different times. These could suggest that an initial priority for PMH is to develop a shared language across professionals, the public and incorporating different social groups. We cannot implement different strategies without a shared language regarding what and how distress is being targeted. This could also include a consideration of how these conversations are held. As suggested here and elsewhere (Peacock, 2014) quick conversations may result in the dominant health framework being drawn upon, but space for exploration can facilitate the use of non-dominant conceptual frameworks.

A further aim of developed a shared language could be a standpoint from which to consider prevention. These findings may suggest, in line with others, that health frameworks may restrict thinking regarding prevention (L'Hôte et al., 2018) which is a neglected research area (Rose-Clarke et al., 2020). Another aim of this is to develop shared language that is not over simplistic. For example, the participants identified multiple ways in which dichotomous positioning of social locations and discourses around social norms, such as the disabled hero or scrounger, are harmful. PMH could work with the public to develop a shared language around which to communicate complex ideas in ways that do not perpetuate harm. This prevents reifying social policy as the only way to address the SDH, which of course extend from the macro to the micro level, embodied and lived within individual's identities and experiences.

Secondly, in the UK mental distress is often supported through healthcare services. Smith (2013) identified that UK public health research does not often address unequal access to healthcare as a SDH because the NHS is free at point of access. However, these findings suggest that there are access difficulties, framed by participants here as neoliberal gatekeeping of resources, and then iatrogenic harm, which may influence re-accessing of services. In these findings iatrogenic harm was a strong narrative, also discussed in relation to other state services including social care, the benefits system and the police. Potentially then, PMH may need to consider unequal access to mental health care and other services as a SDH and develop joined up working with these public services to educate awareness and then prevent this. These findings could suggest that this may need to be a PMH priority, as even if we move towards primary prevention, those with current mental health

problems who need to access services still need to be considered. This focus can be argued as having the potential to be more effective than current PMH interventions that target downstream lifestyle and behaviour choices (Smith, 2013; Whitehead, 2007; Wilson et al., 2013). These findings may add to this literature that suggests the use of these interventions be minimised.

Both of the above priority suggestions may be impacted by these findings that suggest the influential role of emotional processes in discussing SDH, mental health and the psychiatric debate for both the public and potentially professionals. These findings suggest that these emotional processes may be influenced by lived experiences of the SDH and structural discrimination (Sweeney, 2015). As above, we cannot figure out together how to move forward without understanding the emotional processes, as a result of lived experience, that influence engagement with the conversation. Furthermore, when working to minimise iatrogenic harm as perpetuated by public services, this may need to begin with services confronting the ways in which structural violence is enacted through systems that exacerbate health inequalities (Josewitz, 2017). This has the potential to evoke distressing emotions as those who enter the helping professions are likely to have done so in order to help others, which may mean they are susceptible to defences that allow disavowal of responsibility or contribution to harm (Menzies, 1960).

4.6.3 For Practising Clinical Psychologists

Whilst not the aim of the research, I believe the findings may indicate some recommendations for practicing clinical psychologists.

Participants discussed how some of the disabled community are wary of the clinical psychology profession because of our tendency to individualise and psychologise problems related to physical health conditions and pain, which is experienced as invalidating. I recommend that we work to bring the disabled lived experience to the forefront of mainstream clinical psychology, so that we have a better understanding of how to work with this without reproducing further harm, given that 20-25% of our clients may be disabled (DWP, 2018). One way in which this could be achieved would be to engage in more co-production work with service users, in order to

disseminate contextually relevant understandings within specific teams. These research collaborations could then link in with local clinical psychology doctorates in order to embed this lived experience understanding into teaching. This may go some way to begin to mend the distrust some of the disabled community may have towards our profession (Canvin et al., 2007).

Another potential impact for clinical psychologists is around the language and models used to conceptualise distress. As suggested here, psychiatric diagnostic language was utilised less when drawing upon structural causal models for mental distress, which also positioned the distress as understandable and therefore normal. In discussions with services, individuals who utilise these models and underlying assumptions may not be seemed 'psychologically minded' (Larrson, 2013). This could further perpetuate inequalities in access to healthcare as individuals not 'psychologically minded' may be excluded from accessing therapy (Larrson, 2013). Potentially clinical psychologists could better develop an integration of different models by which to conceptualise mental distress and it's causes into service models.

4.7 Concluding Reflections

PMH is incredibly complicated. I believe there is no one 'right' causal understanding of mental health inequalities, but that there are multiple more 'helpful' understandings and that these are ever-evolving according to time, place, and social locations (Rose-Clarke, 2020). Because of this, I think it is important we bring as many difference perspectives to light as possible and managing the resulting complexity, which is what I have endeavoured to do here. However, the process of conducting this research has been immensely challenging, raising uncertainties, complexities and perhaps more questions than answers. With regards to addressing disability as a social location, the various different meanings have been difficult to align when considering other research, participants different opinions and my own views. Regarding intersectionality, I remain uncertain of how these complex, overlapping ideologies can all be considered and discussed without becoming reductionist. Through my attempts to incorporate these ideas and capture the fluidity

of SDH, I have unintentionally reified the linear causal models I set out to critique. This points to a significant limitation of intersectional approaches to PMH, how overwhelming this can seem, which can result in what Nutbeam (2004) terms 'analysis paralysis', the avoidance of engaging in the appropriately complex required research. I certainly experienced this myself when trying to identify, read, interpret and integrate findings from different disciplines, each with epistemological positions, methodology and interpretations. It is likely this has impacted other disciplines and research, and we cannot tackle this large, overwhelming and complex picture if we cannot better integrate different disciplines research, policymakers and public conceptualisations (Josewski, 2017). Therefore, whilst I believe an intersectional framework is the most ethical from a judgemental rationalism perspective to conduct research, is it the most 'helpful' when it comes to supporting policymakers to decide on action? Perhaps not.

Regarding the suggested implications to PMH, substantial further work is required. This research is just a small piece in the puzzle, which I have struggled during the process to come to terms with, feeling the need to 'fix' or contribute something hugely impactful. In reality, to manage time and resource restrictions and 'analysis paralysis', a large amount of small pieces need to be conducted to build the overall puzzle. I hope this is one of them.

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6.0 APPENDICES

6.1 Appendix A - Reflexive Account: Constructing Ethical Research

When constructing the research, it was essential to me that I did not contribute replicating epistemic injustice (Fricker, 2007) and marginalisation through knowledge production. I believe this occurs as the majority of research is people from White, Educated, Industrialised, Rich and Developed backgrounds (WEIRD) and so conclusions drawn from this population are assumed and applied to all.

Intersectionality is key in undoing this gross negligence (Abrams et al., 2020). I myself however come from this WEIRD background and occupy many intersecting privileged social locations, including being white, middle class, cis-gendered and non-disabled. This leads to a significant risk of exploitation, where someone who does not belong to a community, enters the community, takes knowledge and leaves, without benefit to the community itself, replicating a history of colonising knowledge. One of the ways in which I endeavoured to manage this conflict was through paying participants for their time, representing a fundamental valuing of people's time and knowledge. However, this unbeknownst to me at the time lead to another significant ethical issue. The University are subjected to Her Majesty's Regulations and Customs' (HMRC) regulations regarding payments and gifting vouchers, and as such the participants were required to complete a form confirming their receipt of the gift voucher, which included their National Insurance number. Having a disability entitles a person to state support including for example financial support if unable to work. These benefits are 'means tested', which means the level/amount of support is determined based upon an assessment of the level of need. This assessment is conducted through the Department of Work and Pensions (DWP), which works closely with the HMRC. Understandably, some participants felt uncomfortable with providing this information, being unsure as to whether HMRC would alert the DWP to this receipt of the voucher, how the DWP might interpret or use this during means testing, for example, whether accepting this voucher would constitute a one off-payment for work, which may be taken in evidence against any claims of being unable to work. This potential, significant impact may deter disabled

people, who are unequally impacted by the distressing process of the DWP, from engaging in research, meaning that HMRC regulations are discriminatory in this sense. This maintains hegemonical knowledge production, which itself upholds discriminatory practice. The process of applying for ethical approval from the university did not incorporate the details of these forms. Had I been aware of the requirement of this form in advance, I would have included it in my ethical application in order to seek the University's Ethical Committee's guidance regarding this.

My multiple and intersecting privileges, which have protected me needing personal interaction with the DWP, meant that I did not initially recognise the potentially impact of this. This is a demonstration of internalised ableism, present in seemingly innocuous everyday interactions that uphold systemic ableism (Afuape, 2011). It was deeply troubling to me that despite careful reflections and decision making, I had replicated harm. It is important to acknowledge the parallel barriers of discrimination faced whilst carrying out the research that can further lead to the exclusion of marginalised voices to ensure identification, and subsequently disruption of systemic barriers (Hankivsky & Christoffersen, 2008). It is vital to reflect upon my own relationship to systems of power and oppression, and it was due to a failure of this that systemic ableist privileges prevailed and inequality was replicated (Abrams et al., 2020). I was also concerned that institutionally, concerns regarding the NI number and this form appeared to have gone unnoticed and is an ongoing matter. This deeply concerned me and has contributed significantly to my anxiety regarding the risk reifying ableist systems when analysing the data through my own lens of bodily and economic privilege and security. I continue to believe, however, that it is vital for those of us who privilege from ableism to do the work to dismantle and disrupt this oppressive and hegemonical narrative/system, and I include this mistake explicitly in order to normalise taking accountability, apologising and moving forward from our own acts of discrimination.

All aspects of the research, aside from voucher claim form, received ethical approval from the UEL Ethics Committee prior to its commencement. Aside from the issues with the form, which was (hopefully) quickly resolved for the participants, the research did not appear distressing to the participants. On the contrary, the majority of the participants expressed finding their participation beneficial, including for their

valued contribution to lived experience research, and for consideration of concepts they had not explored before.

6.2 Appendix B – Ethical 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: Hebba Haddad

SUPERVISOR: David Harper

STUDENT: Emily Dixon

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Underlying conceptual frameworks used to understand mental health in the context of a global pandemic

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-SUBMISSION 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)

2

Minor amendments required (for reviewer):

3.7 – Data collection. Please be sure the method of data collection will be suitably conducted within lockdown rules at the time. Currently, this should be using MS Teams. Face-to-face interviews should only be conducted when safe to do so and social distancing and all related health and safety measures are met.

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*):

Student number:

Date:

(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 / NO

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*): Hebba Haddad

Date: 22.06.20

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

6.3 Appendix C – Debrief Letter



UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

Your interview has been recorded on an audio recorder and only I will type them into transcripts. I will anonymise the transcript by changing any information which might identify you (e.g. the names of people or places). I will delete the audio file from the recorder straight after the interview but will keep a back-up copy in password-protected computer files. I may include anonymised quotes from our interview in the write-up of the study. The transcripts will be kept for five years on a personal password protected computer and might be used for additional articles or publications based on the research. I will delete the audio files after my thesis has been examined. The audio files or typed transcript may be accessed by the researcher's supervisor at the University of East London and/or the examiners who assess the thesis. No one else will have access to the transcripts or audio recordings.

If you change your mind and would like to withdraw your data from the research, you can do so without providing reason and with no disadvantage to yourself. You have 3 weeks from today to do so.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research. Nevertheless, it is still possible that your participation or its after-effects may have been upsetting. You may find the following resources/services helpful:

- Your GP if you would like to access your local NHS mental health support
- The Samaritans helpline: 116 123 (free 24 hour helpline)
- Mind: 0300 123 3393 (Monday to Friday, 9am to 6pm)
- Sane (emotional support, information and guidance for those affected by mental health difficulties, their families and carers: 0300 304 7000 (daily, 4:30pm to 10:30pm). Textcare: www.sane.org.uk/textcare.
- CALM is the Campaign Against Living Miserably, for men aged 15 to 35. Phone: 0800 58 58 58 (daily, 5pm to midnight)

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:

Emily Dixon. Email: u1826611@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Professor David Harper. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: d.harper@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)

6.4 Appendix D – Interview Schedule

Thesis Interview schedule

1. What comes to mind when I say ‘mental health’?

- Types of mental health problems aware of?
- Personal experience (e.g. someone they know)?
- How different from normal experience?

2. What do you think causes mental health problem X [i.e. one they are familiar with]?

- If they give more comprehensive answers you could maybe introduce the prompts from section 3 here
- How think X causes [mental health problem]?
- Specific to that problem or also relevant to [other problem they mentioned]?

3. I'm going to mention some things that some people think are reasons why people develop [mental health problems]. To what extent do they play a role in [mental health problem] X?

- For all: If so, how? Why some people and not others?
- Negative life events (i.e. things that have happened to people) [bereavement, workplace stress, trauma etc).
- Relationships with others (e.g. family, friendships, neighbours, workmates etc).
- Amount of money (e.g. income, welfare, debt etc).
- Where you live (housing, neighbourhood etc).
- Being a man/woman; ethnicity; employed/unemployed; disability etc.
- Biology (e.g. the kind of body we are born with, genes etc).
- Individual factors (such as personality, resilience, lifestyle choices).
- Religion/spirituality

4. What do you think keeps people mentally well?

- How does X [i.e. financial security] keep people well?
- Do only some people have X? Why/not?

5. Where did you get these ideas from?

6.5 Appendix E – Participant Information Sheet



**University of
East London**

UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus

Water Lane
London
E15 4LZ

Consent to Participate in a Research Study

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

Project Title

How is mental health, its causes and prevention understood by disabled members of the public? ¹

What is the study about?

The aim of the study is to understand what you understand “mental health” to mean, what might be the causes of mental health difficulties and what may prevent them. I am doing this study for my thesis as part of my training as a clinical psychologist.

Why have you been asked to participate?

I am interested in interviewing members of the public. I emphasise that I am not looking for ‘experts’ on the causes of mental health. On the contrary, I think that members of the general population have an ‘expert’ understanding of mental health, because we all experience it. It is this type of ‘expert’ knowledge I am seeking. You will not be judged or personally analysed in any way and will be treated with respect. You are quite free to decide whether or not to participate and should not feel coerced.

What will taking part involve?

I would like to invite you to be interviewed by myself. I will ask you how you understand mental health, the causes of mental health difficulties and what you think prevents this. The discussion will be in general terms and I will not be asking you questions about any personal experience, although you can bring this in if you would like.

¹ This title reflects the name of the study as it was at the time of data collection

What are the risks and benefits of taking part?

Since I will be asking general questions I do not think there are any significant risks to taking part. Some upset is possible if you discuss something personal, though I will not be asking questions about this. If you do become upset we could take a break and/or you could withdraw from the study. I can provide a list of organisations if you felt you needed further support. You will receive a £10 Amazon voucher for your participation. You would also be helping to contribute to our knowledge about mental health.

Your taking part will be safe and confidential

Each interview will be with me. I will record the interview and then transcribe (i.e. type it up) afterwards. I will anonymise the transcript by changing any information which might identify you (e.g. the names of people and places). I will delete the audio file from the recorder straight after the interview but I will keep a back-up copy in password-protected computer files. I may include anonymised quotes from our interview in the write up of the study. The transcripts will be kept for five years on a personal password-protected computer and might be used for additional articles or publication based on the research. I will delete audio files after my thesis has been examined. The audio files or typed transcript may be accessed by the researcher's supervisor at the University of East London and/or the examiners who assess the thesis. No one else will have access to the transcripts or audio recordings.

Location

Interviews with me will be held over the telephone or online, depending on which you prefer.

What if I want to withdraw?

You are not obliged to take part in this study. If you decide to take part, you are free to change your mind and withdraw at any time before or during the interview. After the interviews have taken place, you can contact me and withdraw your data within 3 weeks from the date the interview was conducted (after this I will have begun my analysis). Should you choose to withdraw from the study you may do so without any disadvantage to yourself and without any obligation to give a reason.

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

If you have any questions or concerns about how the study has been conducted, please contact the research's supervisor: Professor David Harper, School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone: 020 8223 4021. Email: d.harper@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.

Tel: 020 8223 4493. Email: t.lomas@uel.ac.uk

Thank you in anticipation. Yours sincerely,

Emily Dixon (Principal Investigator)

u1826611@uel.ac.uk

21st January 2021

6.6 Appendix F – Participant Consent Form



**University of
East London**

UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus

Water Lane

London
E15 4LZ

Consent to participate in a research study

*How is mental health, its causes and prevention understood by disabled members of the public?*²

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

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

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

EMILY DIXON

^{2 2} This title reflects the name of the study as it was at the time of data collection

6.7 Appendix G – Example Thematic Map

6.8 Appendix H – Presentation Key

I have made minor changes to the interview extracts for their presentation and readability. Where superfluous words that do not add to the overall meaning conveyed have been omitted to shorten quotes, a dotted lined within square brackets [...] is depicted. Where an addition to the text has been made to offer further explanation to reader that was dependent on previous utterances, square brackets [text] are depicted. Pauses have been represented by doted lines Some 'filler' words and repetitions of these within extracts have been removed for clarity (e.g. words such as 'like', repeated colloquialism such as 'you know').

6.9 Appendix I – Coded Transcript

health, both mental and physical, are still, most sometimes gate counts by resources and money and post code lotteries. So for me, going back to your originals of open question, it would be. Every individual, regardless of age, ability, um demographic background. They'd be able to either independently or would support, be able to meet most of their daily living needs and the their higher needs is, well. If you think of like Maslow's hierarchy of need, being able to be supported in whatever goal they set for themselves, and have that support to be able to, then not just survive but thrive and be able to see themselves having a future. At interacting with other human beings in their communities and supporting one another.

[R] Thank you, thank you. That's beautiful. And what about? What about when people don't have these things that make up well being?

[PP5] That's where we are now really, aren't we? In my mind it terms of crisis well, the first thing would be isolation in the sense of. Being alone and because like I said with well being in having those opportunities, you're able to share your experiences, you're able to feel free and free of judgment in an ideal scenario. So when you don't have that, you feel scared to share you, you close down? You might have a fear of being judged. You might have a you might not be able to access services, whether that be through ability, whether that be through communication problems because of language because of. An inability to use traditional communicative methods you might not have the support that you once had because some people have support workers to help them with those needs. So I would say it was in the absence of that I would say it's about feeling alone, about feeling afraid about perhaps feeling. I'm starting to feel burdensome towards services, maybe in the sense of feeling like you failed because I know only recently since the pandemic has there been a wider discussion on mental health quite openly because it's gone from what traditionally would be viewed as minority. Oh, people are mental health is only for people that aren't reaching their goals in life, you know or are certain cross section of society. Now it's become a majority problem. think there's been more of a focus on, oh, you know, mental health can happen to everybody whereas before it was very much a stigma. If you were, if you were experiencing mental health, that was because you were you had a deficit in yourself somewhere as to why you're experiencing that. So for me, I think in the absence of good well being, it goes back to those principles of feeling. It's your fault, you're, you know you're not getting out there enough. You're not trying hard enough to find work or. You're not eating healthy enough, but. And I think it's the ignorance of all those support systems are put in place that needed, you know, the encouragement, the sense of community, the sense of providing people with enough self esteem, and enough foundations to feel like they have a future because without feeling like you have a future in that you belong regardless of your abilities, background capabilities it worries a lot of people like. How will I survive? How will I make your future? And if he can't see a future you are you going to quickly spiral on you and you're going to end up? In a very dark place.

[R] Thank you yeah. Um, so you talked about some different things that people could experience in the absence of wellbeing so feeling alone, feeling like you failed, feeling like

Annotations

- For generalising
- Biology
- Construct and purpose
- Implicit
- Constructionism
- Devaluation of lived expertise or testimonial injustice
- Inauthentic Self
- Medical Profession
- Intersectionality
- Perception
- Neg impact of interpersonal power to groups
- Reproduction of inequality
- Against generalising (for individual)
- Reproduction of inequality and intersectionality
- Oppressive Institutions
- Abnormal Irrational

Coding Density

6.10 Appendix J – Title Change To Ethics Application Approval Letter



University of East London Psychology

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

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

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.

Type your name in the 'student's signature' section (page 2).

Using your UEL email address, email the completed request form along with associated documents to: Psychology.Ethics@uel.ac.uk

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.

REQUIRED DOCUMENTS

A copy of the approval of your initial ethics application.

Name of applicant: Emily Dixon

Programme of study: Doctorate of Clinical Psychology

Name of supervisor: Professor David Harper

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	Rationale
--------------------	-----------

Old Title: <u>Underlying conceptual frameworks used to understand mental health in the context of a global pandemic</u>	Changed to remove the reference to the pandemic, as this was not discussed or included at length in the write up so is not relevant for the title.
New Title: Underlying conceptual frameworks used to understand mental health by disabled members of the UK general public	

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	X	
Does your change of title impact the process of how you collected your data/conducted your research?		X

Student's signature (please type your name): Emily Dixon

Date: 20/08/21

TO BE COMPLETED BY REVIEWER		
Title changes approved	YES	
Comments		

Reviewer: Trishna Patel

Date: 02/09/2021