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“If medication isn’t helping me, maybe it’s just me”:

Narratives of treatment resistant depression

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Ella Kroch

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Abstract

A significant proportion of people with depression do not experience expected improvement following treatment and are considered to have treatment resistant depression. Despite this, there is relatively little research exploring the experiences of this group, who represent a significant minority of those who experience depression. The current study explored how people with treatment resistant depression make sense of depression that has not resolved following adherence to professional advice and treatment. The accounts of nine people with treatment resistant depression recruited from a private psychiatry practice in Auckland, New Zealand were analysed using narrative analysis. The participants told stories about what it was like to experience depression that persisted over many years using two narratives: that of order and of disorder. The narrative of order was used to organise and make predictable their experiences. The narrative of disorder was used to describe the ways their depression defied predictability and management. The participants also told stories to account for why they had remained depressed long-term despite receiving treatment. At times, participants attributed their persistent distress to having a treatment resistant brain or personality. There were also two alternative accountings - a narrative of bad patient behaviour and a narrative of it just taking some time to find a suitable medication. These accounts were strongly shaped by narratives of mental distress and recovery that suggest that depression follows predictable patterns and that treatment results in resolution of symptoms. Today, these narratives are increasingly encompassed by powerful and pervasive narratives of neoliberalism. The participants in this research emphasised personal accountability and self-management, and self-blame when they did not achieve the desired and expected outcome of resolution of symptoms. The implications of these findings for those experiencing persistent distress, such as TRD, as well as for health professionals working in mental health domains are discussed.

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CHAPTER ONE: INTRODUCTION

Depression

Major depressive disorder (hereafter referred to as depression) is traditionally conceptualised as a condition that involves sad, empty, or irritable mood, and physical and cognitive changes that impair a person’s functioning (American Psychiatric Association, 2013). From a mainstream perspective, it is a clinical condition objectively defined by symptom-based diagnostic classification systems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). According to the most recent edition of the DSM, depression is characterised by the presence of at least five of the following symptoms: depressed mood, marked loss of interest or pleasure in usual activities, weight gain or loss, insomnia or hypersomnia, psychomotor retardation or agitation, fatigue, difficulties with concentration, feelings of guilt or worthlessness, and recurrent thoughts of suicide or death (American Psychiatric Association, 2013). For a diagnosis to be made, at least one of the symptoms must be depressed mood or marked loss of interest or pleasure in usual activities. These symptoms, which are broadly arranged in cognitive, physical, and emotional clusters, must be present most of the day, nearly every day, for a period of at least two weeks and lead to significant impairment or distress for the affected person.

Depression has been named the leading cause of disability worldwide by the World Health Organisation (World Health Organisation, 2019). It has been associated with significant impairment, physical and mental comorbidity, and mortality. Depression is also highly prevalent in New Zealand. According to the most recent New Zealand Health Survey, the lifetime prevalence of depression among New Zealanders is approximately 16% (Ministry of Health, 2019). This means that approximately 620,000 New Zealanders have been affected by depression, although this is likely an underestimation as the Health Survey definition requires people to have been diagnosed by a medical professional. In New Zealand, depression disproportionately affects women, Māori, and those living in areas of high economic deprivation (Ministry of Health, 2019). This is likely due to the association between mental distress and social and economic inequality (Health Promotion Agency, 2018).

Treatment resistant depression (TRD)

Despite the emergence of new depression treatments over recent years, a significant proportion of people experiencing depression do not experience recovery as expected following treatment. In the 1970s, the term ‘treatment resistant depression’ (TRD) emerged in the literature to describe this group (Murphy, Sarris, & Byrne, 2017). TRD is not a diagnosis present in diagnostic classification systems, such as the DSM or the ICD. Instead, it is a broad label applied to people with depression who experience non-response to treatment. Whilst TRD has been the focus of increasing study, there is a lack of consensus around some basic issues, such as the way it is defined and conceptualised as well as its aetiology (Wijeratne & Perminder, 2008).

Definitions of TRD. There is general consensus in both academic literature and clinical settings that TRD is characterised by the presence of diagnosable depression as well as non-response to treatment (Wijeratne & Perminder, 2008). Beyond this, however, systematic reviews of TRD studies have highlighted considerable heterogeneity in the way TRD is understood and defined (Brown et al., 2019). Additionally, definitions have not been provided or suggested by health guidance bodies, such as the National Institute for Health and Care Excellence. Broadly, there are two predominant approaches to conceptualising TRD: a definitional approach, in which a person is categorised as having TRD if they fit a simple definition, and a staging model approach, in which a person’s treatment resistance is assessed based on progression through a model outlining treatment steps.

Within the definitional approach, a person is said to have TRD when they are experiencing depression and have not responded to a number of treatments. This approach appears to offer a simple way of distinguishing between people with depression that does respond to treatment and people with depression that does not. However, there is little consensus on the details, with employed definitions varying in a number of ways. One recent study found that across the 150 studies included in their systematic review, there were 155 slightly varying TRD definitions used (Brown et al., 2019). The definitions differed in terms of level of detail provided, forms of treatments considered, details of what constituted an adequate dose and duration of treatment, as well as the number of failed treatment rounds required. For example, some merely stated that participants had failed to respond to one antidepressant medication (with no reference to dose or duration), whereas others provided specific details about dose, duration, type, and class of pharmacological treatments. In terms of treatments considered, the majority of studies only considered pharmacological treatments – usually only antidepressants, but sometimes also mood stabilisers or electroconvulsive therapy. Additionally, the number of treatments required to meet treatment resistant criteria ranged from one to six (Brown et al., 2019). This variation in TRD definitions means that studies are not exploring a homogenous group, and that there are significant variations in study findings.

Whilst there is significant heterogeneity in definitions employed, there appear to be some areas where there is more consensus. There is general agreement that 'response' to treatment constitutes a 50% reduction in depression severity, based on the scores of a standardised depression rating scale (Wijeratne & Perminder, 2008). Additionally, Brown et al. (2019) concluded that the mostly commonly adopted definition of TRD was an episode of depression that had not responded to two or more rounds of antidepressant medication at an adequate dose and duration. This appears to be supported by the findings of The Sequenced Treatment Alternatives to Relieve Depression (STAR*D) study, the largest study to date to evaluate the effectiveness of pharmacological depression treatments, which found that the chances of a person responding to and achieving remission following antidepressant treatment reduced dramatically after the second antidepressant trialled. At this point, fewer than 20% experienced remission (Rush et al., 2006). However, with only

50.3% of studies employing this definition, its position as the most commonly employed definition is marginal (Brown et al., 2019).

Definitional approaches to conceptualising TRD have been criticised for oversimplifying the construct of TRD and for treating response to treatment as categorical (e.g., people either do or do not respond to treatment) rather than dimensional (Ruhé, van Rooijen, Spijker, Peeters, & Schene, 2012). As a result, several arguably more nuanced staging models for capturing treatment resistance have been proposed (Murphy et al., 2017). Staging models go beyond the presence or absence of TRD to evaluate people in terms of the extent of treatment they have received. They place people with depression on a scale of treatment resistance according to the number of ineffective trials they have experienced, the duration of their depressive episodes, and the types of treatments they have tried (Mazo, Neznanov, & Krizhanovskii, 2016).

In their systematic review, Ruhé et al. (2012) identified a total of five staging models. The Antidepressant Treatment History Form, the first staging model to be developed, was originally created with the purpose of evaluating vigorousness of any antidepressant treatments a person had received prior to commencing electroconvulsive therapy (Sackeim et al., 1990). When using the Antidepressant Treatment History Form, each treatment round in the current episode of depression is assigned an adequacy score on a 0 to 5 scale based on treatment type and duration, and an overall score is calculated. Several years later, the Thase and Rush Staging Model was developed as a tool for guiding psychiatrists in clinical practice (Thase & Rush, 1997). Within this tool, people with depression are assigned to categories, ranging from stage I to stage V, based on the number and types of failed treatment rounds they have experienced. The European Staging Model (Souery et al., 1999) was developed at a similar time as an alternative to the Thase and Rush Staging Model, and also assigns people to graded categories ranging from ‘non-responder’ to ‘TRD’ to ‘chronic resistant depression’, based on the number and duration of failed antidepressant trials experienced.

In response to criticisms of these various models, Fava (2003) adapted the Thase and Rush Staging Model to develop the Massachusetts General Hospital Staging Model. These adaptations included the addition of more treatment types, removal of the hierarchy system of antidepressant classes and strategies, and a switch to dimensional scoring rather than a categorical system. The most recent staging model to be developed is the Maudsley Staging Model (Fekadu, Wooderson, Donaldson, Markopoulou, & Masterson, 2009). This version calculates an overall treatment resistance score based on duration and severity of depression, number of antidepressant treatment failures experienced, and whether or not other treatment strategies such as augmentation of electroconvulsive therapy have been employed. Despite their similarities, staging models have gradually evolved from assigning a person to a treatment resistance category based purely on perceived adequacy of each treatment trial (e.g., Sackeim et al., 1990) to models that are based on multiple relevant factors and are less categorical in nature (e.g., Fekadu, Wooderson, Donaldson, et al., 2009).

However, as with the definitional approach, there have been criticisms of the use of staging models in conceptualising TRD as these approaches predominantly focus on progression through pharmacological treatment options. Some argue that many factors influence treatment response, including a range of biopsychosocial factors, and that these should be factored into any model aimed at evaluating treatment resistance (Mazo et al., 2016). Additionally, despite growing evidence for the effectiveness of psychotherapeutic treatments for TRD (e.g., Ijaz et al., 2018), none of the staging models take psychological treatments into consideration and only one includes non-pharmacological treatment (in the form of electroconvulsive therapy) (Ruhé et al., 2012). Additionally, none have been thoroughly evaluated. Consistent with the definitional approach, there is not one staging model that has been accepted for widespread use, so different models are employed across research and clinical settings (Murphy et al., 2017; Ruhé et al., 2012).

Not only is there a lack of consensus on TRD definitions within the academic domain, but there also appears to be little overlap between academic understandings and usage in clinical settings. Brown et al. (2019) interviewed health professionals about TRD definitions employed in clinical practice and found significant disconnects between research and practice. Rather than judging non-response based on number of failed treatments, health professionals described considering multiple characteristics of the individual and their context (Brown et al., 2019). Labels such as ‘treatment resistant’ were not commonly employed in clinical realms, either in interactions with patients or between health professionals. Instead, health professionals described using terms such as ‘complex needs’ and ‘struggled throughout their life’. Additionally, whilst most definitions and staging models only take pharmacological treatment into consideration, this was not reported to be the case in clinical practice. When asked how they would define TRD, even if not used in practice, participants reported that patients would need to have received an adequate trial of psychotherapy as well as two to three rounds of antidepressant medications to be considered treatment resistant. This incongruence between academic and clinical understandings likely impedes the application of research findings to clinical practice.

Although the construct of TRD first appeared in the medical literature close to 50 years ago, there remains little consensus on how it should be defined or conceptualised and major incongruence between academic ideas and clinical practice. These conceptual issues have consequences for research focused on TRD, in terms of estimating prevalence, identifying risk factors, and evaluating which treatments are the most effective. These conceptual issues also have significant implications for both people with depression and their families, as well as health professionals working in the field. Despite the apparent issues relating to the manner in which TRD is defined and conceptualised, the term TRD is used throughout this thesis. In the context of this research, it is referred to, not as a unitary or objective ‘condition’, but as a construct evident in medical and academic realms that is used to describe people with depression who have not experienced the expected improvement following treatment.

Comparisons to other forms of depression. Several other categories of persistent depression have been proposed and employed. These categories tend to be confused with the construct of TRD. For example, in the previous version of the DSM, the DSM-IV, there were three potential diagnoses for people experiencing persistent forms of depression: dysthymic disorder, major depressive disorder with chronic specifier, and major depressive disorder with recurrent specifier (American Psychiatric Association, 2000). These diagnoses are commonly referred to in the literature as ‘dysthymia’, ‘chronic depression’, and ‘recurrent depression’ respectively and will be referred to as such hereafter. These terms and diagnostic categories are sometimes used interchangeably with TRD and, whilst there can be overlap (Spijker, van Straten, Bockting, Meeuwissen, & van Balkom, 2013), there are some important differences that should be noted.

Approximately 75% of people who experience a single episode of depression will go on to experience multiple episodes later in life (Hollon & Beck, 1994). The experience of multiple distinct episodes of depression with full inter-episode remission was previously diagnosed in the DSM-IV as recurrent depression (American Psychiatric Association, 2000). In comparison to people with TRD, who may experience some response to treatment but not full remission, people with recurrent depression experience full remission between episodes. Additionally, there is no evidence to suggest that people with recurrent depression experience problems with treatment response (Gelenberg, Kocsis, McCullough Jr, Ninan, & Thase, 2006).

Some people describe experiences of symptoms of low mood that persist, and the DSM-IV classified such experiences as either dysthymia or chronic depression. Whilst an acute episode of depression has an average duration of two to five months (Kessler et al., 2003), to be diagnosed with dysthymia or chronic depression, a person must continually meet diagnostic criteria for a period of at least two years. The difference between these two diagnoses lies in severity – for a chronic depression diagnosis, full depression criteria of five or more symptoms must be met, whereas for a dysthymia diagnosis, only two depression symptoms need be present. It is also this lesser severity that differentiates dysthymia from TRD, as to be deemed ‘treatment resistant’ a person must meet full criteria for depression.

The diagnosis most commonly conflated with TRD appears to be chronic depression, which is thought to affect approximately 15-25% of people with depression (Bschor, Bauer, & Adli, 2014; Hollon & Beck, 1994). However, the widespread belief that chronic depression persists *because* it is treatment resistant has been increasingly challenged (Michalak & Lam, 2002). The two forms of depression are said to have different aetiologies and prognoses (Moore & Garland, 2003). Rather than persisting due to treatment resistance, chronic depression appears to persist, in part, due to inadequate treatment. One study found that only approximately 25% of people with chronic depression had experienced failure to respond to antidepressant medication (Gelenberg et al., 2006). However, as many as 66% of participants with chronic depression had not yet received an adequate trial of antidepressant medication despite experiencing depression for two years or more (Kocsis et al., 2008). When issues of treatment inadequacy are addressed, such as low doses of antidepressants, short durations of treatment, or lack of exposure to evidence-based psychotherapy, it appears that chronic depression often responds favourably to treatment (Gelenberg et al., 2006; Michalak & Lam, 2002). This differentiates it from TRD, which is defined by lack of improvement despite adequate healthcare input.

With the latest revision of the DSM, the DSM-5, an overarching diagnostic category for all persistent forms of depression, labelled persistent depression disorder (PDD), has been created (American Psychiatric Association, 2013). This occurred in light of findings of few demographic, clinical, or psychosocial differences between people with dysthymia, chronic depression, and recurrent depression (Bschor et al., 2014; McCullough et al., 2003; Moore & Garland, 2003). To meet diagnostic criteria for PDD, a person must experience a minimum of two depressive symptoms for a minimum of two years (American Psychiatric Association, 2013). PDD differs from TRD in that fewer symptoms are required for diagnosis. PDD requires presence of only two depression symptoms, whereas TRD requires a full diagnosis of depression, where five or more depression symptoms are present. Additionally, there is no evidence to suggest that people with PDD encounter difficulties with treatment response. As this change occurred relatively recently in 2013, a significant proportion of the existing literature on persisting forms of depression uses the terms chronic depression and recurrent depression.

Whilst there may be overlap between the various forms of persistent depression (Spijker et al., 2013), TRD appears to differ from dysthymia, chronic depression, recurrent depression, and PDD in the way that individuals with TRD must meet full criteria for depression, be seeking help from health professionals, have failed to respond to at least two rounds of antidepressant medication at an adequate dose and duration, and not have experienced periods of remission. These factors suggest that the experiences and understandings of people with TRD may be unique.

Prevalence of TRD. The previously described heterogeneity in TRD definitions has led to significant difficulty in estimating prevalence (Nemeroff, 2007). Reported rates of TRD among people experiencing depression vary according to the TRD definition employed in study inclusion criteria (Murphy et al., 2017). Studies exploring the efficacy of treatments for depression give some insight into just how common it may be to continue to experience depressive symptoms even after receiving treatment. The STAR*D study is considered the largest, most comprehensive, and most community representative study to date to evaluate the efficacy of pharmacological depression treatments (Rush et al., 2008). Of the sample of over 4000 outpatients with depression, only approximately 50% responded (defined as ≥50% reduction on a depression measure) and 37% achieved remission (defined as a score of ≤5 on a depression measure) following the first round of antidepressant medication. Response rates to subsequent trials are unavailable, however, 50% of the sample had not achieved remission following two rounds of treatment and 33% had still not achieved remission after four rounds of treatment (Rush et al., 2008). New Zealand prevalence rates of TRD are unavailable, as data are only collected for major mental disorders, such as major depressive disorder. However, these international findings suggest that TRD is a substantive issue - representing a significant minority of those experiencing depression.

Causes of TRD – patient characteristics. Many studies have explored potential predictors of TRD in the hope of prospectively identifying people with depression who are less likely to respond to treatment. In recent years, a plethora of predictors found to be associated with TRD have been reported. Several factors linked to the clinical presentation of the individual have been associated with TRD. These include experiences of depressive episodes that are more severe (e.g., Gronemann, Jorgensen, Nordentoft, Andersen, & Osler, 2020), have an earlier age of onset (e.g., Dudek et al., 2010), and have melancholic features (e.g., Souery et al., 2007). Other clinical factors include presence of comorbid anxiety disorders, moderate to high suicide risk, experience of previous hospitalisations for depression, and non-response to the first antidepressant ever taken (e.g., Gronemann et al., 2020; Souery et al., 2007). A number of psychosocial factors have also been linked to TRD. Firstly, personality has been implicated in poor response to depression treatments, with some studies reporting associations between TRD and personality disorders (e.g., Papakostas et al., 2003) or personality traits, such as high neuroticism or low extraversion (e.g., Takahashi et al., 2013). Additionally, factors such as experience of stressful life events, trauma, financial difficulties, and relationship problems have been described as common among people with TRD (e.g., Amital, Fostick, Silberman, Beckman, & Spivak, 2008; Tunnard et al., 2014). Older age is the only demographic factors that has been associated with non-response to treatment, with one study reporting increased risk among those aged 65-84 years (Gronemann et al., 2020).

A growing body of literature has also focused on biological and genetic predictors of non-response to treatment among people with depression. In terms of biological factors, several authors have reported associations between abnormal neural function and neurotransmitter dysfunction, and

TRD. For example, TRD has been linked to decreased concentrations of inhibitory amino acid neurotransmitter γ-amino-butyric acid (GABA) in the occipital cortex and anterior cingulate cortex (Price et al., 2009), as well as disturbances in the hypothalamic-pituitary-adrenal (HPA) axis, which is central to a person's stress response (Carvalho, Torre, & Papadopoulos, 2013). More recently, there has been increasing interest in the association between activation of the body's inflammatory system and non-response to treatment (Carvalho et al., 2013; Kubera, Basta-Kaim, Wrobel, Maes, & Dudek, 2004). Genetically, poor response to treatment has been associated with a range of gene polymorphisms. For example, Anttila et al. (2007) reported that people with depression carrying the combination of polymorphisms in both BDNF and serotonin type1A (5-HT1A) had a three times higher likelihood of experiencing TRD.

Two systematic reviews have attempted to make sense of the array of findings regarding predictors of non-response to treatment in depression (Bennabi et al., 2015; De Carlo, Calati, & Serretti, 2016). Recognising the conceptual issues relating to TRD, the systematic reviews employed strict inclusion criteria – only reviewing studies that used standardised definitions of TRD, and concluded that findings are largely mixed and often contradictory so no conclusions regarding correlates of TRD could be made. They did, however, point to some *potential* risk factors. Across the two reviews, the predictors that most consistently emerged were comorbid anxiety disorders, comorbid personality disorders and factors associated with depression severity, such as early onset of depression, higher risk of suicide, hospitalisation, and longer episodes of depressive episodes (Bennabi et al., 2015; De Carlo et al., 2016). Despite much work on the topic, there remains no clear consensus on factors associated with non-response to treatment in depression. Many authors attribute this, in part, to the previously outlined conceptual issues, such as heterogeneity of definitions employed in studies (Murphy et al., 2017). Clinically, this leaves researchers and health professionals no closer to being able to identify people with depression who may experience poor response to treatment.

Causes of TRD – treatment characteristics. The majority of approaches to defining and conceptualising TRD frame non-response to treatment as a phenomenon that occurs as a result of the idiosyncrasies of the individual and their depression. The ineffectiveness of an antidepressant medication is interpreted as indicative of a resistant depression or patient (Dyck, 1994), so efforts have focused on exploring what it is about the person that may be causing this. Dyck (1994) argued that the conflating of antidepressant treatment effectiveness with condition or person description is one of several fundamental flaws in the way that TRD is conceptualised. He refuted the positioning of TRD as a homogenous diagnosis, condition, or syndrome, arguing that the construct says more about health professionals' assumptions about response to treatment than the individual in question. Fava and colleagues (2020) agree, highlighting the taken-for-granted idea that antidepressant treatment is effective, and the tendency to link lack of expected recovery to the characteristics of the patient. Rather than prompting consideration of whether it may be the treatment approach that is flawed, non-response triggers a shift in focus to the individual and any characteristics that may be getting in the way of the 'effective' antidepressant from doing its job. Through this process, people with depression are "implicitly blamed" for non-response to treatment (Fava et al., 2020, p. p. 268).

In light of these arguments, several authors have explored the possibility that non-response occurs as a result of factors relating to the treatment approach or service delivery. For example, some argue that much of the apparent non-response to antidepressant medication can be explained by so-called pseudo-resistance (Murphy et al., 2017). The concept of pseudo-resistance was first termed by Nierenberg and Amsterdam (1990) to describe apparent resistance to antidepressant medication caused by diagnostic and treatment factors. These factors include misdiagnosis, unrecognised comorbidity, delivery of inadequate treatment, strained therapeutic relationship, or poor patient adherence to treatment (Murphy et al., 2017). Once these issues are corrected, it is argued that people with depression that was previously categorised as treatment resistant may experience improvement in symptoms.

Recent studies exploring antidepressant efficacy may also support the hypothesis that a person's apparent non-response to treatment may be related, at least in part, to the treatment approach. The STAR*D study shed light on the fact that antidepressants may not be as effective as previous randomised controlled trials (RCTs) have suggested. A recent systematic review of over 400 antidepressant trials highlighted an average response rate that was significantly higher than the rate reported in STAR*D (Salanti et al., 2018). These studies had similar treatment conditions to the first treatment round of STAR*D and only differed in the way that the treatment conditions were double blinded. After one round of antidepressant treatment, the studies had an average response rate of 59%, compared to 47% in STAR*D. As response is the most common primary outcome measure in RCTs, data on remission rates is less available. However, in the studies that do report remission rates, the same pattern seems to hold. A review of 90 antidepressant trials reported an average remission rate of 44% (Sinyor, Levitt, et al., 2010), again significantly higher than the 28% reported in STAR*D. The STAR*D authors concur, noting that rates of response and remission were significantly lower than expected and the majority of people experiencing depression needed sequential treatments before their symptoms improved (Rush et al., 2008). These discrepancies have been attributed to several factors. As STAR*D was a pragmatic trial, it more closely approximated the real world, so included participants who were less likely to respond or remit, compared to RCTs that employed strict inclusion criteria (Sinyor, Schaffer, & Levitt, 2010). Publication biases (Murphy et al., 2017) and design features (Sinyor, Schaffer, et al., 2010) of RCTs may also make antidepressants appear more efficacious than they really are. In any case, these findings support the hypothesis that antidepressants may not be as effective as once contended.

In addition to being less effective than suggested by previous RCTs, some authors suggest that antidepressant medications have adverse effects that directly contribute to continuation of symptoms. Fava and colleagues (2020) argue that antidepressant medications exert iatrogenic effects that explain the wide array of experiences that are typically labelled treatment resistance. Iatrogenic effects are adverse effects caused by a treatment. Fava and colleagues suggest that several clinical presentations that appear to be resistance may actually be due to these effects. For example, people may experience an antidepressant not working in a current episode when it worked in the past, an antidepressant losing its clinical effect within an episode, or the worsening of symptoms or appearance of new symptoms when an antidepressant is commenced. These experiences may all result from development of tolerance to antidepressant medication, either from taking it previously or from taking it for a long period of time (Fava et al., 2020). The authors suggest that repeated prescription of antidepressants with iatrogenic effects may cause long-term problems. Combined, these authors suggest that rather than the issue of treatment resistance lying in the individual, the issue may lie in the medications – which are either ineffective or exert iatrogenic effects, such as the development of tolerance.

Treatment of TRD. Whilst guidelines exist for the treatment of depression in general, there is no standard approach to treatment when a person does not respond as expected to initial interventions (Davies et al., 2019). In light of this, many studies have focused on exploring the efficacy of conventional and novel treatments for people with TRD. These have included pharmacological, somatic, and psychological therapies.

Pharmacological treatments for TRD. The pharmacological leaning of definitions and conceptualisations of TRD has led to a largely pharmacological focus in terms of treatment (Jenkins & Goldner, 2012). Initial steps with TRD generally involve altering the existing antidepressant treatment regime. For example, the National Institute of Health and Clinical Excellence suggests the health professional consider increasing the antidepressant dose, switching to a new antidepressant from the same or a different class, or augmenting the original antidepressant with another medication (2009). However, evidence for the effectiveness of these strategies is limited. A recent Cochrane review of RCTs exploring these treatment approaches reported that, whilst some of these strategies are empirically supported, others urgently require further research (Davies et al., 2019). For example, the authors described moderate to high quality evidence for the effectiveness of augmenting an existing antidepressant with an antipsychotic medication, and some evidence for the effectiveness of augmenting an existing antidepressant with another antidepressant. This is in keeping with systematic reviews that have specifically explored augmentation strategies (e.g., Zhou, Qin, & Del Giovane, 2014). However, Davies et al. (2019) note that there is limited evidence for the effectiveness of other antidepressant treatment strategies for TRD, such as increasing the dose on an existing antidepressant or switching to a new antidepressant medication. The findings of the STAR*D study also suggest that there are ceiling effects with strategies that involve switching, augmenting, and combining antidepressants, with a relatively low likelihood of achieving remission after two treatment rounds regardless of the strategies subsequently employed (Papadimitropoulou, Vossen, Karabis, Donatti, & Kubitz, 2017; Rush et al., 2008). Concerningly, this suggests that some next step treatment approaches for TRD suggested by health guidance bodies and routinely employed in clinical practice are not entirely empirically supported.

The limitations of antidepressant medication strategies for TRD have led to the development of novel pharmacological interventions. Rather than targeting the monoamine system as do SSRIs, these medications often exert effects on the glutamatergic and opioid systems (Papakostas et al., 2003). Due to their recreational use and abuse potential, they have received significant attention in both the scientific community and the media. Ketamine, a commonly used anaesthetic that targets the glutamatergic system, is one such pharmacological treatment (Green & Li, 2000). It has been described as having superior efficacy when compared to other pharmacological treatments, as it exerts antidepressant effects almost immediately and leads to higher response rates (Papadimitropoulou et al., 2017; Ruberto, Jha, & Murrough, 2020). However, its effects are short-lived, lasting only days to weeks, so current efforts are focused on extending these effects (Thase, 2017). Other medications at the forefront of antidepressant research include buprenorphine (Stanciu, Glass, & Penders, 2017), nitrous oxide (commonly known as laughing gas) (Nagele et al., 2015), and psilocybin (commonly known as magic mushrooms) (Griffiths et al., 2016), all of which exert effects on the opioid system. Additionally, with increasing interest in the association between inflammation, depression, and non-response to treatment, research groups have begun to explore the effectiveness of anti-inflammatory medications in treating TRD (Köhler et al., 2014; Uher et al., 2014). Whilst these treatment approaches show promise, further research is needed to ensure that they deliver safe and effective outcomes long term.

Somatic treatments for TRD. Several forms of somatic therapies have also been investigated among people with TRD (Voineskos, Daskalakis, & Blumberger, 2020). Rather than altering brain chemistry, these treatments alter neural activity through the delivery of electrical currents or magnetic forces. In general, somatic therapies are not delivered as first-line treatments, but are offered if pharmacological or psychological interventions have not led to expected reductions in depressive symptoms (Voineskos et al., 2020). Electroconvulsive therapy (ECT), the delivery of electrical currents to the brain to induce seizure, is the most established of these treatments (Cusin & Dougherty, 2012). Whilst the mechanisms of action of ECT are still largely unknown, its efficacy among people with TRD is now widely accepted with response rates of over 50% consistently reported (e.g., Prudic et al., 1996). The National Institute for Clinical Excellence suggests it is considered as a treatment option for those who have not responded to alternative interventions (2020). In the New Zealand context, ECT is also recommended by the Royal Australian and New Zealand College of Psychiatrists as a treatment for people with depression who have not responded to adequate trials of antidepressant medication and psychotherapy (Weiss et al., 2019).

Several other somatic treatments have also been investigated among people with TRD. Repetitive transcranial magnetic stimulation (rTMS) involves the delivery of magnetic pulses to stimulate neurons in the brain cortex (Cusin & Dougherty, 2012). Unlike ECT it does not require a general anaesthetic, so is being increasingly explored as an alternative that is less invasive and has fewer potential adverse effects. In New Zealand, rTMS is currently only offered in one private clinic, however, the Royal Australian and New Zealand College of Psychiatrists has recommended that it be made more widely available for the treatment of people with depression (2018). Response rates of rTMS are reported to be comparable to ECT (approximately 50%) (Fitzgerald & Daskalakis, 2011) and a recent systematic review and network meta-analysis described both ECT and rTMS as significantly more efficacious than all pharmacological treatments other than ketamine (Papadimitropoulou et al., 2017). Somatic treatments that require surgery, such as deep brain stimulation (DBS) and vagus nerve stimulation (VNS), have also been investigated as treatment options for TRD. These involve implantation of devices that stimulate certain brain areas or nerves (Voineskos et al., 2020). Whilst evidence for the effectiveness of these somatic treatments is growing, there are uncertainties about response rates, administration, and duration of antidepressant effects (National Institute for Health and Care Excellence, 2020).

Non-pharmacological somatic interventions show promise for those with depression who have not responded to other treatments, such as antidepressant medication. However, due to the high costs of administration (~$6,000-$250,000USD)(Cusin & Dougherty, 2012), their relative invasiveness, and, in some cases, the stigma associated with them, they are often reserved for when all else has failed. Many argue, however, that these approaches should be employed much more frequently and swiftly among people with TRD (Mutz et al., 2019).

Psychological treatments for TRD. Despite a lack of consideration of psychological therapies in definitions of TRD, research groups have begun to explore the effectiveness of various forms for psychotherapy in the treatment of TRD. Interventions trialled among people who have failed to respond to other antidepressant medications include cognitive behavioural therapy (e.g., Wiles et al., 2007), dialectical behaviour therapy (e.g., Harley, Sprich, Safren, Jacobo, & Fava, 2008), and interpersonal therapy (e.g., Souza et al., 2016), among others. Whilst high quality work on the area is limited and many of these studies are uncontrolled, the reported findings appear promising. Several systematic reviews including a recent Cochrane study have reviewed these findings and report that, overall, psychotherapeutic interventions appear effective among people with TRD (Ijaz et al., 2018; McPherson et al., 2005; Trivedi, Nieuwsma, & Williams, 2011). Ijaz et al. (2018) note that, due to paucity of high quality studies, comparisons between the different forms of psychotherapy cannot currently be made. Of note, is the fact that the majority of existing studies explored the effectiveness of psychotherapeutic interventions as an adjunct to antidepressant medications, with participants continuing with treatment as usual whilst engaged in psychotherapeutic sessions. This means there is limited evidence for the effectiveness of psychotherapy as a stand-alone treatment for people with TRD. The STAR*D study is one of the few studies to have explored this. The authors reported no significant difference in improvements between those who switched to cognitive therapy after not responding to one antidepressant and those who switched to another antidepressant (Thase, Friedman, & Biggs, 2007). The effects of cognitive therapy were slower to emerge than the effects of antidepressants. However, as research suggests that many people with depression have a preference for psychological input over medication, it is useful to know that these forms of treatment may result in comparable outcomes among people with TRD. Additionally, the effects of psychotherapy among people with TRD have been reported to endure long term (Ijaz et al., 2018).

Summary of treatments for TRD. Over the last few decades the range of available treatments for TRD has expanded considerably. Clinicians and people experiencing TRD are now in the position to choose from an array of pharmacological, somatic, and psychological interventions. Whilst a large number of studies have aimed to explore the effectiveness of these interventions, questions remain about their efficacy. The majority of these interventions have not been specifically approved for use among people with TRD (Papadimitropoulou et al., 2017) and there is still no standardised treatment approach or set of guidelines (Shelton, Osuntokun, Heinloth, & Corya, 2010). This is likely a result of a number of factors. Firstly, the previously outlined conceptual issues relating to TRD also appear to interfere with identification of the most efficacious treatments.

Heterogeneity in TRD definitions leads to some studies including participants who are significantly more treatment resistant than in other studies. This makes investigation of comparative efficacy very challenging (Ruhé et al., 2012). Secondly, many of the studies have been described as methodologically limited in other ways. For example, many do not include follow up beyond 2-4 weeks, control groups, or comparisons of various treatments (Papadimitropoulou et al., 2017; Ruberto et al., 2020). It is likely that these issues have impeded researchers from arriving at more robust conclusions and from developing guidelines for the treatment of this group. In the absence of treatment guidelines for TRD, some have suggested that health professionals base their treatment decisions on the idiosyncrasies of the patient and personal experience (Ruberto et al., 2020; Trivedi, Fava, Marangell, Osser, & Shelton, 2006). It is somewhat concerning that, whilst so much research has been conducted and there is now an abundance of treatment options, this vulnerable group may receive care based on guesswork rather than evidence.

Long term outcomes of TRD. Despite significant research on the area and the development of new and novel treatment approaches, long-term outcomes for people with TRD remain poor. The STAR*D study reported that with each successive treatment failure chances of achieving remission decreased significantly (Rush et al., 2008). Poor outcomes appear to be the case even among people who eventually find a treatment that works. Rush et al. (2008) described a strong association between number of previously failed rounds of treatment and relapse rates after 12 months. This is supported by findings of a systematic review of studies exploring longer-term outcomes of TRD, which reported that 80% of those who had eventually responded to a treatment experienced relapse within a year (Fekadu, Wooderson, Markopoulo, et al., 2009). This review also highlighted that TRD is associated with poorer quality of life, more functional impairment, and increased mortality when compared to depression that does respond to treatment as expected. People with TRD experience longer periods of illness, more severe difficulties, and more comorbid physical and mental disorders – and each of these are factors that increase burden of disease (Fekadu, Wooderson, Markopoulo, et al., 2009). Perhaps understandably then, TRD presents significant economic and humanistic burdens to patients, their families, and healthcare systems (Johnston, Powell, Anderson, Szabo, & Cline, 2019; Mauskopf et al., 2009; Mrazek, Hornberger, Altar, & Degtiar, 2014).

Rationale for the present research

Despite the emergence of the construct of TRD over 50 years ago, there remains a lack of consensus on how non-response to treatment in depression should be defined and conceptualised. These conceptual issues have substantive implications for research on the topic of TRD more broadly, preventing researchers from accurately estimating prevalence and from reaching conclusive findings on risk factors and the most effective treatments. These issues also likely have flow-on effects for those in clinical domains. Faced with a distinct lack of guidance, clinicians may struggle to offer care in a systematic or evidence-based manner and patients with TRD may endure a potentially random spate of treatments for months or years with little improvement.

What approaches to defining, conceptualising, and explaining TRD do appear to have in common, is the tendency to frame the individual and their depression as the reason for non-response to treatment. When people with depression do not experience improvement following the standard pharmacological treatments, they are considered ‘treatment resistant’. This is likely fuelled by widespread assumptions that existing treatments are effective and will therefore result in cure, and the unease that results when this is not experienced or witnessed. Some authors are beginning to explore the possibility that it is the service delivery and treatment approach that is the source of symptom persistence rather than the idiosyncrasies of the person experiencing depression. For example, they have pointed to emerging findings that antidepressant medications are not as effective as once thought and, instead, may exert effects that resemble resistance or lead directly to symptom continuation. The majority of the literature, however, remains focused on exploring why a person is treatment resistant and what new (mostly pharmacological) treatments can be developed and offered to remedy this. Within this framework, TRD has become a pseudo-diagnostic category.

Combined, these factors create a unique context and shape how people experience and make sense of their depression that does not resolve despite treatment. Whilst there is research exploring the experiences of people with other forms of persistent depression, there is no known literature exploring the experiences or perspectives of this group. This research addresses this gap in the literature, by exploring the ways that people make sense of and account for their experiences of depression that does not respond to treatment as expected.

Research aim

The aim of the research was to explore how people make sense of and account for their experiences of TRD. The thesis addresses this research aim using a narrative psychology approach. A narrative approach was employed so that the stories of those experiencing TRD could be explored.

Chapter overview

This thesis takes the form of a thesis by publication. Specifically, the thesis comprises of two findings chapters presented as journal articles, one findings chapter presented in standard chapter format, and five background and supporting information chapters provided in standard chapter format. In this first chapter, **Chapter One**, the research context has been explored, and the basis for the present study as well as the research aim have been presented. This chapter provides an overview of the area of interest without repeating the nuances of the introduction sections of the two journal articles. **Chapter Two** outlines the methodology of the research, including the social constructionist epistemology and the narrative approach. **Chapter Three** outlines the method employed when carrying out the research, including the setting, the recruitment process, the participants, the interview process, the analytic process, as well as ethical considerations. As the method sections of the journal articles were limited in depth due to word count restrictions, Chapters Two and Three provide a more in-depth outline of the research methodology and method.

Chapter Four presents journal article one, which has been published in Qualitative Psychology. This journal article outlines two narratives that structured participants' experiences of

TRD. **Chapter Five** presents journal article two, which outlines two narratives that participants drew on to account for their experiences of TRD. This is being considered for publication by Sociology of Health and Illness. The journals allow authors to include submitted or published articles in a thesis or dissertation. Dr Mary Breheny, Dr Kirsten van Kessel, and Dr Joanne Taylor provided support and guidance throughout this process, assisted with the analysis, and provided feedback on writing and guidance on conceptual and theoretical issues. They were therefore included as co-authors on the journal articles included in this thesis. **Chapter Six** presents the findings of a single case narrative analysis in standard format. It outlines two alternative narratives, which were drawn on to account for experiences of TRD. In time, this chapter will be developed for publication.

Chapter Seven integrates the findings and discussions presented in Chapters Four, Five, and Six, in an overall discussion. It also includes the conclusion. Finally, **Chapter Eight** offers a reflection on the research process and an exploration of the role of researcher in shaping the research findings. Whilst efforts have been made to limit repetition throughout this thesis, some was inevitable due to the thesis by publication format.

CHAPTER TWO: METHODOLOGY

This chapter outlines the social constructionist epistemology and narrative psychology theoretical framework that underpin this research. It begins with an outline of mainstream approaches, which to date have informed the majority of research on depression and TRD. It then provides an overview of social constructionism and narrative psychology as a lens for research on the experience of mental distress, as well as a rationale for their use in the present study.

Mainstream approaches to the study of depression

Psychological research, including the study of depression and TRD, has predominantly been rooted in positivist epistemology. Positivism asserts that it is possible to gain objective knowledge about the world (Willig, 2013). Underpinning this paradigm are a number of assumptions. Firstly, it is assumed that the object of research exists – that there are true realities and phenomena out there in the world to be discovered and understood (Stoppard, 2000). Secondly, it is assumed that objective knowledge about these phenomena can be gained through processes such as measurement, observation or rational deduction (Stoppard, 2000). From this perspective, knowledge assumes the position of 'truth' or 'fact' and is viewed as entirely detached from the values, judgements, subjective experiences, and perceptions of those conducting the research or viewing the world. It is also seen as possible, or even preferable, to discover and understand these 'truths' or 'facts' independently of the sociocultural context in which they are produced (Rohleder & Lyons, 2015; Stoppard, 2000).

Within this framework, the study of mental distress is considered comparable to the study of natural sciences (Stoppard, 2000). With the premise that there are fundamental laws that underlie human experience and behaviour, positivism asserts that objective psychological phenomena can be revealed and understood (Murray & Chamberlain, 1999). Depression and TRD are examples of psychological phenomena that are believed to exist. Under the umbrella of positivism, there are varying theories about the nature of depression and TRD. For example, cognitive theorists assert that depression results from negative biases in cognitive processes (e.g., Beck, 1976) and biological theorists argue that both depression are treatment resistance result from biological abnormalities in the brain or body (e.g., Bennabi et al., 2015; Syvälahti, 1994). These theories are united, however, in their assertions that depression and TRD – and the associated psychological variables or processes – exist.

As well as framing phenomena such as depression as objective realities, positivism asserts that these psychological variables can be unearthed, measured, and understood in an impartial manner (Burr, 1995). As human experiences are often not easily observable by researchers, they must be defined and operationalised in a way that makes them measurable. Subjective human experiences are labelled as ‘mental illness’ or ‘depression’, operationalised using standardised criteria, and assessed or measured using surveys (Stoppard, 2000). In the case of treatment resistance, the persistence of low mood despite treatment is labelled TRD, and operationalised and assessed according to a range of standardised definitions and staging models. Within positivist frameworks, phenomena such as depression are viewed as existing within the bounded individual independent of their socio-cultural context. As a result of this, the experience of depression is individualised and the impact of the surrounding context on the person and their depression is minimised (Stoppard, 2000). This is the case with TRD, with the majority of research focused on the individual as the reason for non-response to treatment.

Rooted in positivism, Western psychology and psychiatry favour individualistic and decontextualizing paradigms. Consequently, they frame depression as a set of symptoms situated within the bounded individual (Newnes, 2014). Signs and symptoms of distress are believed to be objectively assessed and understood by health professionals using clinical interviewing, standardised measures, or diagnostic criteria such as the DSM. Additionally, knowledge gathering also occurs through self-observation and self-measurement on the part of the person experiencing mental distress. Within clinical interactions, patients are trained to engage in self-observation and communicate their findings to health professionals, who then use this information to build an ‘objective’ picture of the person’s subjective experience (Stoppard, 2000). Lastly, regardless of the believed nature of the person’s depression, improvement is deemed to come about through changes to the individual in question. Any impact of the broader sociocultural context tends to be minimised. These positivism-informed framings have long been criticised by scholars across a wide range of disciplines. They reject the possibility of ever achieving objective and value-free knowledge (Stoppard, 2000) and suggest that when broader contexts are ignored, responsibility for mental distress is placed on the individual experiencing the distress (e.g., McLellan, 1995).

Social constructionism

In contrast to positivism, social constructionist ideas argue that it is more appropriate to regard reality as constructed through social interaction (Murray & Chamberlain, 1999). Within this framework, a critical approach is taken towards taken-for-granted ‘truths’ about the nature of the world. The assumption that the world has a true nature that can be unproblematically and objectively revealed through observation is fundamentally challenged (Burr, 1995). Rather than knowledge reflecting an objective reality, social constructionism argues that knowledge arises through interactions with others (Burr, 1995; Willig, 2013). Shared versions of reality and understandings of ourselves are said to be conceptualised through daily social interactions between people. As a result of this, social exchanges and linguistic processes of all varieties are a predominant focus for social constructionists (Burr, 1995; Crossley, 2000). As these social interactions do not occur in a vacuum, social constructionism argues that knowledge is dependent on the surrounding sociocultural and historical conditions. The understandings that a person or group has are highly influenced by the era in which they are alive, the place in which they live, and the economic, social, and political climate at the time (Burr, 1995). For Foucault (1973) this is inextricably linked with power – as within any socio-cultural context, there are institutions with the power to promote their favoured version of reality. As socio-cultural contexts are ever-evolving, social constructionism views understandings as fallible, partial, and provisional (Smith & Sparkes, 2006; Stoppard, 2000). According to Burr (1995), each of the many knowledges carries with it implications for social action. Different constructions of phenomena encourage or discourage certain ways of acting in the world.

From a social constructionist perspective, the taken-for-granted concepts of mental distress, depression, and TRD are not ‘real’ phenomena located within the individual able to be objectively unearthed and understood. Just because these concepts have been framed as distinct categories (e.g., mentally ill or mentally well; treatment responsive or treatment resistant), does not mean that they reflect true divisions. Instead, social constructionism views these understandings as constructs that have been created through social interactions (Burr, 1995). This means that concepts such as TRD have been defined and categorised through social processes, in accordance with the values, beliefs, and powers of those doing the defining (Caplan & Cosgrove, 2004). According to social constructionism, understandings of mental distress are products of the social, political, and economic context. For example, as medicine and science are privileged in modern day Western society, certain constructions – namely, biomedical models – of mental distress are favoured. From this perspective, it is argued that biomedical understandings of depression predominate in Western society today due to the power of certain institutions, such as the pharmacological industry, in structuring shared understandings (Burr, 1995). Constructions of TRD in Western contexts are similarly shaped by the powerful institutions of medicine and science. Each particular understanding of mental distress, depression, or TRD brings with it certain options for social action (Burr, 1995). For example, biochemical constructions of depression and TRD may encourage the social action of widespread antidepressant prescription and consumption, and individualising constructions may encourage people with depression and TRD to take personal responsibility for their distress.

Narrative psychology

Narrative psychology is primarily concerned with exploring the ways in which humans organise, make sense of, and interpret their lived experiences through storytelling (Murray, 2008;

Silver, 2013). According to Sarbin (1993), it is human nature to tell stories about the self, others, and the world, and this process is a fundamental part of everyday life across cultures. When recounting experiences, people arrange the components in a way that can be understood by others, with a beginning, middle, and end to add causality to an otherwise disconnected array of events (Murray, 2003; Polkinghorne, 1988). Narratives structure an account of events in a way that imparts meaning and allows people to make sense of their pasts and predict their futures (Murray, 2003).

Storytelling is particularly evident in situations where people's expected life courses have been disrupted, for example by the experience of significant illness (Stephens, 2011). In these circumstances, it is argued that the narrative which has previously formed the cornerstone of the person's identity is disturbed and a discrepancy between ideal self and actuality may result (Silver, 2013). At these times of significant upheaval, "narrative wreckage" (Frank, 1995, p. 55) or "biographical disruption" (Bury, 2001, p. 169) are said to occur. Or, in the specific case of mental illness, the person is said to experience "an incoherent story" or "an inadequate account of oneself" (Polkinghorne, 1988, p. 179). In these situations, the person becomes ungrounded, ceases to be able to make sense of the situation, and loses a sense of who they are and their life direction. Life feels chaotic and meaningless and there is a breakdown in coherent life story (Crossley, 2000). When disruptions such as these occur, the person is faced with the challenge of making sense of what is going on and reconstructing their life narrative and identity in order to maintain a sense of coherency (Crossley, 2000). At these times, people often turn to storytelling (Silver, 2013). Narrative psychologists argue that through hearing themselves speak of their experiences, observing others' responses, and hearing their stories being retold, people engage in a meaning making process which allows them to make sense of the experience and restore a sense of order (Crossley, 2000; Murray, 2008; Sarbin, 1993).

As well as allowing people to make sense of their experiences, narratives play a central role in the navigation of identity (Hiles & Cermak, 2008). In times of disruption where a coherent sense of self may be lost or challenged, such as the experience of mental illness, people work to reconstruct a meaningful self-concept through engaging in storytelling (Crossley, 2000; Hiles & Cermak, 2008). Narrative researchers note that through the process of telling stories about the self and the world people not only come to *understand* themselves but also *create* themselves (Crossley, 2000). Rather than revealing an ‘essential’ self, narratives allow people to present favoured versions of the self (Riessman, 2003). Through telling stories, people position themselves – as social actors in the world – in certain lights. This occurs through people deciding which stories to tell and which to withhold as they relay certain events and account for their actions, with differences according to the context and the audience (Hiles & Cermak, 2008).

As people are embedded in certain contexts, the stories they tell and the identities or positions they adopt are inextricably linked to the broader social, cultural, and temporal landscape (Crossley, 2000). As Murray (1999) notes, people are born into contexts that are stocked with an assortment of social narratives that they can adopt, resist, and negotiate as they make sense of their everyday experiences. When people tell personal stories about their life experiences and position themselves in certain ways, they are always doing so with reference to these narratives. However, the narratives circulating in society are not value free. Instead, some narratives condition the way people think, speak, and position themselves more than others, due to the fact that they reflect certain power interests (Murray, 2003). As a result of this, even phenomenological accounts are telling about the nature of our world (Silver, 2013; Stephens & Breheny, 2013). In the case of depression, examination of personal stories gives insights into the commonly held beliefs, societal rules, and systems and forces, that structure understandings of mental distress and inform positioning within a given context. For example, examination of depression stories in a Western context may illuminate dominant biomedical narratives of mental distress, which inform the way a person understands their depression (e.g., as biochemical in nature) and positions themselves (e.g., as a chemically imbalanced person requiring recalibration).

Narrative analytic approach

Within the theoretical framework of narrative psychology there are a variety of approaches to analysing narratives. Narrative analysis is a theoretical approach rather than a singular prescribed method. This means that guidelines do not provide step-by-step instructions, but rather, offer a way of considering, exploring, and understanding the way in which people make sense of themselves and their experiences through storytelling (Stephens & Breheny, 2013). Broadly, employing a narrative analytic approach means engaging in in-depth investigation of the content and function of the story that has been told, and exploration of what is telling about what has been included in this story and what has been left out.

Murray (2000) has proposed four levels of narratives to consider when engaging in narrative analysis: personal narratives, interpersonal narratives, positional narratives, and ideological narratives. Personal narratives are individuals' stories about their experiences of certain events or phenomena. At this level, analysis is focused on how the individual is using narrative to understand and explain their experiences and (re)define their identity (Stephens & Breheny, 2013). This level of analysis is similar to other phenomenological approaches within qualitative research and has become the dominant focus in narrative analyses (Murray, 2000). However, as humans are social beings who interact with others and exist and function within certain sociocultural contexts, many researchers are interested in more social levels of analysis, namely, the interpersonal, positional, and ideological levels (Murray, 2000). At the interpersonal level, analysis is focused on how narratives have been jointly constructed by both the storyteller and the audience (Stephens & Breheny, 2013). The level of analysis involves examining the ways in which the interviewer's questions, silences, and responses informed the stories the interviewees chose to tell. It also extends to consideration of the storyteller's imagined audience beyond the interviewer, for example, future readers of disseminated reports or research supervisors (Murray, 2000).

Murray's positional level of analysis is concerned with the moral and social functions that a narrative may perform (2000). At this level, narrative researchers explore how storytellers position themselves by using narratives to perform certain identities and resist or avoid others (Stephens & Breheny, 2013). Additionally, consideration is given to the positioning of interviewers, audience members, and other characters, as well as the power relations that exist. At the ideological level, the narrative analysis is focused on the publicly available narratives that circulate within the wider sociocultural context (Murray, 2000). These include the often taken-for-granted societal and cultural ideas and assumptions that inform individuals' and groups' thoughts, beliefs, stories, actions, and positions. For example, in the domain of mental distress, these may include widely held ideas about recovery, medicine, and what it means to have a mental illness. Stephens and Breheny (2013) combined Murray's positional and ideological levels into the so-called public level. Whilst these narrative approaches, and the manner in which they have been presented above, give the appearance of structured frameworks comprised of distinct levels, the authors highlight that this is not the way narratives are structured. Instead, as narrative production occurs, each of these levels are at play in an interconnected manner at all times (Murray, 2000; Stephens & Breheny, 2013).

Locating the present research

Much of the previous research on TRD has been rooted in a positivist epistemology. This frames TRD as a phenomenon that is biochemical in nature, which exists within the bounded individual and is largely separate from context. From this perspective, TRD can be objectively understood through exploration of causal factors and clinical characteristics, measured using standardised definitions and staging models, and (eventually) effectively treated with medication. From a social constructionist perspective, this view of TRD may prevail in Western settings due to the power of certain institutions (e.g., the pharmaceutical industry) in promoting their favoured versions of reality (Burr, 1995; Foucault, 1973). Much of the existing work on health beliefs and experiences has failed to explore the rich and nuanced contexts within which people are embedded

(Murray, 1999). This is the case with TRD, with the predominant focus of research on the individual as both the site of pathology and the reason for non-response to treatment. By ignoring broader contexts, it is argued that researchers and clinicians assign blame to individuals for their mental distress (e.g., McLellan, 1995).

Grounded in a social constructionist epistemology, this study will employ a narrative approach to research guided by the analytic approaches of Murray (2000) and Stephens and Breheny (2013). With this epistemological and theoretical leaning, the present study will provide an alternative perspective to taken-for-granted understandings of TRD. In contrast to much of the existing literature which is individualising, the research will contextualise understandings of TRD and the corresponding options for social action. As storytelling is particularly evident at times of significant illness, a narrative approach is well suited to the exploration of these understandings (Stephens & Breheny, 2013). Through employing a narrative approach, the research will illuminate dominant narratives of mental distress and recovery that powerfully shape the way these people make sense of persistent depression and navigate identity. With this methodological approach, it is hoped that rich and nuanced insights will be offered into the manner in which the unique construct of TRD is navigated.

CHAPTER THREE: METHOD

To contextualise this research, this chapter begins with an outline of the setting in which the present research took place. This includes a description of the private practice that was the site of recruitment and data collection, an overview of the private practice's surrounding suburb, as well as some context of mental health service provision in New Zealand. This enables the reader to situate the private practice and the participants within a wider social context. This chapter then outlines how this research was conducted. This includes an overview of the recruitment process, a description of the participants, and details of the interview procedure and analytic process. The chapter concludes with a brief discussion of the ethical issues considered in this research. Consistent with the previous chapter, as this document is presented as thesis by publication and the articles are included in their original forms, some of this chapter's content is repeated in the Method sections of the two articles (presented in Chapters Five and Six). This predominantly relates to the content on the recruitment process, the participants, the interview process, and the analysis. As the Method sections of the articles were constrained by journal word limits, the opportunity has been taken to include full and unabridged versions in this chapter.

Setting

The private practice. Recruitment and interviewing for this research occurred at a psychiatry and psychology private practice in an inner city suburb of Auckland, New Zealand. The private practice offered the services of four psychiatrists, two psychologists, and a psychotherapist to adults experiencing a range of mental health difficulties. More specifically, services offered included psychiatric and psychological assessment, diagnosis, and treatment of mental illness or distress. The private practice website defined mental illness in a manner consistent with Western psychiatric conceptualisations of mental distress. Broadly, the website described mental illness as a disorder of the mind that impacts emotional, cognitive, perceptual, and behavioural domains and can interfere with ability to function in society as expected. The private practice gained clientele through either self-referral by an individual or their family/support people or through referral from other health-professionals such as general practitioners (GPs).

The practice was neutrally decorated and had a large reception and waiting room, a small kitchenette area supplied with refreshments, a bathroom, and four consulting rooms. Two reception and administration staff were employed at the practice who frequently greeted clients by name upon their arrival. Interviews were conducted in one of the consulting rooms at the private practice. These rooms were the clinical spaces typically used by clinicians when interacting with clients. The consulting rooms had plain décor and were furnished with armchairs, coffee tables, bookshelves, clocks, and desks. Each room had a large window with blinds drawn for privacy. On display in the consulting rooms were practicing and registration certificates as well as a range of clinical psychology and psychiatry books, including recent and current versions of the DSM.

The surrounding area. The private practice was located in a central, predominantly residential suburb of Auckland, New Zealand. The suburb is significantly less ethnically diverse than other areas of Auckland or New Zealand overall, with predominantly Pākehā (New Zealand European) residents (81.5%). This is disproportionately high compared to the general Auckland region (53.5%) and the total population of New Zealand (70.2%). The number of Māori residents (8.2%) is also significantly lower in this suburb than in the broader Auckland region (11.5%) and New Zealand as a whole (16.5%). This pattern also holds for Pasifika residents and Asian residents (Statistics New Zealand, 2018). Whilst historically a working-class suburb, the suburb has seen significant gentrification in recent years and is now predominantly upper-middle class. Residents of the suburb have higher levels of educational attainment, with over 50% achieving a Bachelor's degree or higher, compared to 31.1% in the general Auckland region and 24.8% in New Zealand overall. Residents are also significantly more likely to be in professional or managerial roles than residents in the general Auckland region and in NZ generally. Unemployment is low and residents of the suburb have a significantly higher median income ($59,500) than residents in the general

Auckland region ($34,400) and the total NZ population ($31,800) (Statistics New Zealand, 2018). Combined, these recent statistics highlight that residents of the suburb are not comparable to residents in Auckland or New Zealand more generally, in that they are predominantly Pākehā (New Zealand European), affluent, and tertiary educated.

The broader New Zealand health system context. New Zealand has a universal publicly funded health service, with a vision to provide equal access to high quality treatment to all New Zealand residents (McLintock, 1966). This public health service comprises of 20 district health boards across New Zealand that provide services free-of-charge to New Zealand residents within their assigned geographical regions (Ministry of Health, 2018). Funding covers the majority of health services, including hospitalisation, mental health, public health, aged care, and services in the community (Ministry of Health, 2016a). Despite the public health service's strengths, people in New Zealand are often faced with long waitlists unless treatment is deemed urgent (Organisation for Economic Co-operation and Development, 2013). This is equally the case for mental health services. The majority of public mental health funding (~96%) is allocated to specialist services, which serve the needs of the 3% of people experiencing the most severe mental health difficulties in any given year (Government Inquiry into Mental Health and Addiction, 2018). Approximately 20.7% of New Zealanders experience a mental disorder in any given year (Oakley Browne, Wells, & Scott, 2006) and this number is steadily on the rise (Ministry of Health, 2019). A small minority of these people can access GP or psychologist care through accessing the remaining (~4%) public mental health funding. This funding is specifically targeted towards particularly vulnerable groups, such as Māori and Pasifika people and those on low incomes (Government Inquiry into Mental Health and Addiction, 2018). However, the majority of New Zealanders experiencing mental distress or disorder who do not make up the 3% most severe are unable to access publicly funded mental health care.

These factors have led to an increase in privately funded specialist services. Private services are paid for either directly by patients or by private health insurance providers, and allow for more prompt access to non-urgent or elective treatments (Ministry of Health, 2016b). Whilst this takes some pressure off the public health service, the costs of both the private services themselves and private health insurance are high and therefore prohibitive for most New Zealanders. Only 35% of New Zealanders are reported to have private health insurance (Ministry of Health, 2016b) and, of this group, it is estimated that less than a third have comprehensive plans that cover mental health services (Health Funds Association of New Zealand, 2019). Whilst it is common internationally for private health insurance to be paid for by employers, the majority (79%) of people with private health insurance in New Zealand pay for it themselves (Ministry of Health, 2016b). In New Zealand, the groups most likely to have private health insurance are those with high incomes who live in larger cities (Ministry of Health, 2016b).

The private practice that served as the setting for this research was one such privately funded specialist service. Clientele of the service – including any research participants – were therefore affluent enough to pay for services directly or to afford private health insurance with comprehensive plans that covered mental health care. This private service would therefore not be accessible to the majority of New Zealanders.

Recruitment

Participants in this research project were recruited by a psychiatrist working at the private practice. This psychiatrist was highly experienced in the domain of general adult psychiatry, with over 20 years of psychiatric experience working with adults in both public and private health settings. His general approach included assessment, diagnosis, and treatment of mental illness as well as evaluation of relevant physical health domains. Treatments offered were largely pharmacological in nature. At the time of recruitment and interviewing, he was also beginning to offer transcranial magnetic stimulation (TMS), a somatic treatment offered to people experiencing depression that had not responded as expected to antidepressant medications. Additionally, the psychiatrist had trained in cognitive behaviour therapy (CBT) and, at times, offered short-term skills-based psychotherapeutic input. He also frequently made referrals to clinical psychologists within the private practice or elsewhere for more comprehensive psychological input.

In order to recruit participants for the research, the recruiting psychiatrist consulted his records to identify existing clients on his personal caseload who met criteria for inclusion in the research (see Participants section below for these criteria). Following this, during or after the clients' routine appointments, the psychiatrist enquired as to whether they were interested in participating in a study on depression. If interested, he provided them with an Information Sheet and Consent Form (Appendix A) that detailed the purpose of the study and what participation would involve. He also asked permission for their contact details to be shared with me and for them to be contacted via telephone. Following this, I contacted those interested via telephone to explain the purpose of the study and answer any questions that had arisen from their reading of the Information Sheet. Following this brief discussion, if the clients were willing to participate in an interview, a date and time was set for the interview to take place.

Participants

To take part in the research, participants needed to be adult clients (at least 18 years of age) of the recruiting psychiatrist at the private practice. Participants also needed to have a current DSM-5 diagnosis of major depressive disorder, and be considered 'treatment resistant' according to the most commonly employed definition of TRD: have failed to respond to two or more rounds of antidepressant medication at an adequate dose and duration. This diagnosis of depression needed to be the primary disorder. Additionally, the participants must *not* have a current or lifetime diagnosis of bipolar disorder I or II or a psychotic disorder, an unstable, serious, or life threatening medical or neurological disorder, or be at serious, high, or imminent risk of suicide. The participants also needed to be able to provide informed consent and participate in 60-120 minute interview. Suitability for participation was based on these criteria and assessed by the recruiting psychiatrist.

Twelve people volunteered to participate in this study. Of these 12, three elected not to participate after being contacted by phone by the researcher, citing mental health issues that made it difficult to engage in an interview. The remaining nine participants ranged in age from 28 – 65 years, with a mean age of 47 years. Three of the participants identified as women and six identified as men, and all participants identified as Pākehā (NZ European). Over half of the participants (56%) had completed a bachelor's degree or higher, and all but one of the participants were currently employed or self-employed. Six of the participants were married or in de facto relationships and three were single or separated. All participants met the criteria for participation in the research outlined above. As well as having current diagnoses of depression, five of the participants also indicated that they had been diagnosed with generalised anxiety disorder. Whilst not essential for participation and not considered in this definition of TRD, the participants had often engaged in a number of other treatments, alternative therapies, and lifestyle changes. These included psychological therapy, yoga and meditation, and exercise.

Interview procedure

To begin each interview, I introduced myself and my background as a clinical psychology trainee and doctoral student. Following this, the Information Sheet and Consent Form, which the Consultant Psychiatrist had previously provided, were reviewed and any questions were addressed. If participants were comfortable proceeding, they were asked to sign the Consent Form. At the time of the interview, participants also completed a brief demographic questionnaire (Appendix B).

Following this, I commenced audio recording and invited the participants to tell the story of when their depression first began. Whilst the term 'treatment resistant depression' was used in the Information Sheet, I used the broader term 'depression' throughout the interviews. Following the initial prompt, the interviews were predominantly participant-led, with an open structure and no fixed interview questions. However, I kept the general aim of exploring how these individuals experienced, understood, and made sense of their depression through storytelling in mind throughout the interviews.

Whilst the interviews were not structured, I attempted to elicit narrative accounts and rich descriptions through broadly employing a style of questioning suggested by Murray (2003). Firstly, I specifically asked for narrative accounts, for example, by asking questions such as, "Could you tell me the *story* of your first experience of depression?" or "Could you tell me the *story* of your first encounter with a mental health professional?". Secondly, I made frequent reference to certain times and places in order to encourage these sorts of accounts. For example, I asked questions such as, "Could you tell me more about the *time* the doctor said you have depression?" or "*Where* were you living when you first experienced depression?" I ended each interview by asking "Is there anything that we haven't talked about today that you think is relevant or important?" The interviews were conducted in a relatively informal manner and I sought to be encouraging, supportive, and empathetic.

Overall, this general interviewing approach allowed for flexibility within each interview as it progressed. The interviews ranged in length from 34-77 minutes. Following the interviews, I offered participants a $50 petrol voucher to thank them for their time and willingness to share their story. After each interview, I also made brief notes on the interaction, for example, the general demeanour or level of engagement of the participant or strong narratives that seemed to have emerged in the interviews.

Data analysis

Analysis was guided by the narrative approaches of Murray (2000) and Stephens and Breheny (2013), with particular focus on analysis of multiple layers of meaning and the intersection between these layers. The interviews were transcribed using Inqscribe, a freely available transcribing tool. Data analysis began at this stage, as I became more familiar with the general structure and content of each participant's account through the process of listening and transcribing. Each transcription was cross-checked for accuracy and then reread multiple times as part of the continued familiarisation process. Following this, the transcripts were printed with double lined spacing and wide margins and notes were made about the participants' accounts.

I repeatedly read through each transcript until personal stories emerged for each participant. Whilst identifying personal stories, I looked for subjective accounts of depression that had characters engaging in certain actions (e.g., a health professional diagnosing depression) and a recognisable plot – a beginning, middle, and end (e.g., an evolving account of a first episode of depression). At times, personal stories were presented in seamless and unbroken sequences. However, at other times they were difficult to follow, complicated, had deviations from the plot, or were abandoned. The structural characteristics of a story were not taken as indicative of its value as narrative data (Wong & Breheny, 2018). Transcripts were then compared and contrasted, with commonalities and differences identified in the personal stories told by participants. To aid this process, highlighters were used to colour code the various personal narratives that emerged.

During this analytic process, when considering the interpersonal level of narratives, I also considered how I had contributed to the construction of the stories that emerged. I considered what I had chosen to share about myself, my presentation and demeanour in the room, my reactions and responses to participants' stories, and how these factors had influenced storytelling - in terms of what the participants chose to disclose and what not to disclose. I also considered how my thoughts, beliefs, assumptions, and prior experiences, which I brought to the interaction, had shaped the interaction, the stories told, and the positions and identities negotiated, adopted, and rejected. My voice is often included in the extracts presented in this thesis, so that this co-construction is evident. A more thorough discussion of reflexivity and the role of the researcher in this research is presented in Chapter Eight.

Throughout the analytic process, I also considered the broader social context in which the participants, the research, and I were embedded. I began to examine the impact of this context on narrative production. To do this, I considered how this context and the publicly available narratives that circulate within it may have influenced the stories that were told, the stories that could be told, and the stories that were discouraged or could not be told. In this research, these publicly available narratives often included narratives of clinical psychology, medicine, mental distress, and recovery that shape how depression and mental distress are storied. The analytic process was not linear. Instead, I created multiple visual brainstorms, drafted multiple written pieces outlining various narratives, and discussed the emerging stories in supervision meetings. Findings were repeatedly reviewed, reconsidered, and rewritten as discussions were had and as the findings section of the thesis was drafted.

Ethical considerations

Ethical approval to undertake this research was granted by the New Zealand Health and Disability Ethics Committee – Northern A (HDEC Ethics Reference: 16/NTA/197/AM05). Details of the ethical considerations relevant to this research were outlined in detail in a comprehensive online form which was reviewed by the committee. Along with two supervisors, I also attended the committee meeting and answered further questions regarding the study. Given that those with TRD are considered to be a vulnerable group, care was taken at every stage of the research process to be aware of the vulnerabilities of participants and to protect their interests. Specifically, primary ethical concerns related to the consent process, maintaining confidentiality when the interviews took place in the existing healthcare provider's place of work, and the potential for distress during or following interviews.

Firstly, the fact that the research took place in the offices of the participants' existing healthcare provider and that the participants were recruited by this healthcare provider presented issues relating to the consent process and potential for coercion into participating as well as confidentiality. To mitigate these risks, both the recruiting psychiatrist and I told the participants that they were under no pressure to participate and, that if they chose not to, there would be no impact on their standard of care at the practice. I also explained that only my research supervisors and I (and not the recruiting psychiatrist or other private practice staff) would hear the audio recordings or read the transcripts and that all identifying information would be removed prior to publication. To ensure anonymity, pseudonyms have been used in this thesis and any published material, and any identifying information has been removed.

Given the sensitive nature of the topics discussed, another concern was the potential for participant distress during or following the interviews. I reminded the participants that they were free to end the interview at any time without consequence. If participants became distressed or upset I was able to use clinical skills to support them through their distress and to ask them if they would like to pause, postpone, or end the interview. On several occasions throughout the interviews participants became mildly distressed. In these instances, after a brief pause and discussion about how to proceed, all participants reported that they were happy to continue. Additionally, the interviews only occurred when psychiatrists or psychologists working at the private practice were on site, so that I could seek out support from registered professionals in managing a participant's distress if need be. Throughout the interviewing process, outside support was not needed. Following the interview, I acknowledged the sensitive nature of the content discussed and enquired as to how the participant was feeling about continuing with their day. In all instances, the participants reported that, whilst the content was somewhat difficult, they had valued the opportunity to talk about their depression and felt able to transition back to their daily lives. I reminded the participants that the Information Sheet (of which they had a copy) contained contact details for the private practice as well as helplines, crisis teams, and the region's public mental health services, which could be contacted for follow-up support if needed.

These ethical considerations were also addressed in the Information Sheet and were discussed in detail with each participant during the Informed Consent process. I also attempted to create frequent opportunity for participants to ask questions: on the phone at first contact, upon meeting prior to the interview, and following the interview.

CHAPTER FOUR: ARTICLE ONE – Narrating the experience of TRD

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Abstract

A significant proportion of people with depression do not experience expected recovery following treatment with antidepressant medication and are considered to have treatment resistant depression. Despite this, there is relatively little research exploring the experiences of this group of people, who represent a significant minority of those who experience depression. The current study addressed this gap in the literature by exploring how people with treatment resistant depression understand and make sense of depression that has not resolved following adherence to professional advice and treatment. A narrative approach was adopted, with a particular focus on personal stories told by participants and interpersonal stories co-constructed between the participants and the interviewer. The accounts of nine people with treatment resistant depression recruited from a private psychiatry and psychology practice in Auckland, New Zealand were analysed. Two narratives were identified: firstly, a narrative of order was used to organise and make sense of their experiences, which was informed by wider clinical psychology assumptions and expectations of recovery. Secondly, a narrative of disorder was used to describe the persistence of depressive symptoms and the difficulty they experienced predicting and responding to these experiences. Across these accounts, there was a general pattern of participants drawing on the narrative of order when storying early experiences of depression and, after outlining experiences that disrupted these ordered constructions, drawing on the narrative of disorder when storying later experiences. However, this pattern was not strict. Instead, a narrative tension emerged, with the participants repeatedly switching back and forth between the two narratives. Ultimately, the participants used both narratives to make sense of and account for their experiences of treatment resistant depression.

Keywords: treatment resistant depression; mental illness; recovery; identity; narrative

Introduction

Major depressive disorder (hereafter referred to as depression) is traditionally conceptualised as a clinical condition that involves sad, empty, or irritable mood, and physical and cognitive changes that adversely impair a person's functioning. It is defined using symptom-based diagnostic classification systems such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013). Depression is a leading cause of disability in the developed world (World Health Organisation, 2019) and affects approximately one in six people in New Zealand (Oakley Browne et al., 2006). Consequently, the development of treatments has been a priority.

Pharmacological and psychotherapeutic treatments have advanced significantly over recent years and have improved outcomes, however, a considerable proportion of people continue to experience significant distress even after receiving interventions (Berlim, 2007). This lack of expected treatment response is frequently termed treatment resistant depression (TRD). TRD is most commonly defined in academic literature as an episode of depression that has not responded to two or more trials of antidepressant medication at an adequate dose and duration (Brown et al., 2019). However, systematic reviews highlight that there is considerable heterogeneity among definitions adopted in empirical studies, and little overlap between academic and clinical understandings (Brown et al., 2019). Some studies employ definitions based on progression through staging models, or consider diverse forms of treatment when calculating number of treatment failures (Brown et al., 2019). This lack of a common definition creates a challenge in estimating prevalence. However, STAR*D, the largest study to date evaluating effectiveness of depression treatments, found that only 50% of the sample had achieved remission from depression following two rounds of treatment (Rush et al., 2008).

The term TRD is often used interchangeably with ‘chronic depression’ and ‘recurrent depression’, which leads to confusion in both clinical practice and scientific literature. However, TRD appears to be unique, as most people with ‘chronic depression’ have not received adequate treatment, and people with ‘recurrent depression’ do respond to treatment and experience periods of full recovery. Therefore, neither group can be considered ‘treatment resistant’ (Gelenberg et al., 2006). People with TRD have sought and received adequate treatment, yet have not experienced expected recovery from depressive symptoms. Consequently, they can feel discouraged and hopeless, report high levels of self-injurious behaviour, and experience poor quality of life (Dunner et al., 2006; Greden, 2001). TRD also significantly influences support people, health services, and society (Wiles et al., 2013) and is considered a major challenge for clinicians (Wijeratne & Perminder, 2008).

Health Service Experiences. When individuals experience depression without recovery, there can be implications for health service experiences (McPherson & Armstrong, 2009; McPherson, Byng, & Oxley, 2014; McPherson, Walker, & Carlyle, 2006). Primary care counsellors’ reactions towards these clients have been found to be predominantly negative. They described feeling deskilled and powerless in their work, finding the sessions painful and draining, and experiencing ‘heartsink’ moments when these clients entered the service (McPherson et al., 2006). General practitioners’ (GPs) described patients as burdensome, manipulative, or difficult people with generally unpleasant characteristics, and there was a general loss of empathy when patients did not improve over time (McPherson & Armstrong, 2009). Whilst these health professionals typically draw on medical models of depression, this was not the case for patients with TRD. Instead, they used psychosocial explanations, such as previous trauma, problematic attitudes or personalities, social deviance, and deficits in coping skills to explain prolonged symptoms (McPherson & Armstrong, 2009). This suggests that, when individuals respond to treatment as expected, GPs label them as depressed and situate their experiences within a medical framework. However, when patients do not respond to antidepressants, responsibility is attributed to the client for not recovering due to them being ‘difficult’, ‘manipulative’, ‘unpleasant’ and ‘socially deviant’. These explanations for TRD can be understood in terms of publicly available narratives that frame how clinicians and patients understand depression to progress and resolve.

Narratives of Depression and Recovery. Personal narratives of single episodes of depression tend to follow a typical sequence, which broadly includes a) an initial realisation that something is wrong, b) a struggle to come to terms with and understand the new experience and identity, c) a period of help seeking, and d) a transition to recovery (Karp, 1994; Schreiber, 1996). Similar patterns are documented in recent studies exploring the experience of depression (Bygstad-Landro & Giske, 2017; Hajela, 2013; Hänninen & Valkonen, 2019; Ridge & Ziebland, 2012). Hänninen and Valkonen (2019) found that depression and recovery were experienced as a gradual shift from disengagement and isolation to reengagement with everyday life. Similarly, Bygstad-Landro and Giske (2017) describe the experience of depression in terms of the grounded theory of ‘risking existence’, which consists of four phases: a deep sense of isolation, shame, and turmoil, beginning to open up to others, learning how to manage their depression, and accepting themselves and their depression and re-entering the world. When narrating their depression, people describe profound feelings of sadness, hopelessness, apathy, irritability, and fragility (Hajela, 2013). Depression has also been described as a painful paradox. As well as experiencing significant struggle, withdrawal, and isolation, people simultaneously want to engage, take control, confront their issues, form relationships, recover, and make plans for the future (Danielsson & Rosberg, 2015; Rapmund & Moore, 2000; Sarkohi, Frykedal, Forsyth, Larsson, & Andersson, 2013). These studies highlight a shared public narrative of depression that progresses from onset of difficult experiences, recognition and naming of these experiences as depression, engagement with treatment, to ultimate recovery.

These public accounts of depression all include a recovery phase, which tends to follow a period of help-seeking. People who have recovered from depression highlight the importance of periods of introspection and reflection (Hänninen & Valkonen, 2019). They attribute their recovery to the personal insights, such as becoming more aware of the factors contributing to their depression and learning to trust their instincts (Ridge, 2018; Steen, 1996). People who have recovered from depression also tell of shifts in the way they view themselves, the world, and their futures (Ridge & Ziebland, 2006; Steen, 1996). For example, they stop engaging in self-blame, begin to adopt more hopeful attitudes about recovery, and begin to see depression as an experience distinct from the self, rather than part of the self (Ridge, 2018; Ridge & Ziebland, 2006). Eventually, people tell of being able to look back on their depression experience and rewrite it more positively (Hajela, 2013; Hänninen & Valkonen, 2019; Karp, 1996; Ridge & Ziebland, 2006; Schreiber, 1996). For example, depression is reconstructed as a spiritual journey, an experience leading to increased self-awareness, as motivation to find meaning in life, or as means to connect with a more authentic self (Ridge & Ziebland, 2006). Throughout this process, people impose a sense of meaning and order to their experiences of depression.

These personal narratives of depression are consistent with broader publicly available and favoured narratives of illness. For example, the findings are consistent with Western recovery narratives that suggest "yesterday I was healthy; today I am sick; but tomorrow I will be healthy again" (Frank, 1995, p. 77). This is the culturally dominant narrative of illness; inherent in this narrative is the modernist expectation that behind every suffering there is a remedy, and that health is the normal condition that people ought to have restored (Frank, 1995). This aligns with dominant and publicly available accounts of depression in which seeking help and following medical advice will result in recovery.

Narratives of Depression Without Recovery. The publicly available illness and depression narratives may not usefully frame the experience of depression for people who do not experience recovery. Those who experience ‘chronic depression’ or ‘recurrent depression’ describe feeling stuck or like a failure, dreading future recurring episodes, and contemplating suicide (Ridge & Ziebland, 2006). Their stories have profound themes of hopelessness and fatalism (Gask, Aseem, Waquas, & Waheed, 2011; Stigsdotter-Nyström & Nyström, 2007). In contrast to the accounts of linear progression through phases told by people experiencing single episodes of depression, people with ‘longer-term depression’ tell of cyclical or fluctuating symptoms as well as differences from episode to episode. Whilst some people experience symptom-free periods, others tell of continual symptoms with constantly fluctuating severity (Chambers et al., 2015). These people struggle to establish, or even imagine, a recovery narrative (Ridge & Ziebland, 2006) and, instead, speak of the need to accept depression as a chronic condition (Chambers et al., 2015). Those with ‘chronic depression’ or ‘recurrent depression’ may be unable to situate their experiences within a broader process of meaning-making (Stigsdotter-Nyström & Nyström, 2007). This sits in contrast to the sense of hope and expectations of recovery evident in dominant publicly available narratives of depression (Rapmund & Moore, 2000; Sarkohi et al., 2013).

These longer-term depression accounts (Gask et al., 2011; Ridge & Ziebland, 2006; Stigsdotter-Nyström & Nyström, 2007) have links to chronic illness narratives. Chronic illness has been likened to a “biographical disruption" due to the illness’ significant impact on the person’s expected life course (Bury, 2001, p. 169).When a biographical disruption occurs, the individual is faced with the challenge of reconstructing their identity and life story in order to maintain a coherent sense of self (Crossley, 2000). The same has been said for long-term mental distress, with the suggestion that these individuals are experiencing “an incoherent story” or “an inadequate account of oneself” (Polkinghorne, 1988, p. 179). In these cases, “narrative wreckage” may ensue, where people draw on a chaos narrative of uncertainty about the future, lack of order, and life never getting better (Frank, 1995, p. 68). Unlike the culturally favoured recovery narrative, there is widespread discomfort in hearing and telling the chaos narrative. In terms of depression, the chaos narrative undermines any sense of the controllability of the experience of mental distress. Depression without resolution undermines the widespread expectation that help-seeking will result in recovery.

Drawing on these publicly available narratives about illness, people diagnosed with depression are likely to expect recovery, at least initially. However, a person with TRD does not experience recovery and, instead, may try many antidepressant medications without significant improvement (Berlim, 2007). When expected recovery does not occur, they may be viewed as difficult patients by medical professionals (McPherson & Armstrong, 2009). As a result of this, people with TRD do not have dominant narratives of recovery from depression to draw on. They must search for new ways of making sense of their experiences. There is no known research exploring how people with TRD experience, understand, or make sense of depression that does not resolve. This study will address this gap in the literature by conducting an in-depth narrative analysis of the stories told by nine people experiencing TRD.

Method

Narrative Psychology. This study used a narrative approach to explore how people understand and make sense of TRD. Narrative psychology is concerned with the ways in which people organise, make sense of, and interpret their lived experiences through storytelling (Murray, 2008; Silver, 2013). Storytelling is particularly evident in situations where people’s expected life courses have been disrupted (Stephens, 2011). It is used to make sense of changes in life circumstances and facilitates understanding of why and how an event happened and who the individual was before the event occurred. Storytelling also helps a person to renegotiate their identity and restore a sense of coherence (Crossley, 2000; Murray, 2008; Sarbin, 1993; Stephens, 2011). Narrative psychology is also concerned with the ways people construct and maintain their identities through storytelling (Hiles & Cermak, 2008). In this study, a narrative approach provides insight into how people make sense of the disruption of TRD, and how they take up and negotiate identities such as ‘depressed’, ‘mentally ill’, ‘patient’, or ‘treatment resistant’. As narrative psychology is also concerned with the surrounding socio-cultural context, insights are gained into the publicly available narratives or local moral orders that shape how people describe and account for their experiences of TRD.

Participants, Setting, and Procedure. This study took place at a private psychiatry and clinical psychology practice in an upper middleclass suburb in central Auckland, New Zealand. The practice receives self-referrals and referrals from GPs and specialists in the Auckland region with patients paying for services either directly or through private health insurance. New Zealand has a universal healthcare system and comparatively few people have private health insurance (Ministry of Health, 2018). As a result of this, it is expected that the clientele of this private practice were affluent.

Participants were recruited by a psychiatrist working at the private practice, who identified people on his caseload with TRD and enquired as to whether they were interested in participating in a study on depression. The recruiting psychiatrist specialised in psychiatry over 20 years previously and had worked in private practice full time for 15 years. His general approach included assessment and diagnosis of mental illness and physical illness, as well as provision of medication and/or transcranial magnetic stimulation. The psychiatrist was also trained in cognitive behavioural therapy and, at times, provided short-term skills based therapy or made referrals for therapy elsewhere. Those who expressed interest in the study were given information sheets and asked for permission to be contacted. The first author then contacted those interested, provided a brief overview of the study, and answered any questions. If they were willing to be interviewed, a date and time was set for the interviews.

Nine people with TRD volunteered to be interviewed for this study. Participants met DSM-5 criteria for major depressive disorder (American Psychiatric Association, 2013) and their depression was assessed to be ‘treatment resistant’ by the recruiting psychiatrist, based on the most commonly employed definition: two or more antidepressant medications from different classes had not produced significant clinical improvement (Berlim, 2007). The delivery of these medications needed to be considered adequate in terms of dosage, duration, and compliance. Whilst not essential for participation, the participants had often also engaged in other treatments, such as psychological therapy. Participants ranged in age from 28 - 65 years, with a mean age of 47 years. Six participants identified as men and three identified as women, and all participants identified as New Zealand European. The study aimed to recruit people who were receiving adequate treatment for their depression. As a result of this, the sample was not representative of the population with depression in New Zealand in terms of age, gender, socioeconomic status, or ethnicity (Oakley Browne et al., 2006), which is likely due to the study setting.

Data were collected through individual semi-structured interviews. Interviews took place at the private practice where the participants had been recruited, once participants had given informed consent and completed a demographic questionnaire. The interview started with the participant being invited to tell the story of when their depression first began. Following this prompt, the interviews had an open structure with no fixed interview questions. The aim was to explore how people understood and made sense of their TRD through storytelling. As suggested by Murray (2003), the interviewer attempted to elicit narrative accounts and rich descriptions, by, firstly, asking "Could you tell me the story of when you first sought help?" and, secondly, by encouraging them through reference to times and places, for example, "Could you tell me more about the *time* the doctor told you that you have depression?" This approach allowed for flexibility in response to each interview as it progressed. Although the information sheet used the term 'treatment resistant depression', the term 'depression' was used in the interviews. The interviews ranged in length from 34 to 77 minutes and were audio recorded. Following the interviews, participants were offered a $50 petrol voucher to thank them for their time. Ethical approval was provided by the New Zealand Health and Disability Ethics Committee (16/NTA/197/AM07).

Analysis. The first author transcribed the interviews and cross-checked the transcriptions for accuracy. In the extracts, words are underlined to show emphasis. Analysis was guided by the narrative approaches of Murray (2000) and Stephens and Breheny (2013). This involved focusing on multiple levels of meaning, including personal stories, interpersonal stories, and publicly available narratives, as well as the intersection between these levels. First, personal stories about subjective experiences of TRD were identified. Accounts of experiences were categorised as personal stories if they had a plot: a beginning, middle, and end, as well as characters. Secondly, the accounts were examined for interpersonal stories co-constructed between the participants and the interviewer. According to Murray (2000), narratives exist in a social world and are co-constructed between multiple people (a narrator and an audience). "Interviewers are not neutral bystanders" Stephens and Breheny (2013, p. p. 16); they bring to the interaction a set of characteristics and a particular perspective which shape the narratives that emerge. In the present study, interpersonal stories were understood as stories of experiencing and managing mental distress co-created in the interview room. The exploration of interpersonal stories involved consideration of how the first author's position as a clinical psychology trainee and the setting of a psychiatry private practice may have shaped the stories told (see Findings for detailed discussion of this). Lastly, publicly available narratives were considered. Publicly available narratives are the beliefs and ideas shared within society that shape the personal and interpersonal stories told. In this study, these included broader narratives of clinical psychology, medicine, mental distress, and recovery, for example, the expectation of return to wellness following help-seeking (Frank, 1995) and the Western psychiatric framing of mental distress as a set of observable, measurable, and targetable symptoms located within the individual (Newnes, 2014). Narratives such as these circulate widely through popular psychology and the media and shape how depression is storied. In the analysis, exploration of publicly available narratives involved reflecting on assumptions shared by participants and the interviewer about the nature of and expectations surrounding mental distress. These became evident through identification of ideas about "how things should be" (Wong & Breheny, 2018, p. p. 252) shared across stories, questions, participants, and encounters. In telling stories about *their* depression, the participants reflected societal ideas about depression *in general*. Similarly, in asking questions about participants' depression, the interviewer subtly reproduced constructions of depression shared within broader social structures. Whilst publicly available narratives were an important part of the analysis, the focus of the present study was predominantly on personal and co-constructed stories. Given the social nature of narratives and the co-construction that occurs, Murray (2000) suggests that both the interpersonal context and the social context be considered during narrative analysis.

Findings

Two narratives that structured the participants' accounts of TRD were identified: a narrative of order, in which depression was storied as predictable and understandable, and a narrative of disorder, in which depression was storied as unpredictable and incomprehensible.

A narrative of order.

Depression has clear causative factors. Participants told stories of interrogating their external worlds and experiences for patterns in order to predict shifts in their symptoms. They linked shifts in their depression to changes in their external environments. At times, they linked the onset of episodes to these factors. For example, Dean linked the initial onset of his depression to going "to university the first time around the 1980s, because I spat the dummy badly [behaved in a petulant manner] and sort of intentionally failed exams and shit like that" and Chris linked his first episode to a "bit of a binge drinking episode". Similarly, Darryl attributed his first episode to the fact that "my mother died and we'd just had our first baby and my wife's stepmother at that time was also diagnosed with cancer" and his second episode to "the break-up of my marriage". The participants told of carefully examining their external environments and experiences in order to understand past depressive episodes and anticipate and forestall future episodes. In doing so, they framed their depressive episodes as predictable: logically linked to external factors, such as challenging life events.

Participants also told of interrogating their external environments for factors that contributed to the more subtle shifts of their depression across the days, weeks, and months. For example, Chris described identifying a link between time of day and mood, highlighting a predictable pattern of gradual improvement across the day, but "every morning without consideration, I wake up back down again". In a similar vein, both Paul and Dean looked for patterning across time and questioned whether "winter" led to the worsening of their depression. Dean also suggested that his depressive symptoms returned on a cyclical or "annual basis". Paul's pattern seeking attempts also extended to observation of others' experiences. He spoke of other peoples' seasonal changes in mood, noting that "a lot of people, even if you're not depressed, middle of winter is still bad for you". Through interrogating their external worlds, the participants narrated a degree of patterning and predictability to their depression. Telling stories of these patterns offered a sense of order and certainty, and this was reflected in the decisive tone of the stories. These stories were also used to demonstrate that the participants had developed awareness of the self in relation to the external world.

Depression is a discernible internal process. Participants also narrated accounts of interrogating their internal worlds for patterns to help them make sense of their experiences. They told of looking for and becoming "attuned" to internal cues that signalled shifts from periods of relative wellness to periods of depression. In storying their experiences in this way, depression was framed as an internal condition that could be observed and understood through careful introspection. For example, Dean told of how he had learned to become "more attuned" to his current internal state and how he could now "recognise" when he was "getting the wobbles".

Dean: *This year's been good. But I'm sort of getting the—I don't think I'm getting depressed but I'm certainly getting the wobbles, I can recognise that.*

Int: *Yeah. So can you recognise it then because you've been through those cycles [of depression]?*

Dean: *Yeah. Well I suppose I'm just much more attuned to stress, I suppose, and avoidance. And I know I'm avoiding shit.*

He described evaluating a set of internal factors, which he viewed as closely linked to his depression, such as his perceived level of "stress" and the degree to which he believed he was "avoiding shit". Dean's assertions that "I can recognise that" and "I'm much more attuned" positioned him as the expert in his internal experiences, capable of registering subtle shifts and skilfully discerning between "getting the wobbles" and "getting depressed". Similarly, using a weather watching metaphor, Paul highlighted an idiosyncratic set of signs and symptoms that indicated to him that the "cloud" of depression was "coming on" again. These signs included his "mood changing", his "head getting heavier", and shifts in the way "he do[es] things" and "talk[s] to people". Through his detailed and fluent listing of these signs and his assertion that "once you know the symptoms" you can recognise them quickly, Paul positioned himself as someone with a high level of self-awareness. He also framed depression as set of internal symptoms that, with work, could be observed and understood. Paul also noted that his wife had begun to engage in this pattern-seeking and learned to "pick" when "the cloud" of his depression was returning. In highlighting that others also engaged in this pattern-seeking, he legitimised it as a process and framed depression as something that could be objectively understood. These stories framed depression as a set of internal signs and symptoms that, through self-awareness and introspection, could be objectively observed. They further framed TRD as an ordered experience.

Depression is measurable. In their attempts to identify patterns in their depressive experiences the participants told of using nuanced rating systems. These stories framed depression as a measurable construct. Chris, for example, described using a 10-point wellness scale as a tool for assessing his current internal state and to story shifts in how he was feeling. He highlighted that whilst “the majority of the time, [he’ll] go to bed feeling good, like sort of 9 or 10 out of 10”, he wakes up in the morning “back down” the scale again. Similarly, Sarah told of using a percentage system, where 100% was wellness and 0% was depression, to monitor shifts in her mental state.

> *Sarah:* *So, you’re thinking, you’re on edge to think “um, okay, I’m going along alright” and you’re constantly judging, also the other thing is you’re judging what level you’re at. So you’re trying to figure out “am I 50% of the way there, am I 20% of the way there? Am I 70% of the way there? Or am I going downwards again, am I going up?” And you’re sort of constantly aware of what you’re thinking and how you’re feeling. And where it should be just something in the back of your mind that “ok I’m having a bad day” or “things are going really well” but when you’re in a depressed state you’re constantly having to judge whether “am I well or not? Am I not well?” and that’s difficult.*

Through using these percentage and number systems, which are commonly utilised in medicine and clinical psychology to quantify subjective emotional states, the participants reduced the complex and multifaceted experience of depression to a single number or point on a scale, and so presented their experiences as contained. Their depression was narrated as constantly moving up and down this scale, however, these fluctuations were limited by the scale endpoints. They presented an ordered construction of depression as an experience that, with effort, could be tracked and understood. In narrating shifts in this way, the participants attempted to translate their internal experiences into an objective system that could be communicated to others. They became dispassionate observers of their own subjective experiences. Depression was positioned as a project separate to the self that they were tracking and containing. Again, this contributed to the construction of the ordered narrative of TRD. However, as Sarah described, whilst “it should be just something in the back of your mind”, the assessment of current state became a major life focus. These rating systems were not simple to manage.

Co-constructing the narrative of order. This ordered construction of depression occurred in conjunction with the interviewer. Narratives exist in a social world and are co-constructed between people. In this study, stories about TRD were shaped by understandings of mental distress and recovery shared by participants, as long-term service-users, and the interviewer, a clinical psychology trainee. The first author contributed to the ordered construction of depression by eliciting accounts of internal processes, such as thoughts and feelings, that she saw as factors contributing to the participants' depression. For example, during Paul's story of the return of his depression she asked, "What was that like?" and during Sarah's account of her diagnosis she asked, "How were you feeling when that happened?" These questions encouraged descriptions of symptoms, interpretations, thoughts, and feelings. Depression was reduced to a discrete set of symptoms located within the participants. The interviewer also supported the narration of depression as having clear causative elements by interrogating the participants' experiences for factors that explained the onset, improvement, or worsening of their depression. For example, she asked Paul, "so at that time where you first became depressed, what was going on in your life? You said you had a couple of kids then?" and, following mention of when he first became depressed, she asked Dean, "what was happening at that time?" Similarly, following the story of Chris' worsening depression and attempted suicide, she asked, "can you tell me more about the time when you took the overdose? Like what was going on for you there?" At times this was led by the first author, at times this was led by the participants, but always they engaged in this process together.

This narrative was informed by publicly available narratives of clinical psychology, medicine, mental distress, and recovery. As both interviewer and participant were deeply embedded in this paradigm (the first author as a clinical psychology trainee and the participants as long-term service users), their interactions were strongly influenced by clinical psychology assumptions.

Clinical psychology strives to understand, categorise, and contain experiences of mental distress. It seeks predictability and certainty. To do so, it employs diagnostic categories, rating scales, and explanatory and causative models. Mental distress is framed as a set of symptoms situated within the person that can be objectively assessed, measured, and targeted. Depression is constructed as having logical or causative elements (Newnes, 2014). Publicly available narratives place value on building self-awareness about these internal processes and potential external contributing factors, by engaging in a careful process of introspection (Hänninen & Valkonen, 2019; Ridge, 2018). Alignment with these publicly available narratives was supported by the setting. The interviews took place in a private practice where the participants usually received clinical services. Upon entering they were greeted by a receptionist and seated in the waiting room where other service users were coming and going. The interviews were in a consulting room with armchairs, annual practicing certificates displayed on the walls, bookshelves of clinical books, a clock on the wall, and plain décor, and the interviewer was conservatively dressed and well-spoken. These setting related factors reinforced the therapeutic context and supported the familiar narrative of depression as understandable.

A narrative of disorder. Despite the pervasiveness of the order narrative and the way that it was reinforced by the interviewer and setting, it did not completely frame the participants' experiences. In making sense of and accounting for their experiences of TRD, participants also told another story; of depression as an experience characterised by disorder.

Depression is random and unpredictable. Within the overarching narrative of disorder, depression was described as an unpredictable ebbing and flowing of experiences. Participants narrated their depression as a disorganised and confusing experience. They described their experiences as characterised by constant movement, with symptoms storied as constantly "coming and going". This troubled the previously outlined story of depression as having clear and logical causative factors. Dean, for example, highlighted how fluctuations in depressive experiences could not be predicted and, instead, "just happened".

> *Dean:* *…the depressive episodes and the no sleep and the sleep problems and shit didn't seem to match any sort of stresses, if you know what I mean. It wasn't as though, "ooh I'm stressed" or, "ooh, I've made a mistake," or whatever. They just happened. Maybe it's winter, I don't know. But it sort of happened a lot.*

The participants' depression appeared to be storied as less predictable over time. Whilst, as outlined previously, early episodes were narrated as strongly linked to external triggering factors, this was not the case with current or recent experiences of depression. This is evident in Chris' story summarising his history of depression:

> *Chris:* *It initially started—what, maybe 35—probably 35 years ago. My first instance was a bit of a binge drinking episode with my flatmates. I woke up the next morning all anxious, depressed, confused. So anyway, that subsided and I've learnt my lesson from that, obviously. Uh and then when was the next one? It also happened in Australia when I was living over there with a group of flatmates. So gradually I thought, "gee, these symptoms are coming back again", so I ended up coming home—not the sole reason for that but partially. So I went and saw a doctor, they gave me some antidepressants, they never really worked. So then at that stage my depression was coming in and going out type of thing, and it wasn't there permanently at that stage. So in the end I went and saw [a psychiatrist] and spent a few years with her. She put me on fluoxetine and lithium and I had some really good, long spells on that medication. And then after a while it started to come back again.*

At the beginning of his story, Chris narrated his early episodes of depression as discrete; with a clear beginning and end. He carefully examined them for causative elements by linking them logically to prior events, such as living in Australia. However, after experiencing depression for many years, Chris' account shifted to describing depression as a series of undifferentiated amorphous episodes with no clear triggers. He described the depression "coming in and going out" over time without much detail.

Similarly, whilst Darryl's descriptions of early experiences of depression were clearly linked to external life stressors, such as births, deaths, relationship breakups, and illness, current and recent episodes were described as the opposite. He noted that, with his most recent depressive experiences, "there wasn't any sort of obvious sort of stressors that were starting it" and that, unlike early episodes triggered by life events, recent episodes have "been sort of different in that yeah I suppose it really was quite a sort of insidious sort of coming on to me". However, they described being unable to do this over time. Ultimately, they narrated the search for a "match" between depressive episodes and circumstances as futile. As Chris highlighted, no amount of interrogation of their experiences could explain their depression:

Chris: *I don't know why I get depressed. So many people ask the question, you know, "has something gone on in your life?" And yeah, I used to try and find things that it could be and then I just gave up because I couldn't find anything to cause it.*

Depression is not observable or measurable. Within the narrative of disorder, the participants also told of how constant fluctuations led to difficulty accurately gauging and communicating one's current internal status. Again, this troubled ordered accounts of depression as a discernible internal process that could be objectively observed and measured. Sarah, for example, repeatedly questioned her ability to accurately assess what was occurring in her internal world. She described how fluctuations in her depressive symptoms occurred so regularly and randomly that she was constantly questioning "…is this just a bad day? Or is this a bad moment? Or, is the drugs not working?" Despite concerted efforts to track, understand, and contain her depressive experiences, she described how "it's hard to recognise what it might be" that caused these shifts. At times, Sarah also questioned whether a shift had even occurred in the first place, separate from her perception of it, which she felt she could not necessarily trust. Paul also storied uncertainty regarding his internal state as a result of the frequent fluctuations. He told of falsely interpreting bodily sensations associated with physical illness or fatigue as depressive symptoms. This meant that he often believed that he was experiencing the "onset of another episode" when he was merely experiencing "a flu coming on" or was "just tired because I've been doing this, this, this".

Similarly, Dean described how frequent changes in mood led to a sense that he was no longer a reliable interpreter of his own experiences.

Dean: *Well, when I'm in it [depression], I think it'll never stop. I mean, intellectually, you know it will, but sort of emotionally, you think, "this is it for life, I better start making plans to jump off a bridge or take an overdose", something like that. And then it passes, whether it's because of medication or because it's just body chemistry or something. Um and then you just think back and think "the past year is just a total stranger". So I don't know. I mean, a lot of it is self-deception. A lot of it is self-deception.*

Int: *What do you mean by that?*

Dean: *Um, I don't know. Sort of like lying to yourself all the time, that "things will get better". Or that "things won't get better. I should check out". Um, I don't know.*

Dean described the confusion he encountered as a result of this constant cycle and his need to interpret these shifts. Unlike ordered stories of the self as an objective observer of internal processes, Dean positioned himself as "in" his depression; caught up in an emotional vortex of uncertainty. Switching back and forth between viewing his depression "emotionally" and "intellectually", he framed depression as an experience that could not be dispassionately observed and measured. Instead, his depression was storied as elusive – difficult to gauge or understand. Dean storied his experiences as characterised by “self-deception” – he felt there was some internal duplicity occurring. This stood in stark contrast to ordered accounts of depression as an experience that, through introspection and self-awareness, could be understood and contained. As a result of these constant fluctuations, Dean no longer saw himself as an honest and reliable interpreter of his inner world. In these stories, participants framed depression as something that was so frequently shifting, that it was impossible to accurately gauge their current status. They described feeling doubtful about their abilities to be experts in their internal worlds and to accurately report what was going on for them. The participants’ attempts to determine patterns and understand the triggers of depressive symptoms depended on reliable access to their internal worlds. Without this, attempts to seek and confirm patterns were described as fraught and leading to the sense of self-deception.

Depression is unrelenting. Within the narrative of disorder, depression was also storied as an experience that would be ongoing. Whilst participants described initial surprise when depressive symptoms returned after periods of relative wellness, with time, they came to narrate the return of depression as inevitable. Chris, for example, described feeling shocked when his depression returned after his initial episode and round of treatment—“gee, these symptoms are coming back again”. However, as the fluctuations in depression continued over the months and years, the return of depression was presented as an expected outcome. Sarah described how, despite experiencing periods of feeling “really positive”, she had now come to expect that her depression would always return:

Sarah: *I’ve had a couple of times where I’ve had the drugs last for about 9 months or maybe 12 months before I’ve started to go downhill again. So you have these times where you think “right, I’m really positive, I’m really good, I’m going along” and then you’re going along for a long time and you’re doing different things and then you start to gradually go “okay, that could be just a blip” or, you know, “I’m having a bad day” or “I’m having a bad couple of days” or,*

> *you know, "these things happen", you know, "you need to find a different way of coping" or things like that and it gradually goes back and back and back and back... and then you get very sad and upset that things go backwards, because, you know, you expected it to last. And you get to the point where I am now where you don't expect it to last, where you should expect it.*

Sarah told of a recurring pattern of improvements in her mood being disrupted by the re-emergence of depressive symptoms. Periods of wellness were narrated as progress - "going along" - towards apparent resolution of symptoms. Initially, she described active efforts to stay on this upwards trajectory through engaging in positive self-talk. She told of reassuring herself that recovery is not linear and that a "blip" or "bad day" was not necessarily indicative of full on relapse. Staying on this course appeared precarious, however, with Sarah suggesting that, despite her efforts, she usually ended up going "downhill again". Repeated experiences of progress being derailed lead Sarah to "get to the point" where she no longer believed consistently good mood was possible. Paul described a similar gradual realisation that his depression would be an ongoing struggle:

> *Paul:* *I had my first bout and I was good for a while then I had another lot then I was alright then I had another lot and that's when I thought "I don't think this will ever pass". It's like it's gonna reoccur and reoccur.*

In these accounts, participants told of letting go of personal expectations of progress and eventual resolution of symptoms. Whilst they did describe experiencing periods of relative wellness, the return of their depression was narrated as inevitable.

Order and disorder: a profound narrative tension. Across the participants' accounts, a tension emerged between narrating depression as understandable and ordered and narrating depression as chaotic and confusing. Rather than drawing on one of these narratives in isolation, each of the participants drew on both. They repeatedly switched back and forth between these two narratives and, in doing so, navigated an ongoing narrative tension. The participants used both narratives to make sense of and account for their experiences of TRD - and both had advantages and disadvantages for the participants as social actors in the world. The narrative of order made experiences of depression more knowable and predictable. It also allowed participants to remain aligned with medical paradigms or publicly available narratives of depression and position themselves as good patients doing all they could to recover. This is the narrative made available in clinical contexts and there is an expectation by clinicians and patients alike that this will be the narrative adopted. To resist this narrative would be to let go of the alliance with psychiatry and psychology and disrupt the expectations regarding how people conduct themselves within clinical encounters. However, for the participants with TRD, this narrative did not completely frame their experiences – they also drew on a narrative of disorder. This narrative allowed them to account for the fact that they continued to experience depressive symptoms long term.

Across the use of these narratives several shifts were evident in the way that depression was storied. First, there was a temporal shift in the adoption of these narratives. Stories about early depressive experiences included more frequent, confident, and comprehensive accounts of order. Participants described ordered constructions of depression matching their experiences – they told stories of being able to identify patterns, observe their own internal experiences, track and measure changes, and predict shifts. However, this appeared to be less the case with episodes described over time, with participants outlining repeated experiences that undermined and troubled this narrative. They described a recognition that this narrative did not account for their trajectory of depression as a whole. Whilst this general pattern in narrative adoption was evident, it was not strict. Participants continued to shift back and forth between these narratives throughout the interviews.

As this temporal shift in narrative production occurred, so too did participant positioning. In aligning themselves early on with publicly available narratives of depression and mental illness – by narrating early experiences of distress as contained, understandable, and manageable – the participants positioned themselves as no different from the 'typical' person experiencing depression.

However, with recognition that the narrative of order did not completely represent their experience, the participants shifted to subtly framing themselves and their depression as different from the norm. Sarah, for example, concluded her account above with the assertion that “you should expect it [wellness]” to last and, in doing so, pointed towards the dominant Western expectation of recovery from illness. She suggested that, whilst it was reasonable for the average person to expect return to wellness, she was different and this was not the case for her. Similarly, Chris’ in his comment that “so many people ask the question, you know, ‘has something gone on in your life?’” made reference to the publicly available narrative of depression being caused by “stressors” and, therefore, a logical and predictable phenomenon. He highlighted his difference from the norm, however, in stating that whilst “[he] used to try” to apply this thinking to his own depression trajectory, it did not fit so he “gave up”. It was with time and repeated experience of their depression journeys deviating from expected trajectories that people with TRD began to narrate their experiences and position themselves as different from those experiencing depression that does respond to treatment as expected.

Discussion

A significant minority of people with depression do not experience recovery following several rounds of antidepressant medication (Crown et al., 2002). Emerging research now also suggests that antidepressant medication is not as effective as once thought (Rush et al., 2006; Rush et al., 2009). The current study explored how people understand and make sense of depression that has not resolved even with seemingly adequate input from health professionals. The process of narrative analysis revealed some of the ways people with TRD make sense of this experience. Two narratives that structure participants’ accounts emerged: a narrative of order and a narrative of disorder.

The narrative of order was informed by powerful publicly available constructions of depression within psychiatry and psychology. Within these fields, depression is framed as a discrete set of symptoms situated within a person with causative elements and maintaining factors (Newnes, 2014). For example, recent research frames TRD in almost exclusively biological terms; a biological flaw situated within the individual to be rectified with pharmacological treatment (Akil et al., 2018; Ragguett, Tamura, & McIntyre, 2019). Once targeted through treatment, the assumption is that the prior level of mental health will be restored. In this study, both the participants and the first author were embedded in this paradigm and imbued with these expectations and, consequently, co-constructed the ordered account of TRD. These publicly available narratives may align with experiences of people who recover from depression as expected, for example, people whose experiences follow a linear progression from illness to wellness (e.g., Karp, 1994; Schreiber, 1996). However, they may not completely represent the experiences of those who experience depression without recovery. Conversely, the narrative of disorder was akin to findings of the limited existing research on experiences of longer-term depression, which suggest that the experience is characterised by constantly fluctuating symptoms (Chambers et al., 2015).

As well as not completely representing the experiences of those who do not experience recovery as expected, narratives of order may also be unhelpful for this group. McPherson and colleagues (2014) suggest that the inherently structured medical paradigm may not create the most appropriate health service context for people with TRD. Instead, the focus on models, categorisation systems, and standardised questioning restricts the discourses and identities that can be adopted and negotiated within clinical encounters. As a result of this, the narratives that emerge do not reflect the multifaceted realities of people with TRD; shared understandings between health professionals and patients are not reached and effective solutions are not offered. McPherson et al. (2014) suggest that rigid adherence to this paradigm may lead to frustration among both GPs, when patients do not ‘fit’, and patients, when GPs’ constructions of their difficulties do not reflect their realities.

The context of this study likely shaped the stories that were told about TRD. Researchers have stressed the importance of considering the impact of storytellers’ social positions, for example race, gender, social class, and level of affluence, on narrative production (Bury, 1982; Riessman, 2003). In the present study, the participants were affluent with considerable security in terms of employment, housing, and support systems. These factors afforded them a high level of access to resources. As described in the interviews, they were able to register at a private psychiatry practice, to trial unfunded medications, to take leave from work, and to engage in alternative approaches such as yoga and meditation classes. Available resources affect people's ability to respond to and make sense of life disruptions (Bury, 1982; Stephens & Breheny, 2013). With ample time, security, and resources, they were able to focus on self-development, making sense of their experiences, and revising their identities in the face of illness. In terms of narrative production, their affluence may have made them more committed to the medical paradigm and the narrative of order, as they were able to mobilise whatever resources necessary to continue to pursue treatment to manage their depression. They were also easily able to story virtuous identities as good patients doing all they could to recover, even when the odds were against them. Without this level of privilege, people with TRD may produce very different kinds of stories. People with TRD struggling to access appropriate mental health services or to maintain secure housing and employment may produce narratives less aligned with this medical paradigm and have to work harder to produce virtuous identities. Further research in alternative settings would strengthen our understanding of the impact of social circumstances on shaping how people make sense of TRD.

It is important to consider how these findings may provide insights that could improve healthcare experiences and outcomes for people with TRD. Clinicians enter encounters with clients with their own set of often unexamined assumptions. Stories of long-term chaos and distress are challenging to hear in clinical encounters (Frank, 1995). Embedded in powerful medical paradigms, clinicians search for order to make sense of the 'dis-order' they witness. They co-construct or impose narratives of order with their clients and, in doing so, attempt to bring about narrative resolution to mental distress. Diagnostic categories and explanatory models are fundamental components of Western psychiatry and psychology aimed at helping clinicians make sense of the complexity of human existence. There is undoubtedly reason to continue employing these approaches as they appear useful for the majority of people who recover as expected. However, these findings suggest that a different approach may be beneficial for people with TRD. Specifically, this may include the following: 1.) increasing self-awareness about the tendency to impose order in clinical encounters, 2.) creating space for alternative stories that may frame clients' experiences, 3.) integrating approaches based on chronic illness models, 4.) adopting 'living well' models of recovery rather than symptom reduction models, 5.) encouraging a move away from constant symptom monitoring and 6.) utilising third wave therapeutic approaches which focus on acceptance. In turn, these approaches may lead to more fulfilling clinical interactions for both client and clinician and allow space for the conception of more effective or fitting management strategies.

Conclusion

Much of what is known about depression is based on people who respond to treatment as expected. This paper sheds new light on the narratives people draw on to structure their accounts and to make sense of their experiences of depression that do not respond to treatment as expected. Through the process of narrative analysis, two narratives emerged: a narrative of order and a narrative of disorder. The order narrative was informed by wider clinical psychology assumptions and expectations of recovery. This narrative introduced a sense of containment: TRD was made more understandable, predictable, and manageable. Conversely, within the narrative of disorder, TRD was storied as a constant yet unpredictable ebbing and flowing of symptoms. Across these accounts, there was a general pattern of participants drawing on the narrative of order when storying early experiences of depression and, after outlining disruptions to these ordered constructions, drawing on the narrative of disorder when storying later experiences. With this came a general shift from positioning the self as a 'typical' person experiencing depression to a person experiencing depression differently. Whilst the narrative of order may be helpful for many people experiencing short-term mental distress, it may not completely represent the experiences of those with TRD. There is a constant striving to tell this ordered story, a comfort in hearing this story, and an expectation in healthcare settings that this will be the story co-constructed, however, for this group of people, this narrative does not appear to completely encapsulate their experiences. Recognising and addressing the tensions between these narratives may improve clinical interactions and lead to more effective therapeutic relationships.

CHAPTER FIVE: ARTICLE TWO – Accounting for the experience of TRD

This chapter is being considered for publication as: Kroch, E., Breheny, M., van Kessel, K., and Taylor, J. (2020). “If medication isn’t helping me, maybe it’s just me”: Accounting for treatment resistant depression. *Sociology of Health and Illness.*

Abstract

A significant proportion of people experiencing depression do not respond to treatment as expected. Whilst there is growing literature exploring the ways in which lay-people, patients, and health professionals conceptualise depression that does resolve, there is no known literature exploring how people account for persistent distress. The current study aimed to address this gap by specifically exploring how people account for the persistence of their depression despite receiving treatment. Nine participants were recruited through a private psychiatry and psychology practice in Auckland, New Zealand. Participants’ interviews were analysed using a narrative approach and two overarching narratives were identified: (i) a *treatment resistant brain* explanation, in which persistent distress was attributed to flaws in personal biochemistry rendering antidepressants ineffective, and (ii) a *treatment resistant personality* explanation, in which persistent distress was attributed to fundamental flaws in character that were beyond the reach of medications. Rather than linking their depression to external factors, as is seen in accounts of depression that does resolve, people with TRD strongly attributed their persistent distress to factors within themselves. Whilst alternative narratives were at times drawn on by participants, these explanations also situated depression and recovery as the responsibility of the individual. It is now widely recognised that causal beliefs about health and mental health influence patients’ approaches to help-seeking and health professionals’ approaches to service delivery. Health professionals need to be aware of patients’ tendencies to shift to self-blame when antidepressants are ineffective, but they must also be cognisant of the role they – as social actors embedded in powerful medical contexts – play in constructing and perpetuating these narratives.

Keywords: New Zealand; depression; treatment resistant depression; narrative; qualitative research; causal explanations; identity

Introduction

A growing number of studies have explored the ways people explain their depression and depressive symptoms. Beliefs about the cause of distress or illness are thought to have considerable impact on people's approach to help-seeking and engagement in treatment (Prins, Verhaak, Bensing, & van der Meer, 2008). Similarly, the views of health professionals have been explored, as they are thought to influence treatment decision-making, interactions with clients, and the views of patients themselves (Geraghty et al., 2017). Whilst there is increasing interest in how depression is understood and explained, there is little work exploring how the persistence of depression is accounted for. This is the case even though persistence of distress following treatment is experienced by a significant proportion of people with depressive symptoms. For instance, STAR*D, the largest study to date to evaluate the efficacy of a range of depression treatments, found that only 50% of people experienced remission following two rounds of treatment (Rush et al., 2008). Those who do not experience significant clinical improvement following treatment are frequently referred to as having treatment resistant depression (TRD). TRD appears to be unique from so-called chronic depression and recurrent depression as most people with chronic depression have not received adequate treatment and people with recurrent depression do respond to treatment and experience periods of remission (Gelenberg et al., 2006). People with TRD have been found to experience poor quality of life, high levels of physical and mental health comorbidity, and significantly impaired functioning (Brown et al., 2019; Greden, 2001).

Explanations of depression. Among people currently experiencing depressive symptoms, depression is commonly believed to result from external social factors. In their systematic review of qualitative studies, Prins et al. (2008) found that depression was often framed as an understandable outcome of challenging life events, such as divorce, bereavement, or physical illness. This appears to be especially the case early on in depression experiences. People experiencing their first hospital admission were more likely to name recent and distinct stressful life events as triggers of their depression compared to people who had been hospitalised multiple times (Buus, Johannessen, & Stage, 2012). Similarly, in a previous study exploring experiences of TRD, early episodes of depression were presented as isolated incidents clearly linked to external events (Kroch, Breheny, van Kessel, & Taylor, 2021). Psychosocial causative explanations frame depression as understandable given the circumstances and even predictable. Buus et al. (2012) suggest these explanations may be predominant as they espouse the idea that recovery is possible through personal action. Additionally, some argue this way of understanding depression carries fewer moral implications, as people are seen to be responding to challenging aspects of normal life rather than being fundamentally unwell (Kangas, 2001).

Whilst not the predominant causative explanation, people do at times provide biological reasons for their depression. Within this explanatory accounting, depression is framed as the result of a chemical imbalance in the brain. In their systematic review, Prins et al. (2008) found this explanation for depression was more commonly presented by people who were currently experiencing depression compared to lay-people who had not experienced depression. A number of studies also suggest that, whilst not central to people's accountings of depression, biochemical explanations continue to be drawn on to some degree, especially when justifying engagement with treatment (Buus et al., 2012). This is consistent with findings of recent thematic syntheses of qualitative studies exploring patients' views of antidepressant use (Malpass et al., 2009; Maund et al., 2019). These syntheses found that patients endorsed biochemical explanations as well as psychosocial explanations to legitimise their continued use of antidepressant medication. Biochemical explanations position depression as a treatable condition for which the individual is not personally responsible. Using biochemical explanations may increase patients' sense of control and have strong links to culturally favoured narratives describing progression from illness to treatment to cure (Buus et al., 2012; Frank, 1995).

These studies suggest there is an inconsistency between the explanations people give for the occurrence of their depression and the rationalisations they provide regarding treatment. Rather than drawing on a single explanation, participants drew on psychosocial explanations whilst remaining open to biochemical explanations to explain use of antidepressant medication. Both accounts worked to increase perceived control over depression through either changes to life circumstances or biochemistry (Buus et al., 2012). People's views about the causes of their depression are multidimensional and complex (Prins et al., 2008). Their explanations appear to shift and evolve over time, often in relation to the stage of their depression and their engagement in treatment (Buus et al., 2012; Kroch et al., 2021).

Health professionals' explanations of depression. Similar findings have emerged in studies exploring health professionals' understandings of depression. Meta-syntheses of qualitative studies suggest that, again, two predominant yet contrasting causal explanations are held: a psychosocial explanation and a biomedical explanation (Barley, Murray, Walters, & Tylee, 2011; Schumann, Schneider, Kantert, Lowe, & Linde, 2012). The psychosocial explanation was primarily adopted by clinicians in primary healthcare, with a minority attributing depression to chemical imbalances. But, similar to the views of patients, rather than employing either one of these explanatory accounts, clinicians negotiated and switched between them. There appeared to be some dissonance in the accounts: whilst depression was largely framed in psychosocial terms, it was treated as a medical illness (Barley et al., 2011; Schumann et al., 2012). Clinicians highlighted that, after repeated exposure to patients with challenging life circumstances, they had come to view depression as largely psychosocial in nature. However, embedded in medical contexts, they held medicalised models of distress, employed medicalised discourse, and described antidepressants as their most commonly adopted treatment approach (Barley et al., 2011; Schumann et al., 2012).

As with patients' accounts, these contrasting causal explanations likely held different functions. Psychosocial models contextualise a person's distress within their life circumstances and may be normalising for patients (Geraghty et al., 2017). Conversely, clinicians described employing biochemical explanations in a number of circumstances, even when they themselves did not believe them. These circumstances included instances where they wanted to instill a more concrete sense of hope, when they believed a chemical imbalance explanation would be experienced as less stigmatising, or when they wanted to encourage antidepressant use (Johnston et al., 2007; Rogers, May, & Oliver, 2009). Biochemical explanations were also endorsed when patients were not experiencing challenging life events to attribute the depression to (Schumann et al., 2012). This indicates that clinicians provide explanations strategically, not entirely in response to their objective assessment of the cause of patients' depression. These studies highlight that, similar to patients, clinicians draw on and negotiate contrasting reasonings when accounting for their patients' depression, engaging in clinical encounters, and delivering treatment.

Explanations of persistent depression. Despite the research on explanations of depression, there is little research exploring how the persistence of depression is accounted for. People in this group make up a significant proportion of those experiencing depression. The limited work in the area suggests causal explanations among people experiencing longer-term depression may differ significantly to beliefs of those experiencing early episodes of depression. For example, in contrast to the psychosocial explanations given for depression, Buus et al. (2012) found people who had been hospitalised for depression multiple times did not reference specific external index events at all. Instead, as their depression persisted, emphasis was placed on enduring factors such as stress, fatigue, and personality. As time goes on, people experiencing long-term depression shift to framing depressive episodes as unpredictable and unexplainable (Buus et al., 2012; Chambers et al., 2015). Similarly, people experiencing TRD describe early depressive episodes as discrete periods of low mood clearly and logically linked to external events, but shift to describing later depressive experiences as a series of undifferentiated amorphous episodes unrelated to external life situations. In early episodes, efforts are made to resolve depression through rectifying these social circumstances, however, this is less the case over time (Kroch et al., 2021).

The little work in this area also suggests that health professionals' causative beliefs about depression evolve as their patients' depression persists. When working with people with TRD, McPherson and Armstrong (2009) found that general practitioners' (GPs) explanations shifted from being largely biomedical in nature to being focused on people's enduring traits or the experience of trauma. For example, clinicians attributed patients' lack of improvement following treatment to problematic attitudes, social deviance, and deficits in coping skills. This shift in conceptualisation of depression likely has significant impacts on health professionals' approaches to treating this patient group, patients' experiences of receiving services, and patients' own explanatory accountings. For example, counsellors and GPs' attitudes towards people with TRD were found to be predominantly negative (McPherson & Armstrong, 2009; McPherson et al., 2006). Furthermore, recommended clinical interventions, such as cognitive behavioural therapy, were not deemed useful for this group so few referrals were made (McPherson & Armstrong, 2009).

In summary, the ways people experiencing TRD explain their depression may differ significantly from those with depression that does respond to treatment. However, there is no known literature focused on how this group accounts for their persistent distress. This is of particular interest as, unlike people with other forms of long-term depression, those with TRD have received adequate treatment yet have not experienced significant clinical improvement (Gelenberg et al., 2006). For many people with TRD, their depressive symptoms last for years and lead to significantly reduced quality of life and functioning (Greden, 2001). As this group make up a significant proportion of those experiencing depression (Rush et al., 2008), it is important to understand how they account for this. This study explored how people experiencing TRD explained the persistence of their distress in spite of treatment.

Method

Narrative Psychology. This study employed a narrative approach to explore how people experiencing TRD made sense of and accounted for the persistence of their depression through the process of storytelling. Storytelling helps people make sense of disruptions to their expected life courses, as it facilitates understanding of how and why an event occurred (Stephens, 2011). As a process, it also helps people makes sense of and renegotiate identity in the face of such life changes, and, over time, facilitates a restored sense of order and coherence (Crossley, 2000; Murray, 2008; Sarbin, 1993). Narrative psychology is interested in the ways people make sense of and account for lived experiences and negotiate identities through the process of hearing and telling these stories (Hiles & Cermak, 2008; Murray, 2008; Silver, 2013). Concerned with the surrounding socio-cultural context, narrative psychology also considers broader societal structures and publicly available narratives that shape how individuals and groups story their experiences (Murray, 2008). In the present study, a narrative approach provided insight into how people with TRD made sense of and accounted for the persistence of their depressive symptoms in spite of adequate treatment. It also explored how these people took up and negotiated identities such as ‘depressed’, ‘patient’, ‘chemical resistant’, or ‘personality disordered’, and how publicly available narratives and local moral orders informed their accountings of TRD.

Participants, Setting, and Procedure. The study took place at a private psychiatry and clinical psychology practice situated in an upper middleclass suburb in central Auckland, New Zealand. The private practice gains clientele through either self-referral or referrals from other health professionals, with services either paid for directly by clients or by private health insurance. Participants were recruited by a psychiatrist at the practice, who identified patients with TRD, informed them of the study, and enquired as to whether they were interested in participating. This psychiatrist had over 20 years of psychiatric experience and had worked full-time in a private practice setting for 15 years. Broadly, his approach included assessment and diagnosis of mental and physical illness and provision of treatment, in the form of medication, transcranial magnetic stimulation, and/or short-term skills based cognitive behavioural therapy. Clients who expressed interest in participating in the study were provided with information sheets and asked for consent to be contacted. The first author then made contact, provided further information on the study, and answered questions. If they agreed to participate, a time and date was arranged for an interview.

Nine people experiencing TRD agreed to participate. The participants ranged in age from 28-65 years, with a mean age of 47 years. Three participants identified as women and six identified as men, and all participants identified as Pākehā/New Zealand European. Participants met DSM-5 criteria for major depressive disorder (American Psychiatric Association, 2013). They were also deemed by the recruiting psychiatrist to have TRD based on the most commonly employed definition: two or more antidepressant medications from different classes at adequate doses and durations had not produced significant clinical improvement (Brown et al., 2019). The study aimed to recruit a specific sample of people who had received adequate treatment for their depression. As a result of this, many of the participants had tried many more than two antidepressants and had also engaged in other treatments, such as psychological therapy. Based on the practice location, the costs associated with accessing the service, and the high level of engagement in other privately funded treatments, it is expected that the participants were affluent. When compared to the population experiencing depression in New Zealand (Oakley Browne et al., 2006), the sample was not representative in terms of age, gender, socioeconomic status, or ethnicity. This was likely due to the study setting.

Data were collected through individual semi-structured interviews conducted by the first author. Interviews occurred at the recruitment site, once participants had given informed consent and completed a demographic questionnaire. They began with the interviewer inviting participants to share the story of the onset of their depression, for example, by asking, “Could you tell me the story of when you began experiencing depression?” Following this, interviews were open in structure with the general aim of exploring how participants accounted for TRD. Based on the suggestions of Murray (2003), the interviewer attempted to encourage rich descriptions and narrative accounts through referencing times and places, for example, by asking, “Could you tell me more about the *time* the doctor said you have depression?” Interviews were audio recorded and ranged in length from 34 to 77 minutes. Participants were offered a $50 petrol voucher to thank them for their time. Ethical approval was gained through the New Zealand Health and Disability Ethics Committee (16/NTA/197/AM07).

Analysis. The first author transcribed the audio recordings and cross-checked the transcripts for accuracy. In terms of transcription conventions, words are underlined to show emphasis and bracketed ellipses show where transcript sections have been edited for brevity or clarity. The names and identifying details of the participants have been changed. Analysis was informed by the narrative analytic approaches of Murray (2000) and Stephens and Breheny (2013), which involve exploration of multiple levels of meaning: personal stories, interpersonal stories, and publicly available narratives, as well as how these levels intersect. Initially, personal stories the participants told about their subjective experiences of TRD were identified. Accounts were deemed to be personal stories if they included characters engaged in an overarching plot. Secondly, interpersonal stories were considered, and were understood to be stories of experiencing mental distress co-constructed between the participants and the interviewer. Lastly, publicly available narratives that shaped the personal and interpersonal stories were considered. These included broader narratives concerning mental distress, recovery, clinical psychology, and medicine that circulate in society through popular psychology and the media.

Findings

Two narratives that accounted for the persistence of depression were identified: (i) a narrative of a *treatment resistant brain*, in which depression persists due to a flaw in biochemistry which makes antidepressants ineffective and (ii) a narrative of a *treatment resistant personality*, in which depression persists due to fundamental flaws in personality that are beyond the reach of antidepressants.

(i) A treatment resistant brain. Some participants accounted for the persistence of their depression by suggesting they had a treatment resistant brain. Their biochemical constitution was understood to resist the effects of medication and, consequently, antidepressants did not lead to resolution of depressive symptoms. The participants used this understanding as the foundation for why their depression had persisted even in the face of adequate treatment, when others treated in similar ways had recovered.

"I'm definitely chemical resistant". Chris provided a clear articulation of this narrative. In spite of persisting with several antidepressants as prescribed, he had experienced, at the most, short term relief of symptoms. He accounted for this by suggesting he was "chemical resistant":

> *Chris:* *Anyway, once again I probably spent 18 months, two years with [the psychiatrist] trying out different medications. When I say trying different medications, I must have tried at least 20 different antidepressants over that period of time, and none of them gave me long-term relief. Very short-term in some cases, sometimes none (...) [The psychiatrist] is getting a machine in from the States I believe, and it's for treating people that haven't had any luck with medication. Like medication resistant, which I obviously am because I just keep trying and trying and trying all different ones and no relief at all (...) I'm sort of, not so much at my wit's end, but I'm definitely chemical resistant, yeah. Definitely, for the amount that I've tried (...) I was peeved off because it would've been nice to find the right medication that would put me on the straight and narrow.*

In these accounts, Chris' body was presented as resisting the psychotropic effects of the medications tried. Chris presented this explanatory accounting in a confident manner, repeatedly making the statement that he was “chemical” or “medication” resistant throughout the story. He defined a category of people who are treatment resistant - “people that haven’t had any luck with medication” - and positioned himself definitively within this group, “convinced” that medication would not work for him. Throughout these accounts, Chris made references to a “machine” for treating this group of people. This machine’s mechanism of action is not the delivery of chemicals, as is the case with antidepressant medication, but, instead, the delivery of magnetic fields. This accounting allowed for the possibility of future treatment success, with Chris expressing hope that the machine may be “the candidate for me”.

Similarly, Michael provided an explanatory account of the persistence of his depression despite treatment rooted in a biochemical resistance to medications. Michael described in general terms the ways some severe illness might not respond to medications: “yeah, just a medical illness that was bad and didn’t respond to medications.” He then linked this explicitly to why his depression had not resolved because it too was beyond the scope of medication - “but no, I think it was probably just treatment resistant illness for some reason.” Michael suggested that the severity of his depression had meant that medications were ineffective in resolving his symptoms. He also likened his depression to medical illnesses that do not improve with medication, firmly situating his depression as biological. Michael situated this resistance within his depression – a “treatment resistant *illness*” - whereas Chris situated it within himself – “*I’m* medication resistant”. However, both participants framed biochemical processes occurring within the body as the explanation for non-response to medication.

These stories of the experience of TRD framed depression as a biological disorder that can be resolved through interventions that alter brain biochemistry, such as antidepressant medication or transcranial magnetic stimulation. This idea was common throughout the participants’ stories, but explicitly stated by Dean:

> *Dean:* *[The psychiatrist] said it was just regular old depression and anxiety and that could be treated with chemicals. So that's my story really. I've sort of like always been a depressive, had problems for a long time. And then I've tried for treatment over a long time and the treatments have been hit and miss. And I've got my own sort of episodic load of bullshit, that's just me, it's my chemistry, I presume. I assume it's just chemical, I dunno. Is it?*

Drawing on what he has been told by his psychiatrist, Dean accounted for non-response to treatment by suggesting that he had a certain type of "chemistry" that leads to "episodic" depression. He framed his depression - "my own sort" – as different to other people's, who may have different chemical constitutions. Although "regular old depression" was viewed as a biological disorder that could be resolved with antidepressants, in Dean's case, his chemistry was seen to interfere with this process.

Within this explanatory accounting, symptoms of depression were not viewed as relevant or meaningful components of the participants' identities and, instead, were viewed as resulting from and persisting due to the misfiring of a disordered brain that resisted the balancing effects of antidepressants. Accounting for TRD in this way located the responsibility for persistent distress on biological processes within the body; either the chemical makeup of the person or the nature of their depressive illness.

"I'm just really unlucky". The "chemical resistant" brain accounting provided an explanation of why depression may persist despite antidepressant medication, but it did not explain why it was the case for *these* people. To account for this, participants framed their lack of response to antidepressant medication as a simple misfortune. Lily, for example, after questioning aloud in the interview, "why am I in that group of people that trial all these different ones and nothing happens?", suggested that she was simply "unlucky":

Lily: *Um, I mean there'll always be a percentage of people, I guess, that don't respond. (...) In the past when I didn't respond to anything I was kind of like, "I'm just really unlucky", like that kind of became more a focus. Like, for example, at university they show a graph of people responding to antidepressants, it's like, you know, two thirds of people respond to the first one, but then there's this percent of people that don't respond to the first one. But then some of those people respond to the second one, but then there's another group… So I was like, "I'm just in that group at the end which didn't respond".*

Drawing on knowledge of antidepressant response rates acquired through her mental health training, Lily accounted for her lack of improvement by situating herself as part of the small group who statistically lie at the tail end of a distribution and do not respond to medication. Chris (above) similarly referred to himself as one of the "people who haven't had any *luck* with medication". It was assumed that antidepressants do work for most people, even if it was not the case for them. Through references to luck, lack of improvement in symptoms was attributed to chance and uncontrollable biochemical processes rather than participants' actions or character.

(ii) A treatment resistant personality. The second narrative attributed persistent distress to problematic personality factors that were viewed as beyond the reach of antidepressant medication. Participants suggested that these treatment resistant "personality" factors either maintained the depression, prevented improvement, or were, in and of themselves, the problem. Throughout this narrative, participants used phrases such as "temperament" and "tendency" when speaking about their personalities. These words were treated as equivalent terms which described a central stable self that had particular enduring characteristics.

"That sort of contributes a lot to my low mood" - Personality maintains depression. When accounting for the persistence of their depression, some participants suggested that certain personality factors maintained their depressive symptoms. For example, Amanda attributed her long-term distress to elements of her “temperament” that meant she continued to experience “low mood”.

Int: *What’s that been like, trying out different [medications] along the years?*

Amanda: *Um, it’s been really frustrating because firstly, I don’t know how much change I should expect from medication, because I know my thinking and stuff tends to be quite negative and, you know, like that sort of contributes a lot to my low mood. (...) Um and I guess it’s sometimes going, yeah it would be great if medication fixed it. Like it’s not going to fix everything and I know that but, um, to make it easier. And I guess that’s why sometimes I wonder - if medication isn’t helping me, maybe it’s just me (...)*

Int: *And earlier you mentioned thinking about whether it’s something about you, the reason why the medications aren’t working (...)?*

Amanda: *Um, I don’t have the best self-esteem and my self-talk’s not very good. And so I guess I think maybe it’s just because of that and because of things like I sort of feel a bit out-of-control in life and stuff like that, and maybe if I just did life better then I wouldn’t feel so down. Um yeah, and maybe no amount of medication will change because I can’t change until I change the way I see myself (...) I would say it’s a lot to do with temperament. Um, that I am someone who is more sensitive and takes things on—everything—even more so than my siblings. I’ve always been an internaliser (...) I tend to be a perfectionist and everything like that, and I guess for as long as I can remember I’ve learnt the way of thinking that I’m not good enough and nothing I do is good enough. I remember talking to someone once and they were like, “no wonder you feel depressed”, with all the stuff that I say to*

> *myself and everything all day long and constantly berating myself and everything.*

Amanda provided a clear causative account, suggesting that her “temperament” explained her persistent depression. Amanda told a story of receiving feedback from someone who suggested it was “no wonder” she continued to “feel depressed” when she thought this way. Amanda framed these personality factors as essential components of her identity, present “for as long as I can remember”. Most of Amanda’s accounts centred around concrete and global descriptions of identity (“an internaliser”, “a perfectionist”). They were also framed as enduring, with Amanda indicating she had “always” been this way. She also described having “learnt” a “way of thinking”, suggesting this way of seeing herself had become a stable part of her identity over time. Similarly, Lily (p. 94, below) explained that “people have a tendency” and “people are just like that”, suggesting there are certain types of people with certain enduring sets of characteristics that can be objectively unearthed.

“I’m not doing it right” - Personality prevents improvement. At times, participants also storied personal attributes as factors that interfered with resolution of symptoms. Amanda (above) noted that her personality led her to feel unable to “[do] life” in a way that was conducive to good mood. She suggested that if she could behave differently and do “life better” she may experience some improvement. However, when asked directly by the interviewer about whether this was possible, Amanda stated that, “I’d like to think I could, but I don’t think I can”, suggesting that control over this might be wishful thinking rather than an accurate assessment of a possible alternative.

Darryl also blamed his personal failings for his persistent depression:

> *Darryl:* *I’m not doing it right, because if I was doing it right I’d be alright now (...) There are these things that <u>should</u> work but they don’t actually seem to be working.*

Darryl attributed persistence of his difficulties to his inability to do “it right”. He positioned antidepressant medication as a treatment that “should work”, and his personal failings as the factor that interfered with this happening for him. Dean also drew upon this explanation when describing a chance interaction with a stranger, which prompted him to consider the role of personal attributes in persistent distress:

> *Dean:* *I was just thinking, “well, fuck, if he can get it together when he’s got the responsibility of a disabled—severely disabled—child, then why am I indulging myself and feeling this way?” [Int: And that stuck in your head?] Well, I suppose it’s the thing that, um, I’m taking up valuable space for no good reason, you know? I should either get with the programme or fuck off.*

Dean attributed his continued difficulties to his inability to “get with the programme”. He compared himself to a stranger he perceived to be functioning well despite significant adversity, suggesting that if someone like this could live happily then he should also be able to. Dean suggested that the persistence of his distress may have resulted from him “indulging myself” and allowing himself to continue “feeling this way”.

Michael also provided an account of his personal attributes preventing improvement, rooted in the idea that he lacked the effort or ability to do what was necessary for his depression to resolve:

> *Michael:* *You also, like, almost felt a responsibility. Like a disappointment in yourself for each step, for each failure. If something wasn’t working it was like, “that’s because of me”, like “it’s my personality, I’m pathetic, I’m weak”, all sorts of stuff, “and that’s why this isn’t working”. “Everyone’s putting in all this effort and I’m still not getting better”. And how that reflects upon you as well (...) You can’t even respond.*

Michael viewed himself as responsible “for each [treatment] failure” due to being “pathetic” and “weak”. Just as Darryl noted that medications “should work”, Michael framed improvement as the natural result of medication taking and as something that should not be difficult to achieve. The fact that he "can't even respond" was taken as further proof he was fundamentally flawed. Whilst participants clearly described doing something wrong, they were vague about what doing better would involve. Instead, they drew attention to global failings in character that prevented them from recovering from depression.

"I don't actually have depression"- Personality is the problem. At times, rather than suggesting that personality flaws maintained their depression or prevented improvement, participants framed personality as the problem in and of itself. They suggested they were not actually experiencing depression and, instead, their distress lay directly in these personality factors. Lily, for example, accounted for her persistent distress in this way:

Lily: *I don't know if it's just me being really paranoid, but it kind of feels like maybe I'm just trying to get attention or maybe I'm just a really negative person who is really pessimistic, and I don't actually have depression, and I'm kind of making it up essentially. And even though it's like, "no, you have all these really strong symptoms that you wouldn't really be able to make up", it's still kind of hard to see it rationally.*

(...)

Lily: *I guess, it's always kind of been like, "am I actually just quite a cluster B type personality, kind of with like emotional distress or maybe slightly manipulative?", I don't know. But that's just kind of, I don't know, the tendency to pathologise everything. But in my work as a [mental health professional], I've seen people who haven't responded to treatment before, and it's like, "oh well, they don't actually have depression, they actually have more of a personality disorder." So it's always like, "is that me?"*

(...)

Lily: *I think it's hard to deny that the symptoms of depression that I have are there (...) But I don't know if there's also—like it's potentially to me a possibility that there's something else at play at the same time. I mean, obviously, people have a tendency to be more negative or pessimistic (...) And I think people are just like that. And obviously people can change and stuff, but I think I've been like that since I was a child. And obviously I could still change that and that would be ideal, because obviously that means that I'm vulnerable to these periods of low mood.*

Lily suggested that her long-term distress was caused, not by depression, but by a pervasive and problematic personality – "just a really negative person who is really pessimistic" – that could not be rectified with antidepressants. She also suggested she may have an underlying personality disorder: an enduring and impairing pattern of thinking, feeling, and behaving. Drawing on her mental health training, Lily indicated that, more specifically, she may have a "cluster B" personality disorder characterised by emotional, erratic, and dramatic behaviours. Lily framed her mood difficulties as the "emotional distress" commonly experienced with such disorders, noting that her "manipulative" traits may have led her to "make up" her depression. This accounting was justified through Lily's mental health training and employment, framing this account as reasonable and legitimate. Michael similarly described the possibility that his persistent distress was due to the fact that "I'm not actually depressed. I'm just being silly". He described himself as "just being pathetic" or needing to "stop being ridiculous".

In these stories, the lack of effectiveness of antidepressant medication was presented as supporting evidence that the problem lay in personality rather than depression. For example, Amanda described wondering, "if medication isn't helping me, maybe it's just me. Maybe I can't do life very well or something". Similarly, Lily questioned, "if it [my depression] was real, wouldn't it respond to medications?" Inherent in these stories was the assumption that antidepressants are effective in treating depression. As a result of this, the observed ineffectiveness of antidepressants led participants to question their diagnoses of depression.

"Medication isn't going to fix everything". Throughout accounts of personality either fuelling depression, preventing improvement, or being the problem in and of itself, participants suggested they were not experiencing symptom resolution because antidepressants could not address these enduring problematic traits. Amanda, for example, questioned "how much change I should expect from medication" when the root of her depression was seen to be pervasive personality traits. She expressed doubt that antidepressants could target these habitual and deeply engrained thinking patterns, suggesting, "yeah it would be great if medication fixed it, like it's not going to fix everything". Lily also expressed doubt and drew on her mental health training to assert that "obviously for those type of [personality] problems, medications don't work as well". With medications viewed as futile, improvements were viewed as possible only through direct changes to who they were as people. Amanda asserted, "I can't change, until I change the way I see myself" and Michael suggested improvements would occur if he managed to "stop being like this" and "stop being ridiculous". Similarly, Lily suggested it "would be ideal" if she could change her tendencies as they made her "vulnerable to these periods of low mood".

Counter narratives. Cutting across these attributions of persistent distress to personality factors were two counter stories; of personality as malleable, and of flawed personality accounts as a symptom of depression.

"People can change". Although most descriptions framed personality as stable and unable to be targeted with medication, Lily at times grudgingly acknowledged the possibility that people "can change". Following an extended account of personality as set, Lily shifted to stating that "obviously people can change and stuff…and obviously I could still change that and that would be ideal". In entertaining the idea that personality is potentially malleable or that problematic tendencies can be "fixed", Lily presented the self as able to be worked on through individual effort. Attachment to this narrative of personality as changeable, however, was weak. Lily’s recurrent use of the words “obviously” and “ideal” suggested she was demonstrating a commitment to this narrative as it was the culturally favoured and idealised narrative in Western mental health settings, rather than because it usefully framed her experiences.

“I kind of believe it’s the depression”. Also challenging the attribution of persistent distress to personality, participants at times suggested that their negative appraisals of their personalities may be a symptom of mental distress. This narrative accords with psychiatric conceptualisations of negative thinking and feelings of worthlessness as symptoms of depression. For example, Lily questioned whether the belief she had a personality disorder was “just me being really paranoid” or had come about due to a “tendency to pathologise everything”. She also noted she had “really strong symptoms that you wouldn’t be able to make up” and that “it’s hard to deny” she was experiencing depression. In doing so, she switched to grounding her persistent difficulties in mental distress rather than personality. Similarly, Michael shifted to framing the belief that “I’m not actually depressed” as a potential symptom of depression, rather than an explanation for his persistent distress. He prefaced his shift by saying, “there’s that thing in depression”, where “a lot of people” experiencing this condition may believe they are “not actually depressed”. When asked directly by the interviewer about his assertions that his depression was “something to do with me as a person”, Michael elaborated on this counter-story:

> *Michael:* *No, I don’t really believe that anymore. I kind of believe it’s the depression and that altered sense of self you get at the time, and like the guilt and stuff. But no, I think it was probably just treatment resistant illness for some reason. I don’t think it’s me. It couldn’t have been me (laughs), but I don’t know.*

Michael was aware that these interpretations may have been a result of his depression, however, even whilst presenting this story, Michael used tentative language suggesting he was uncertain about whether or not this was the case.

Discussion

A significant proportion of people experiencing depression do not respond to treatment as expected. Participants in this study were among this group and described long periods of distress despite significant input from health professionals, use of multiple medications, and engagement in psychological therapy, alternative treatments, and lifestyle changes. This study focused on the ways people with TRD accounted for the persistence of their depressive symptoms in spite of this high level of help-seeking and treatment engagement. Two predominant and overarching narratives emerged that structured the participants' explanatory accounts. TRD was described as resulting from either a flawed brain that was resistant to the mood improving effects of antidepressants, or a flawed personality that was beyond the reach of medication.

Interestingly, both narratives attributed persistent distress to factors within the person. This contrasts existing literature, which suggests that explanations for depression predominantly centre around external psychosocial factors (Prins et al., 2008). For example, both patients and clinicians have been found to frame depression as an understandable consequence of challenging life events, such as bereavement, illness, or divorce (Barley et al., 2011; Prins et al., 2008; Schumann et al., 2012). These accounts may differ because they are from people whose depression responds to treatment as expected. Whilst previous research found that psychosocial factors were referenced by people with TRD when speaking about initial episodes of depression (Kroch et al., 2021), this was no longer the case in the present study when participants were specifically accounting for the *persistence* of their depression in spite of treatment.

These findings are consistent with the limited existing literature exploring patients' accounts of persistent depression. Although Buus et al. (2012) did not specifically recruit people with TRD, they found that, at each subsequent interview in their longitudinal study, as depression persisted, the significance patients placed on triggering index events reduced. Similarly, accounts of people who had been hospitalised multiple times for depression prior to recruitment were void of references to specific index events (Buus et al., 2012). Several factors may explain why people with TRD do not draw on psychosocial explanations. Emerging research suggests TRD is described as a constant yet unpredictable ebbing and flowing of symptoms with shifts unrelated to external events (Kroch et al., 2021). This account of TRD troubles psychosocial explanations, in which depressive experiences are storied as discrete episodes neatly linked to biographical events and resolved through personal action (Buus et al., 2012). This likely means acute psychosocial narratives do not usefully frame experiences of people with TRD and are consequently not drawn on.

With acute psychosocial explanations absent, participants negotiated and switched between the two internal attribution narratives as they made sense of the persistence of their depression in spite of treatment. The *treatment resistant personality* narrative aligns with previous findings that both patients' and clinicians' causative models become increasingly focused on enduring personality attributes when depression persists or is considered treatment resistant (Buus et al., 2012; McPherson & Armstrong, 2009). McPherson and colleagues (2009) found that, when patients did not respond to antidepressants, they were demedicalised by GPs; their difficulties were no longer labelled as 'depression' or conceptualised biomedically and, instead, were attributed to problematic traits or behaviours. This demedicalisation was mirrored in the present study, with participants interpreting lack of response to medication as evidence to support a shift from an illness-based model to a personality deficit-based model. In McPherson and Armstrong's (2009) research, personality flaws were at times framed as personality disorders (remedicalisation) by GPs. Findings from the present study suggest this explanation may also be available to patients, with two participants questioning whether they were experiencing a personality disorder rather than depression. This highlights a clear narrative that lack of expected symptom reduction following adequate treatment indicates a fundamental personal issue.

Participants also attributed the persistence of their depression to having a *treatment resistant brain*. When numerous antidepressants did not alleviate depressive symptoms, they interpreted this in terms of their personal biochemistry rather than questioning the effectiveness of the pharmaceutical treatments. Throughout their accounts, participants continued to draw on this biochemical explanatory framework; framing depression as a chemical imbalance and antidepressants as a suitable and effective way of rectifying this, and accounted for their own lack of improvement by positioning themselves as unfortunate exceptions to the rule. When medications said to rectify depression-causing chemical imbalances do not result in cure, it may be expected that biochemical narratives of depression would be fundamentally challenged. However, despite the now widely accepted lack of evidence (Lacasse & Leo, 2015), the chemical imbalance story remains a pervasive and alluring conceptualisation of depression – even for those it seemingly does not serve. The strength of this accounting can be interpreted in several ways. Firstly, it enables those with TRD to retain hope of future recovery. As noted in other studies (e.g., Buus et al., 2012), biochemical models of depression allow for sustained alignment with Western expectations of treatability. Aware of this link between biochemical models of depression and restitution narratives, clinicians have described strategically employing such explanations in order to encourage antidepressant use and promote prognostic optimism among patients (Lacasse & Leo, 2015; Rogers et al., 2009). Especially relevant in the case of TRD, continued alignment with biochemical narratives appeared to legitimise participants' continued time and resource intensive search for an antidepressant cure, which is consistent with findings of studies exploring patients views towards antidepressant taking (Malpass et al., 2009; Maund et al., 2019).

Secondly, biochemical explanations may persist because of the power of the medicalisation of mental distress. Biochemical explanations reflect powerful processes that shape mental health services in important ways. Even when biomedical explanations were troubled by persistent depression, GPs in previous research were reluctant to completely demedicalise patients' distress and, instead, responded by assigning personality disorder diagnoses (McPherson & Armstrong, 2009). Entirely rejecting a biochemical explanation has implications for the role of health professionals in responding to mental distress. At least some of the basis of their expertise and capability in responding is dependent on these explanations. Moving away from these explanations undermines this and can explain, in part, how biochemical accounts continue to be perpetuated despite lack of evidence.

These two causative explanations had different implications for the participants as social actors in the world. The *treatment resistant brain* narrative allowed for an account of persistent distress that was not morally laden. Any perceived flaw was confined to biological mechanisms of the brain. Reproducing a mind-body dualism inherent in psychiatry, these biological mechanisms were firmly positioned as distinct from the 'self', so there were no implications in terms of social or moral worth. This is consistent with suggestions that biochemical accounts of depression reduce sense of personal responsibility for distress (Buus et al., 2012) and are viewed and experienced as less stigmatising (Barley et al., 2011). Conversely, the *treatment resistant personality* narrative had profound implications for character. With flaws situated in personality and, therefore, considered stable and enduring features of the 'self', participants had to manage presentations of themselves as inherently flawed people.

Several sample and setting specific factors may have influenced narrative production in this study. Participants had very specific characteristics: they attended a private clinic in an affluent area so likely had the resources to support both favourable social circumstances and unlimited and high-quality treatment. This may have contributed to the lack of adoption of psychosocial explanations – a less privileged group of people with TRD may have attributed persistent distress to ongoing psychosocial difficulties such as poverty. This setting also likely bolstered use of biochemical explanations. The settings in which stories are told are crucial to how they unfold. This Western psychiatric setting provided a powerful structure for explanations the participants provided, both in terms of their alignment with biomedical models of mental illness and in their positioning of the interviewer as aligned with this profession (see Kroch et al. (2021) for a more thorough exploration of the influence of this study setting on narrative production).

This shift from external to internal explanations has important clinical implications. The way mental distress is conceptualised matters deeply as it informs people's approaches to help-seeking and health professionals' approaches to service delivery. These explanations for persistent distress likely influence the level of agency people feel they have and the degree to which they persist with treatment. Biochemical explanations, whilst less problematic for those who do respond to antidepressants as expected, may encourage an ongoing search for the elusive biochemical 'cure'. Additionally, as seen in this study, biochemical explanations are so pervasive that when antidepressants do not result in remission, the assumption is that it is the fault of the individual. Whilst psychosocial explanations of TRD suggest improvement will occur when challenging life circumstances resolve, internal attributions may culminate in a profound sense of hopelessness for people with TRD and lead to representations of the self as inherently and permanently flawed. From a psychological perspective, these views are harmful – or at the very least unhelpful – and are likely, in and of themselves, to perpetuate depressive symptoms. Counter-narratives espousing the potential for recovery through transformation of the self are available and encouraged by health professionals, but they too place ultimate responsibility on the individual. Clinicians need to be aware of patients' tendencies to shift to self-blame when antidepressants are ineffective, but they must also be cognisant of the role they – as social actors embedded in powerful medical contexts – play in constructing and perpetuating these narratives.

Conclusion

Like anyone experiencing a health or mental health issue, people with TRD want to make sense of their experiences. They draw on narratives available to them in the spaces they inhabit to understand and explain the fact that they remain depressed despite adequate treatment. When their experiences of persistent depression trouble so many – if not all - Western expectations of illness and recovery, their options for sense-making are limited. This study has shown that, when the biochemical ‘cure’ that is seen to work for everybody else does not work for people with TRD, they look inwards. Reinforced by the notions of personal responsibility for one’s state or behaviour inherent to Western mental health settings, people with TRD come to attribute their continued difficulties to personal flaws and believe that the only way to achieve recovery is to fundamentally change themselves.

CHAPTER SIX: SINGLE CASE ANALYSIS – Accounting for the experience of TRD

Findings

This chapter includes the findings of a single case narrative analysis. It explores the narratives of one participant, a woman in her forties, experiencing TRD. This participant, Sarah, was selected from the wider participant group for this analysis due to the fact that she demonstrated the most significant commitment to pursuing treatment and to a narrative of depression resolution. Throughout her accounts, she clearly narrated two explanations of persistent distress that differed to those outlined in Chapter Five. In contrast to other explanations, these narratives framed distress as temporary rather than an issue of fundamental treatment resistance. As a result of this, they allowed Sarah to remain more definitely aligned with expectations of return to wellness. Whilst these two narratives were evident to some degree in the wider participant group's accounts, they were storied much more tentatively by others. They were also only illuminated through the identification of Sarah's narratives. The striking nature of Sarah's accounts meant that they epitomised these narratives. They were therefore analysed separately and chosen as the focus of this chapter.

Sarah is a single 48-year-old woman of Pākehā (New Zealand European) descent. At the time of the research, she was living in Auckland, New Zealand and was employed in a full-time sales role. Sarah had been experiencing depression for approximately nine years. Over this period, she estimated that she had been treated with up to 20 medications prescribed by either GPs or psychiatrists. Each of these medications had provided only short-term or minimal relief from symptoms. As well as receiving pharmacological treatment, Sarah had been attending psychological therapy sessions with a clinical psychologist for seven years.

A narrative of help-seeking and resolution. Sarah described the initial onset of her depression in terms of changes she had noticed in her mood and energy. She described having worked hard in her sales role for several years without breaks, and beginning to experience a lack of enthusiasm and enjoyment. Sarah attributed these changes to being *"worn out"* and, as a result of this, decided to take a break from work and go on holiday. On her return, however, Sarah described realising that she felt no better and, as the weeks passed, she deteriorated further. She sought help from her GP, was referred to a psychiatrist in private practice, and was prescribed an antidepressant medication.

Sarah's account of the onset of her distress followed the standard story of depression, in which she realised she was struggling and attempted to address this by seeking professional help. This standard story also includes the expectation of return to wellness following help seeking, and this was evident in Sarah's accounts. Sarah recounted the explanation she had given to her colleagues after a period of time off due to poor mental health. She described acknowledging to her colleagues that she had been having difficulties with her health which had affected her performance, and informing them that she was now on the path to recovery:

> *Sarah:* *…there was a point at the first couple of years where I was very depressed and then I had something that was making me better. And I went to a sales conference that we had for our staff and said, "oh look, I know that I haven't been very well and helping you guys very much and that's because I've been sick and I just want to tell you that I am now getting better".*

Everything about this story fit the expected and dominant account of depression; a trajectory from illness to help-seeking to wellness. In this story, depression was narrated in the past tense. Sarah firmly said, "I was very depressed" and "I am now getting better", describing the depression as over and the present and future as characterised by wellness. This story was archetypal; familiar to both the interviewee and interviewer as an account of the onset and resolution of an episode of depression. It was rehearsed, a story of telling a story about depression, and delivered confidently and fluently. In the context of an interview nine years later, after which her depression has ultimately not resolved, Sarah still recounted this story. It was her preferred story of depression and the story she hoped yet to be able to tell. This story of Sarah telling her colleagues about her depression resolution set the tone for the rest of the encounter and the narrative arc of depression resolution was evident throughout the interview.

However, as well as providing accounts characterised by this expectation of return to wellness, Sarah also more tentatively told of depression as an ongoing struggle. In these accounts, she explained that, within the nine year period since the initial onset of her depression, “nine months” was “probably one of the longest periods” she had experienced of relative wellness. In making sense of this persistent distress despite significant input from health-professionals, Sarah provided two narrative explanations. At times, she attributed her ongoing depression to an unresolved search for medication. At other points, she attributed her persistent distress to her engagement in bad patient behaviours.

It can take time to find a suitable medication. At times, Sarah accounted for the persistence of her depression by suggesting that she was experiencing the temporary inability to find the right drug to resolve her depression:

Sarah: *... because I know that sometimes it can take time to find something that works for you. Like we make skincare...so it doesn’t work for everybody, or some people have reactions to certain things and some people cannot drink dairy or gluten so, you know, it’s a matter of your body adjusting to it.*

In providing this explanation for her persistent distress, Sarah noted that, just like “skincare”, a person may need to try several medications before finding one that suits them, or, just like “dairy or gluten”, a person may react badly to one antidepressant and need to try alternatives. Although not all medications work for everyone, inherent in this account is the assumption that a suitable pharmaceutical treatment exists for each person and is waiting to be discovered. Through storying persistent distress in this way, Sarah framed TRD as a temporary difficulty rather than an issue of fundamental treatment resistance.

Sarah continued with this way of accounting for persistent distress even when narrating several turning point moments. These moments involved her learning from her psychiatrist that she was somewhat different from other patients with depression, and her reading the online blog of a woman who had been experiencing TRD for over 15 years. But even as Sarah narrated these turning point accounts, which deviated significantly from her preferred narrative of depression resolved and – arguably, troubled her explanation of distress being a temporary issue – she continued to account for her continued depression in this way.

Int: *Was there a time that you sort of realised that, you know, you were expecting that you would get better and then you realised that it wasn't quite going to plan? You know early on?*

Sarah: *No, I probably didn't realise. I thought it was just me. I thought, "oh well, maybe it's just me". And so it wasn't until a couple of years in that [the psychiatrist] said, "oh well, um, those people with major depression like yourself", and I'm going, "okay, I didn't know there was <u>different types of depression"</u>. So that's when it sort of clicked that there's more than just trialling a couple of different things, that these are people who have the inability to find something. And then I read online in a couple of forums and there's this one lady who started up a group called blue something or other and she's had major depression and a lack of finding a drug for about 15 or 20 years. So that's a <u>really long</u> time.*

For Sarah, TRD was about not yet having found the right medication – "the inability to find something". Her focus on "finding" the drug suggested that a suitable pharmaceutical treatment for depression for each person does exist, just has not yet been found. Sarah characterised the experience of the woman in the blog as a "lack of finding a drug for about 15 or 20 years". TRD was not described as the struggle of enduring depression, but as the struggle of the search for an appropriate medication. Through accounting for TRD in this way, Sarah was able to make sense of her longer-term depression and continue drawing on an overarching resolution narrative despite her stories of ongoing depression. This allowed her to keep alive the idealised story of depression offered to her colleagues: that after considerable searching she would find something that works and her depression would resolve.

Bad patient behaviour. Within Sarah's accounts, a second narrative attributed her persistent distress to engagement in patient behaviours that were not viewed as conducive to resolution of symptoms.

Sarah: *Um, but I find that when I get quite depressed I tend to withdraw into myself and I will cancel [psychology] appointments, and I'll do the same thing with [the psychiatrist] as well. So I tend to withdraw into myself (...) Or—which I tend to do a lot—stick my head in the sand and it will go away (...)*

Int: *Okay. Yeah, I think those are quite natural responses, hide your head in the sand.*

Sarah: *Oh, I do that as a general rule (laughs). Like I was meant to go to the doctor because I have some other health things I need to sort, but if I don't go it'll go away.*

Int: *Yeah. Or it feels like it's not real for a little bit.*

Sarah: *Yeah (laughs). Try a year!*

Bad patient behaviour was characterised by withdrawal. It involved disengagement from help-seeking and health professionals' advice and from the search for "an answer". Accordingly, Sarah presented an account of struggling to adhere to her treatment regime at times. Whilst she had been engaged in mental health services for many years, she highlighted her tendency to "stick my head in the sand" and avoid appointments with healthcare professionals. By drawing attention to this, Sarah accounted for the fact that she had not recovered from depression as expected. Given that Sarah had, at times, not been unwaveringly committed to the search for the right medication, it was unsurprising to her that her depression had persisted. Rather than entertaining the possibility that she may never recover, Sarah's enduring symptoms were attributed to this withdrawal and disengagement.

Whilst the bad patient positioning allowed Sarah to make sense of her lack of improvement despite significant input from health professionals, she was aware of the disadvantages of being associated with this group:

> *Sarah:* *Um, I think I was surprised that I had ended up in that area (...) And, I mean, he [the psychiatrist] made a comment the other day actually where I went, "um, am I one of those difficult people am I?" (laughs).*
>
> *Int:* *You asked that?*
>
> *Sarah:* *No, he said something along the lines of, "well, um, you're one of those patients that have been around for a long time" and I went, "um, ok, I'm one of those people" (laughs).*

Sarah had an impression of the type of people who have "ended up in that area" and was aware of the possibility of being viewed as one of these "difficult people". She consequently stated that she was surprised by the psychiatrist's comments and, in doing so, distanced herself from "those patients". Sarah navigated a fine line between using this positioning to make sense of her lack of lasting improvement and resisting alignment with this "difficult" group.

This bad patient behaviour accounting allowed Sarah to make sense of her persistent distress and, similar to the "it can take some time" explanation, it also allowed her to continue drawing on the overarching narrative of depression resolution. Again, TRD was framed as temporary rather than an issue of fundamental treatment resistance. Inherent in this bad patient behaviour explanation was the assumption that, if or when Sarah did choose to fully engage with treatment, her symptoms would resolve. This meant that, as well as providing accounts of bad patient behaviour, Sarah frequently provided accounts that positioned her as a good patient:

Int: *What was that like for you when [the psychiatrist] said that [you have been around for a long time]?*

Sarah: *Um, no that didn't worry me. Um, because I know it's said in a safe place, so it's never ever anything that's said in a negative fashion or something to put you down. Where other people can do that, but with [the psychiatrist], you know he's been through it so he knows what it's like. And I know that I'm a bit of a… um, because three or four months ago when we went onto a trial drug from America and I'm the first one to try it of his patients. It didn't work, but I was the first one of his patients to try it! (laughs)*

Int: *Oh that's exciting. Sounds like he's doing everything he possibly can. He's got the trial drug and you were the first person.*

Sarah: *Well, it's trialling in New Zealand. They've never had anyone trial it in New Zealand. Um, and it was $600 a month, so we tried it for six weeks to see if it did anything, so yep.*

In this account, Sarah highlighted her motivation and willingness to continue attending appointments with her psychiatrist. She also spoke enthusiastically about trialling new, infrequently used, and often very expensive medications. Sarah alluded to a positive relationship with her psychiatrist, in which he disclosed his personal experience of depression and chose her to be the first patient to trial a new American medication for depression. Her use of the personal pronoun, "we", positioned her and the psychiatrist as working alongside each other to find a medication that worked. In drawing attention to these experiences, Sarah resisted the absolute positioning as that of a bad patient. Additionally, she was able to remain aligned with the narrative of depression resolution. If she engaged in good patient behaviour and remained tirelessly committed to finding the "answer" to TRD, her distress would one day end. She would be able to story her depression as an overcome obstacle of the past.

This narrative analysis revealed how one participant, Sarah, made sense of her experiences and navigated positioning in light of a 9-year depression trajectory that had involved taking over 20 medications with no significant or sustained improvement. In contrast to the accountings outlined in Chapter Five, these explanations did not frame the self as fundamentally treatment resistant. Instead, both accounts framed distress as a temporary issue that would be resolved once a suitable medication was found or bad patient behaviour ceased. Throughout her accounts, Sarah negotiated and switched between these narratives. These explanations of persistent distress allowed Sarah to remain aligned with Western expectations of return to wellness. They allowed her to hold onto hope that she would one day be able to narrate her depression as a thing of the past, as she did to her colleagues at the conference close to nine years earlier.

CHAPTER SEVEN: DISCUSSION AND CONCLUSION

This chapter provides a summary of the findings presented across the three findings chapters. This research explored how people experience and make sense of depression that has not improved as expected following treatment. Using narrative analysis, this research identified a number of narratives that people drew on when describing their experiences of TRD. These narratives shaped the positions or identities adopted, resisted, or negotiated by people experiencing TRD. These findings provide insight into how people make sense of the experience of depression that does not improve following treatment as well what it means to be a person with TRD. This chapter contextualises these findings within the existing literature, discusses clinical implications for health professionals working with people experiencing TRD, explores the limitations of the research, and outlines potential directions for future work.

Overview of findings

When storying experiences of depression that had not improved despite treatment, participants drew on two narratives: one of order and one of disorder. Drawing on the narrative of order, participants framed their depression as predictable, measurable, and understandable. They used the narrative to organise and contain their experiences of depression and draw attention to patterns in these experiences. Drawing on the narrative of disorder, participants narrated their depression as a random ebbing and flowing of experiences that could not be measured or made coherent. This narrative was used to make sense of experiences of unrelenting depression. Across the participants' accounts, a tension emerged between narrating depression as understandable and ordered and narrating depression as chaotic and confusing. Rather than drawing on one of these narratives in isolation, both were used throughout the participants' meaning making processes.

The participants also told stories to account for why they had remained depressed long-term despite receiving treatment. At times, participants attributed their persistent distress to having a treatment resistant brain or a treatment resistant personality. As illustrated in the single case study, there were two alternative accountings - a narrative of bad patient behaviour and a narrative of taking some time to find a suitable medication. Three of these accountings linked persistent distress to factors relating to the individual that prevented antidepressants from working effectively. The treatment resistant brain accounting attributed ongoing depressive symptoms to brain biochemistry that could not be rectified with antidepressant medication, and the treatment resistant personality accounting linked persistent distress to character traits that were beyond the reach of medication. Similarly, the bad patient narrative attributed TRD to certain patient behaviours, such as withdrawal from treatment, that prevented the expected trajectory of symptom resolution from occurring. Whilst these three accountings located the treatment resistance in different facets of the self – biology, personality, and action – they were all built on a foundational assumption that antidepressants are effective for most people. Antidepressants were assumed to result in resolution of symptoms for those without flawed brains or personalities, or those who do not engage in problematic behaviours. Two of the accountings – the bad patient behaviour account and the explanation that it can take time to find a medication that works for you – differed in that they did not construct the self as fundamentally treatment resistant. Throughout their stories, participants consistently negotiated these narratives as they worked to make sense of their experiences of TRD and explain why they had remained depressed long-term.

The influence of neoliberal narratives

Several broad ideological narratives served as powerful structuring devices which influenced the way people narrated and accounted for TRD and navigated identity. These included publicly available narratives of depression, mental distress, and recovery that circulate in clinical psychology and medical settings in the Western world. These narratives frame depression in predominantly biomedical terms and espouse the idea that resolution of symptoms will occur after a person engages in a period of help-seeking, which usually involves medication (Buus et al., 2012; Karp, 1994). These publicly available narratives have long histories. Today, however, they are increasingly and powerfully shaped by Western frameworks of neoliberalism. Neoliberalism has shaped political, economic, and social life in Western countries since the 1970s (Carr & Batlle, 2015). Neoliberalism refers to both a political approach that favours free-market capitalism and an ideology that frames people as individuals, as autonomous actors responsible for their own lives (Brown, 2009). As an ideology, neoliberalism frames good fortune as the outcome of hard work. As a result of this, people are encouraged to take charge of their lives, act out of self-interest, and create their own fates (LaMarre, Smoliak, Cool, Kinavey, & Hardt, 2018). It follows then, that neoliberal principles assign responsibility for misfortune, such as illness or poverty, to the individual or family in question (Lemke, 2001).

Neoliberalism in mental health contexts. When applied to the domain of mental health, neoliberal narratives frame the pursuit of mental wellbeing as an individual task. Failure to achieve this is seen as reflective of lack of individual drive or merit, rather than failure of the social system within which the person is embedded (Carr & Batlle, 2015). Distress is conceptualised as a phenomenon that exists within the bounded individual, which abates when the person engages in a process of self-mastery, self-control, and self-growth (LaMarre et al., 2018). Rose (1998) argues that this framing of mental distress truly came to pass in the 1990s with the closing of state psychiatric institutions and the transition to community psychiatry. Mental health services began to be delivered predominantly in the community, families were required to take on the majority of care work, and governments took a step back and began to govern at a distance (Rose & Miller, 1992). It was at this stage, according to Rose (1998), that the culture of individual blame and accountability in mental health domains arose. In the present research, these neoliberal narratives of mental distress and recovery strongly shaped the way participants storied their experiences of TRD and navigated positioning within these narratives. Embedded in a strongly neoliberal context, the participants internalised and reproduced these powerful narratives of personal responsibility.

Becoming self-managing subjects with TRD. When the pursuit of contentment is framed as an individual task, the neoliberal directive in times of discontent is to learn to manage and master the self. Self-management is predicated on the idea that the person is a stable rational 'self' who can preside over and manage the separate entity of their 'disease' (Weiner, 2011). The participants' narratives contained strong themes of self-management. Whilst, as a concept, self-management initially originated in the domain of chronic illness, the allure of empowered and self-managing patients has led to the adoption of self-management approaches more broadly (Brijnath & Antoniades, 2016). Currently, self-management practices, such as active involvement in health care, self-monitoring, and shared decision making are encouraged among people of all health statuses in a diverse range of health settings. In the present research, self-management was promoted in the narrative of order, with participants presenting their depression as a phenomenon separate from the self that they, as self-aware and empowered subjects, were capable of managing and controlling.

A core component of self-management is surveillance of the self. As a rational manager, the self must learn to observe and understand the inner workings of the disease as part of the work of mastering and controlling it (Weiner, 2011). In the present research, with a great level of detail, participants told of predicting changes in their symptoms in response to environmental triggers, observing subtle internal shifts in mood, and using rating systems to measure and communicate their current status. At times, they took this a step further and included their partners or family members in these self-surveillance practices. Similarly, in an ethnographic exploration of self-management discourses among members of a bipolar disorder support group, Weiner (2011) described the "self-surveilling accountable subject" (p. 463) who engages in the practices of mood charting, record keeping, and becoming attuned to environmental triggers. When the self is a project to be honed, improved, and mastered, having a nuanced and in-depth understanding of one's inner workings is of paramount importance. These neoliberal themes of self-surveillance are also evident in accounts of recovery from depression. Within these accounts, people who were no longer experiencing depression attributed their recovery to their engagement in reflection, introspection, becoming aware of contributing factors, and becoming attuned to their instincts (Hänninen & Valkonen, 2019; Ridge, 2018; Steen, 1996). Consistent with the present research, the message inherent in these accounts was that wellbeing is earned through self-surveillance and self-mastery.

As evident in these studies, within neoliberal mental health contexts, there is a degree of moral value ascribed to existing in the world as an introspective and self-aware person. In the present research, this was evident in the participants' positioning. Throughout their accounts, the participants continually worked to position themselves as detached, rational, and self-aware experts on their internal worlds. However, whilst self-surveillance was storied as common and important, it was also storied as problematic in some ways. The problematic side of self-surveillance was seen in the narrative of disorder, with participants questioning their abilities to be objective and reliable interpreters and reporters of their own internal workings. Similarly, Weiner (2011) noted that, whilst engaging in self-monitoring, people with bipolar disorder began to distrust themselves, their thinking, and their behaviour and have difficulty distinguishing between themselves and their disease.

As well as engaging in continual self-surveillance, neoliberal subjects experiencing mental distress are encouraged to engage in more general self-labour (Brijnath & Antoniades, 2016). This self-labour, aimed at maintaining or restoring a content or productive state, involves engagement in a toolkit of practices. For example, in Brijnath's (2016) study, people in Australia experiencing depression described engaging in a range of "transformative lifestyle practices" (p. 6) aimed at controlling their depressive symptoms. They spoke of taking up meditation and yoga, beginning healthy eating regimes, engaging in frequent exercise, and starting practices of reflection and journaling. These practices were direct attempts to manage and control fluctuations in mood. In the present research, participants also described engaging in a range of self-labour practices. Their stories consistently involved mention of attending numerous appointments with health professionals, of having an unwavering commitment to trying new and often expensive medications, of frequent engagement in alternative practices such as meditation and yoga, and of lifestyle changes such as healthy eating and exercise. Again, such frameworks create the ideal identity of the good patient who assumes responsibility for making good choices in order to improve their wellbeing and engages in a high level of self-labour (Lorig & Holman, 2003; Teghtsoonian, 2009). In the present research, through drawing attention to these activities and their unwavering dedication to them over months and years, the participants aligned themselves with the virtuous position of self-labouring, self-responsible patients who take responsibility for decision making, problem solving, and accessing services and resources. This was epitomised by the narrative positioning of the good patient.

Becoming biomedical self-managing subjects with TRD – the intersection of neoliberalism and biomedicine. Several authors have highlighted the compatibility between neoliberalism and biomedicine and have argued that, as a result of this, the two ideologies support each other (Moncrieff, 2008; Rose, 2007). The neoliberal agenda to create self-managing subjects relies on a distinction between rational self and disease, and this is a dichotomy perfectly upheld by biomedicine (Weiner, 2011). In modern day psychiatry, distress, which is said to result from biological abnormalities, most commonly chemical imbalances, manifests as a contained set of symptoms within the individual. The individual - a stable, separate, and rational self - can learn to manage and control these symptoms, frequently by choosing to consume medications (Moncrieff, 2008). Hamilton highlights that “a permanent state of unfulfilled desire” is “the essential state for consumers in modern capitalism” (2004, p. 87). The notion of chemical imbalances fuels the idea that there is an ideal level of chemical balance that we should all strive for in order to rectify this unfulfilled desire (Moncrieff, 2008). Essentially, this notion has allowed for discontent, dissatisfaction, or difficulty to be medicalised and consumption of chemistry-altering medications to be sold as the answer. As many authors have pointed out, this alliance between biomedicine and neoliberalism greatly benefits the pharmaceutical industry (Moncrieff, 2008).

As a result of this “marriage of convenience” between neoliberalism and biomedicine (Moncrieff, 2009, p. 235), many modern-day accounts of self-management relate to the alteration of biochemistry. Accordingly, a significant component of the self-management that participants in this research engaged in was related to biomedicine. Embedded in a psychiatric private practice, mastery of the self was predominantly framed as a biomedical endeavour and narratives of self-improvement were strongly linked to altering brain chemistry through antidepressant medication. The participants’ self-surveillance not only involved tracking shifts in depression symptoms, but also playing close attention to the effectiveness of antidepressants and the degree to which they produced side effects. Their self-labour involved attending frequent appointments with their psychiatrist where the expectation was that they would accurately communicate the findings of this self-surveillance and engage as an active participant in finding a medication that was effective. Additionally, the participants’ stories of continued commitment to finding a biochemical cure can be interpreted as demonstration of their positions of self-managing and self-responsible patients. The tweaking of biochemistry is not the only means of mastering the self within neoliberal contexts, however. For example, psychotherapeutic approaches, such as cognitive behavioural therapy, emphasise self-mastery through the alteration of cognitions (Rasmussen, 2017). In another setting, therefore, such as a private psychology clinic, narratives of self-improvement may have been more strongly located in the alteration of thinking or behaviour patterns.

Recovery within a neoliberal biomedical context. For participants in this research, accounts of recovery were strongly influenced by narratives of biomedicine and neoliberalism. Under neoliberalism, recovery is equated with a return to existing as a productive member of the market society (Esposito & Perez, 2014). To be a normal person means to be capable and willing to act as a productive and consuming neoliberal subject (Rose, 1998). Accordingly, there is significant moral value ascribed to being a person who pursues productivity and power (Carr & Batlle, 2015). If a person does not live in this way, they are likely positioned as deviant, abnormal, or pathological (LaMarre et al., 2018).

This framing of recovery was evident in the participants' accounts. Each of the participants emphasised the fact that, despite their often severe and long-term difficulties, they had largely remained in employment or tertiary study. Often this work involved running their own business, managing teams, or high levels of responsibility. Through these stories, the participants positioned themselves as worthwhile, productive, and 'normal' members of society, despite significant health difficulties. The equating of recovery with productivity was epitomised by the accounts of the participant in the single case study. Stories of return to wellness centred around a return to functioning as a responsible, productive, and contributing member of her sales team. Returning to work was highly significant. This, above all else, was framed as indicative of the return to good health. It was fitting that, in her account of informing her colleagues about her return to work and normalcy, she was at a sales conference. This conflating of good mental health with desire and capability to engage in work also plays out in mental health settings (U'Ren, 1997). Focus in therapeutic settings is often on reducing a person's distress so that they are able to return to work or equipping them with the skills to manage the stress associated with work (Esposito and Perez, 2014). For example, a person may be taught relaxation techniques, communication skills, or strategies for managing 'unhelpful' thinking in order to help them perform better or cope in their role.

With neoliberalism and biomedicine strongly entwined, the return to existing as a normal, content, and productive person is frequently articulated as coming about through antidepressant treatment. Esposito and Perez (2014) argue that prescription medications are adopted in neoliberal societies as a tool to modify behaviours and emotions in order to meld the ideal neoliberal subject. For example, they are used to improve concentration or reduce feelings of apathy or stress, ultimately creating people who are higher performing and more competitive people across the domains of work, education, and personal life (Esposito and Perez, 2014). As has been argued, this was the case in the present research, with the participants' accounts of help-seeking, self-management, and recovery predominantly centred around biomedicine. Under a neoliberal framework, people are encouraged to demonstrate mastery, recovery, and improvement regardless of level of impairment. This was evident in the participants' narratives. Despite months and years of depressive symptoms, they were committed to narrating their experiences as having some resolution that would come about through altering biochemistry.

Lack of recovery in a neoliberal biomedical context. Whilst framing people as autonomous subjects capable of managing their own health may, to some, appear helpful or positive, this framework has more advantages for some people than others. These narratives of personal responsibility may be comparatively easy to navigate for some people with depression, for example, those whose depression follows the expected trajectory from illness to wellness. However, these narratives appear more complicated for people with persistent forms of distress. In instances where the assumptions inherent in these narratives do not hold, such as among people with TRD, there are significant implications for the individual experiencing distress.

The individual is assigned responsibility. Under neoliberalism, wellness is earned through self-mastery. As a result of this, responsibility for not achieving all that is promised within this framework – health, success, normality, happiness – is ascribed to the individual (Carr & Batlle, 2015). This played out in the present research, with participants assuming full accountability for their persistent distress, through referring to personal characteristics or behaviours. In some instances, such as accounts of "if I just did life better…" or inability to "get with the programme", they framed themselves as people unable to manage the neoliberal imperative to be rational managers controlling and containing their distress. In the bad patient narrative, lack of improvement was attributed to not acting as the ideal neoliberal patient – disengaging from perpetual self-labour and attempts to self-master and self-control.

Taking responsibility for outcomes and attributing lack of improvement to individual factors have been mirrored elsewhere. Literature suggests that, among both people experiencing illness or distress and the health professionals who work with them, outcomes are linked to self-control and personal effort. People experiencing depression in Australia attributed their depression to a lack of self-control and, subsequently, their failure to experience improvement as due to an inability to reinstate or learn self-control (Brijnath & Antoniades, 2016). Working-class women in the United Kingdom took full responsibility for all areas of life, from health to parenting to finances, and spoke disparagingly of anyone who did otherwise (Peacock, Bissell, & Owen, 2014). In terms of health professionals, general practitioners in the UK shifted to focusing on the personality traits of people experiencing depression when they did not experience improvement following antidepressant treatment. For example, they began to attribute their clients' difficulties to social deviance or poor coping skills (McPherson & Armstrong, 2009).

Additionally, in healthcare more broadly, doctors have been found to construct patients as bad, difficult, or challenging when they do not meet the core assumptions of medicine – that treatment results in prompt cure (Dubbin, Chang, & Shim, 2013; Shim, 2010; Sointu, 2017). Shaw (2004) suggests that in Western contexts patient worth is based on the degree to which a person meets the core tenets of medicine. The ideal patient is active, courteous, clearly fits a diagnosis, is motivated and compliant, and promptly recovers (Sointu, 2017) When this is not the case, patients have been regarded as non-compliant, inactive, non-communicative, and not entirely deserving of recovery (Shaw, 2004; Sointu, 2017). In these descriptions, recovery is closely tied to the status of actively involved patient. When a person does not engage in self-management, their right to the experience of recovery is questioned. This is because, under neoliberalism, work is seen to be the defining factor in the circumstances of one's life.

The system is absolved of responsibility. As well as assigning personal responsibility, this neoliberal and biomedical focus on the individual – as both the site of pathology and the rational self-manager – obscures the broader sociocultural factors that contribute to distress (LaMarre et al., 2018). In the present research, this individual focus shaped the participants' narratives. When explaining their persistent distress, the participants made very few, if any, references to social circumstances that could be contributing factors, and when they did, they were used solely to account for the onset of initial episodes of depression. This focus was mirrored in Brijnath and Antoniades' (2016) study, which found that people with depression in Australia did not talk about social factors or reforms as the cause or solution to their depression, despite sometimes experiencing significant social disadvantage. Similarly, Peacock et al. (2014) found that healthy women in the United Kingdom did not draw on social explanations when making sense of their challenging life circumstances, such as parenting, health, or finances, despite experiencing struggle and financial constraint.

Neoliberal conceptualisations of depression and distress appear to disqualify important aspects of a person's depression experience and erase the potential for socially oriented explanations of distress. This likely contributed to the lack of socially situated explanations for the participants' persistent distress in the present research. Within a neoliberal framework, social explanations may be accepted as the catalyst or 'trigger' of distress, but not offered as explanations for long-term distress. As depression persists, social accounts are no longer deemed legitimate and, imbued with narratives of personal responsibility, a person must assume responsibility for both the persistence of distress and the discovery of a solution. This shift in causative accounting is mirrored in the broader literature. For example, psychosocial factors appear to be favoured when accounting for acute and early episodes of distress (Buus et al., 2012; Prins et al., 2008), however, when distress persists, explanations shift to be rooted in personality (Buus et al., 2012; McPherson & Armstrong, 2009). This is the case among both those experiencing distress as well as health professionals.

These findings demonstrate the pervasiveness of the neoliberal framing and the manner in which principles such as personal accountability are adopted and internalised by those experiencing mental distress. Even when people are experiencing significant hardship, they appear not to refer to this when explaining their distress. Within mental health settings, this framework culminates in socio-structural factors such as poverty, unemployment, sexism, and racism being largely ignored. When the baton of responsibility is handed to the individual and their family, institutions of power are released from their responsibilities of tackling systemic contributors of distress (Brijnath & Antoniades, 2016).

Positioning and moral implications. Each of the narratives outlined in the present research made available different options for relational positioning. Narratives of disorder, problematic personalities, and bad patient behaviour were characterised by accounts of unsuccessful attempts to live up to the neoliberal ideal. In drawing on and negotiating these narratives, participants adopted the position of flawed neoliberal self-manager – a person unable to self-monitor and self-master in order to recover from depression. Whilst the participants used these narratives to make sense of their experiences of long-term distress, there were significant moral implications associated with them. Esposito and Perez (2014) note that failing to live up to the neoliberal imperative is at best associated with irrational idealism, but more commonly with individual pathology or deviance. Additionally, Sointu (2017) has highlighted that failure to inhabit the virtuous position of actively involved patient leads to a person's right to recovery being questioned.

Aware of the potential problematic identities of flawed, incapable, or difficult patients not worthy of recovery, the participants in this research worked to manage their social positioning by, at times, distancing themselves from these perceived groups. This is seen in the narrative of order, with the participants framing themselves as effective self-managers and 'typical' people with depression, and in the good patient accounts, with participants framing themselves as people who were engaging in significant self-labour. Another way this was managed was through counter-narratives of potential for eventual self-mastery. Through drawing on these narratives, which were aligned with neoliberal discourses, participants adopted and negotiated the virtuous position of patient who is capable of engaging in self-surveillance and self-labour, and who is worthy of recovery. This position was associated with a high degree of moral value.

As well as managing the moral implications associated with the position of failed neoliberal subject, the participants in this research had to navigate the potential moral implications of evading personal responsibility for this failure. Esposito and Perez (2014) highlight that under neoliberalism, assigning blame for one's situation to factors outside the self is generally regarded as further proof of a fundamental issue or pathology. In keeping with this, Peacock et al. (2014) found that participants in their study viewed the use of socially contextualised perspectives as a way of actively evading responsibilities. The women in their study solely drew on individual explanations and interpreted social explanations as a way of justifying failure to achieve what was expected of them. They also expressed guilt about using these explanations and fear about others viewing them negatively for making excuses. Participants in both the present research and the study by Peacock et al. (2014) at times actively resisted the potential identity as that of a shirker. The women in Peacock et al.'s (2014) study engaged in othering – they pushed this stigmatised identity away from the self by highlighting differences between themselves and people who they perceived to make up this group. In this research, the lack of social explanations could be interpreted as the participants resisting the potential positioning as that of a person who avoids or neglects responsibilities.

Throughout their accounts, participants adopted, resisted, and negotiated multiple positions as they made sense of their experiences of persistent distress. Whilst narrating accounts of unsuccessful attempts to self-manage and self-master, participants resisted absolute positioning of that of a failed neoliberal subject. This occurred though them working to remain aligned with the virtuous neoliberal identities of good patient or typical person with depression who is worthy of recovery and worthy of re-emerging in the world as a productive and normal person. The participants in this research continually navigated this challenging landscape as they storied their experiences of persistent distress. Combined, these findings highlight that there are significant moral implications associated with being unable to live up to the neoliberal imperative to self-manage (e.g., as seen in the narratives of treatment resistant personality) and with being unwilling to take self-responsibility (e.g., as seen in the bad patient accounts and in the lack of social explanations). Either way, failure to exist as a self-managing self-responsible neoliberal subject is viewed as evidence of a fundamental personal issue (Peacock et al., 2014).

Arguably, the experience of depression may also fuel these narratives and positionings, impacting the manner in which people make sense of their experiences and navigate identity. Disturbances in corporeality have long been considered central to the experience of depression. Across time, cultures, and contexts, depression has been described as an experience that involves altered bodily sensations and functions (Doerr-Zegers, Irarrázaval, Mundt, & Palette, 2017). For example, it has been described as an experience of "hyperembodiment", in which the body feels heavy and rigid and serves as a barrier between the self and the world (Fuchs & Schlimme, 2009, p. 572), and as an experience where basic bodily functions, such as sleep, energy, sex, and appetite, shift dramatically (Pfeiffer, 1968). These embodied experiences of distress or discomfort may influence the way people make sense of depression or TRD. They may have an impact on the narratives adopted, drawn on, and reproduced, and the identities or positions taken on, negotiated, or rejected. Unfortunately, however, narrative approaches that privilege linguistic accounts inevitably neglect these embodied or physiological experiences. A critical realist approach would allow for a more nuanced exploration of the interplay between embodied experience, sense-making, and positioning in the domain of TRD.

Implications

In Western societies, such as New Zealand, it is likely that these powerful and pervasive narratives play out in clinical encounters. Disciplines such as clinical psychology, with their emphasis on the individual as both the site of pathology and the source of change, play a key role in reproducing and extending neoliberal notions of normalcy and personal responsibility (Rose, 1990).

To the health professional, the process of empowering people to take charge of their own wellbeing may seem like a positive approach. Indeed, for many people experiencing mental distress, the ideas and expectations inherent in these frameworks may be unproblematic, or even helpful. However, for some – perhaps those who do not fit the expected trajectory, especially - the neoliberal imperative appears to carry with it several significant burdens.

As described by participants in this research as well as participants in other studies (e.g., Weiner, 2011), engagement in endless self-surveillance results in people questioning their abilities to accurately gauge and communicate their internal workings and struggling to differentiate between themselves and their disease. Wiener (2011) argues that this is because the experience of mental distress undermines the neoliberal and biomedical distinction between self and disease. Instead, the experience of mental distress highlights the inextricability of sense of self and manifestations of distress. This means that whilst enacting highly encouraged, valued, and expected self-surveillance practices, people experiencing mental distress simultaneously come to recognise that they are unreliable and uncertain interpreters of their internal workings and increasingly view themselves as never fully knowable (Weiner, 2011). This played out in the present research – with a profound tension emerging between narrating depression as understandable and ordered (the narrative of order) and narrating depression as chaotic and confusing (the narrative of disorder). This tension, which is likely fuelled by messages circulating in mental health settings, appears extremely challenging to navigate. This is particularly the case for people experiencing persistent distress, such as TRD, who must endure this long-term. From a psychological perspective, a mismatch between lived experience and expectations in health settings may lead to further distress.

Findings from both this research and studies exploring the uptake of neoliberal ideology in mental health settings suggest that there may be negative implications associated with the imperative to self-manage. Across several studies, participants experiencing mental distress described the number of self-management practices they were encouraged to engage in as overwhelming or unmanageable (Brijnath & Antoniades, 2016; Peacock et al., 2014). They spoke of the difficulties associated with managing endless appointments and medications, engaging in healthy eating and exercise regimens, and constantly monitoring symptoms. In some cases, participants described having to opt out of some of these responsibilities in order to cope. In the present research, the withdrawal described in the bad patient behaviour narrative could be interpreted as a temporary opting out of the unrelenting neoliberal imperative to be a rational self-manager.

As well as leading to disengagement from treatment, the pressure to self-manage also appears to encourage engagement in dangerous behaviours. In desperate attempts to reduce depressive symptoms and be seen as effective self-managers, participants experiencing depression described self-medicating with alcohol and drugs, altering their prescription medication doses without health professional consultation, and consuming unregulated alternative remedies alongside or instead of prescribed drugs (Brijnath & Antoniades, 2016). These findings illuminate the negative consequences of the neoliberal imperative to master, contain, and control symptoms. They suggest that the burden associated with these narratives is high and the value placed on being an effective and rational self-manager may lead to people engaging in unhelpful behaviours when they cannot live up to what is expected of them. This suggests that vulnerable groups of people, such as those with TRD, may be left isolated, putting themselves at risk, and without the support of appropriate services.

In addition to the potential burdens of perpetual self-management, the individual focus in explanations of persistent distress within neoliberal contexts also appears highly problematic. From a psychological perspective, blaming the self for lack of recovery is unhelpful, or even harmful, and is likely to maintain feelings of low mood or distress. Additionally, this framing appears to have significant implications in terms of the services made available to people. As McPherson and Armstrong (2009) have pointed out, health professionals who endorsed narratives of individual self-blame, particularly those that centre around personality, often deemed certain interventions such as psychological therapy not useful. This meant that, for individuals whose difficulties were linked to personality, referrals to psychological services were not made.

In assigning responsibility for lack of improvement to the individual, little focus is paid to social factors that may contribute to persistent distress. In the case of TRD, this may manifest as health professionals paying insufficient attention to the social or economic conditions of the patient or client that could be hindering recovery. In the New Zealand context, deflected attention from social contributors of prolonged distress has particular implications for Māori, the indigenous people of New Zealand. Colonisation has had profound and enduring negative impacts on Māori. Acts of colonisation have resulted in dispossession of Māori culture, language, and land and have manifested in significant intergenerational trauma (Russell, 2018). This, combined with modern-day racism, socio-economic stressors, and cultural disconnection, has culminated in Māori being disproportionately affected by mental health difficulties (Russell, 2018). It is argued that, through reproducing neoliberal framings of mental health, health professionals play a role in obscuring and perpetuating the social inequalities born out of neoliberalism. In doing so, they release the government of its responsibilities (Brijnath & Antoniades, 2016; Pavón-Cuéllar & Orozco Guzmán, 2017).

This neoliberal framing is also mirrored in the way that TRD is defined and conceptualised. The majority of approaches to defining, conceptualising, and explaining TRD frame the individual as the reason for lack of improvement and non-response to treatment. As Dyck (1994) highlights, the ineffectiveness of antidepressant medication in the case of depression is interpreted as indicative of a treatment resistant person. This leads to the majority of research on TRD being focused on discovering why a person is treatment resistant and developing new treatments to remedy this. As is argued with neoliberal ideology more broadly (e.g., LaMarre et al., 2018), the focus on the individual as the site of the problem in TRD obscures focus from broader systemic issues. In the case of TRD, this manifests as relatively little focus on the unresolved conceptual issues, the apparent ineffectiveness of many of the offered treatments, or the socio-cultural factors that could contribute to continued distress. For example, despite the category of TRD existing for over 50 years, there remains a concerning lack of consensus on several basic issues, such as the way it is defined and conceptualised (Wijeratne & Perminder, 2008). Additionally, in both clinical and academic domains, there is little evidence to support chemical imbalance hypotheses of depression and it appears that antidepressants are significantly less effective than previously thought (Moncrieff, 2008; Rush et al., 2008). However, in the case of TRD, antidepressants continue to form the basis of treatment (Jenkins & Goldner, 2012). Relatively little attention is paid to the social factors that may contribute to lack of recovery in TRD. Some studies have suggested that experiences of difficult life events, trauma, financial stress, and relationship issues are common among people with TRD (e.g., Amital et al., 2008; Tunnard et al., 2014). However, as the authors of the Power Threat Meaning Framework highlight, these studies are limited in the way that they predominantly conceptualise social or economic factors as discrete ‘triggers’ or ‘maintaining factors’, rather than as pervasive systems of power and oppression that negatively impact individuals on a daily basis and directly contribute to lack of recovery (Johnstone & Boyle, 2018).

In the domain of mental health, neoliberal narratives have been described as “highly toxic” (Peacock et al., 2014, p. 179) and the practices they encourage have been described as “highly problematic” (Brijnath & Antoniades, 2016, p. 2). The findings of the present research, as well as other studies, suggest that neoliberal narratives of self-management and self-responsibility place high burden on the person experiencing distress. This potentially manifests as confusion, disengagement, dangerous behaviours, and self-blame on the part of the individual, and patient-blame, reduced provision of services, and little attention paid to social factors on the part of service providers. This is particularly relevant in the case of TRD, where depressive symptoms persist long-term. For those who recover as expected, navigating healthcare under neoliberalism may be a challenging but relatively short-lived endeavour, however, for people with TRD or other persistent forms of distress, this likely spans months or years. Combined, these findings suggest troubling clinical encounters may be experienced by an already vulnerable client group.

The more these neoliberal narratives of distress and recovery are privileged in clinical settings, the less likely it is that alternative narratives will flourish (Peacock et al., 2014). In turn, it may become more challenging for people to narrate their distress in ways that reflect the complexity of their experiences and the rich contexts in which they are embedded. Concerningly, these narratives are reinforced by health professionals in Western contexts in an unintentional and unconscious manner in their interactions with clients (LaMarre et al., 2018). Based on these findings, it may be beneficial for health professionals to consider the degree to which they reproduce these narratives of self-responsibility, self-management, and self-blame. Health professionals could consider how they can make space within clinical interactions for the creation of alternative narratives that more fully or usefully represent the multifaceted complex existences of those experiencing TRD.

Considerations for future research

The findings of this research represent the narratives of a small group of people experiencing TRD in the context of a private psychiatry practice in Auckland, New Zealand. Whilst a small and homogenous group of participants is not deemed a limitation within social constructionist research (Burr, 1995) discussion of the impact of participant characteristics and setting on the research findings is useful in guiding future scholarship. The participants in this group were all Pākehā (New Zealand European), affluent, and had high levels of educational attainment and employment. Six of the nine participants in this research identified as male. The participants had been all been diagnosed with major depressive disorder and assessed to have TRD and were receiving pharmacological treatment delivered by a psychiatrist in a private practice in a wealthy inner-city suburb of Auckland, New Zealand. This setting may have contributed to the reproduction of narratives of TRD which reinforce neoliberal biomedical mental health explanations. The practice was a private sector enterprise where wealthy consumers purchased pharmacological services from highly trained professionals in order to manage their own health. Embedded in this particular study context, it is perhaps unsurprising that the participants in this research drew so heavily on neoliberal and biomedical narratives when storying their experiences. With a wealth of resources available to them, they were also well equipped – perhaps more so than any other potential participant group with TRD – to embark on the neoliberal pursuit of self-mastery.

The participant and setting characteristics will have significantly influenced narrative production and the findings of this research. Other than this research, there is no known literature exploring the experiences of people with TRD, so comparisons to narratives used by other groups cannot be made. Further research, therefore, could explore how other groups in varying contexts make sense of and account for the experience of the persistence of distress following treatment. Research exploring narratives of TRD among people of other genders, socio-economic statuses, and ethnicities embedded in different contexts would elucidate the pervasiveness of these narratives and the manner in which other groups take up and enact these narratives. This could include research on TRD in other settings. For example, research on narratives of TRD among people engaged with the public health system may be instructive. Those receiving publicly funded services may have less control over the amount and types of services they have access to and may experience considerable barriers to engaging in pervasive self-management behaviours such as healthy diets or meditation classes. Similarly, people who live rurally may struggle to access psychological and psychiatric services, and these gaps in service provision may shape the narratives used to account for their persistent distress. Research in settings like these would demonstrate how narrative production differs in contexts that may be less archetypically neoliberal or biomedical.

Although this requires further exploration in the context of experiences of TRD, the limited existing literature on adoption of neoliberal discourses in health domains suggests that there may not be as much variation across groups and localities as one might expect. For example, Brijnath and

Antoniades (2016) found no differences in way that Indian-Australian and Anglo-Australian participants with depression understood and engaged with the neoliberal imperative to self-manage. Additionally, neoliberal narratives of personal responsibility were also found to consistently shape accounts of healthy working-class women and unemployed men of all ages in the United Kingdom (Crawshaw, 2012; Peacock et al., 2014) and members of a bipolar support group in the United States (Weiner, 2011). Whilst this research is limited, the little work in the area suggests that narratives of personal responsibility are drawn on regardless of age, gender, ethnicity, wellbeing status, or location. These findings again highlight the power and pervasiveness of the neoliberal directive. They suggest that these narratives may shape accounts of TRD among different groups in different contexts. However, further research is needed to explore this.

Within the New Zealand context, exploration of the experience of TRD among Māori would be valuable. Māori, the indigenous people of New Zealand, have been heavily impacted by colonisation. With the well-recognised link between Māori mental illness and colonial trauma (Russell, 2018), structural contributors may feature more heavily in accounts of persistent distress or lack of recovery. Māori views of mental wellbeing differ significantly from Western biomedical models in that they are holistic – framing mental, physical, social, and spiritual health as interconnected and interdependent (Mark & Lyons, 2010). Given this, narratives of TRD may vary among Māori in New Zealand. Perhaps the availability of alternative conceptualisations of mental health would lead to reduced commitment to biomedical narratives, when compared to Pākehā (New Zealand European) participants. Neoliberal narratives are pervasive, however, even shaping processes of indigeneity among Māori (McCormack, 2012). It may be the case, therefore, that these powerful narratives structure the accounts of Māori, or other indigenous groups, experiencing TRD. Further research would shed light on this.

Conclusion

A significant proportion of people experiencing depression do not experience the expected improvement following antidepressant treatment. The present research sought to explore how these people – who are deemed to have TRD – make sense of and account for these experiences. Set in the milieu of a private psychiatry practice in a wealthy inner-city suburb of Auckland, New Zealand, this research employed a narrative approach to explore the stories of people experiencing TRD.

In this research, participants consistently conceptualised their depression as biochemical in nature and narrated accounts of becoming self-surveilling, self-managing subjects embarked on a mission to understand and contain their depression through engagement with the system of biomedicine. When failure to contain and control occurred, and antidepressants did not bring about improvement, the participants often assumed responsibility for this. They told of treatment resistant brains, personalities, or counter-productive patient behaviours that prevented antidepressants, which were assumed to be effective, from working and their depression from abating. These accounts were strongly shaped by narratives of mental distress and recovery that circulate in clinical psychology and psychiatry settings which are underpinned by discourses of neoliberalism that prioritise personal responsibility and self-management.

In emphasising personal accountability and self-management, and self-blame when they did not achieve the desired and expected outcomes, the participants in this research were shaped as failed neoliberal subjects. It might have been expected, given their experiences, that people with TRD would resist these narratives. Following lack of the promised improvement following months or years of biomedical self-management, it might have been expected that participants would question biomedical and neoliberal ideologies. Instead, the participants drew on and reinforced the neoliberal narratives that provided problematic positions for them. This demonstrates the pervasiveness and power of the neoliberal directive. Even when all that is promised within these frameworks does not eventuate, people continue to make sense of, account for, and position themselves with reference to these ideas.

This research has illuminated several broader unexamined assumptions about mental distress and recovery that circulate in Western mental health settings. Whilst this work is specifically focused on TRD, these findings are relevant for all people experiencing mental distress as well as health professionals working in mental health domains. The findings of this research point to the importance of health professionals reflecting on their roles in perpetuating cultures of individual blame and accountability within mental health settings. This research has also revealed a distinct lack of literature exploring the experiences of persistent distress. This highlights the need to explore the experiences of people who do not fit the expected trajectory of illness to wellness within neoliberal contexts. As rates of mental distress continue to rise, especially within Western contexts, it is vitally important to explore how people navigate experiences of mental distress amid these powerful and pervasive narratives.

CHAPTER EIGHT: FINAL REFLECTIONS

This research was powerfully shaped by the fact that, alongside conducting this study, I was also training to become a clinical psychologist. This training meant that I commenced the research process imbued with the narratives that circulate in Western mental health settings that have been written about in this thesis. As a trainee psychologist, I viewed mental illness as a discrete set of symptoms located within individual that, with the right skills, could be objectively unearthed, understood, and treated. I had full confidence in the discipline and in my ability to help people increase their awareness of the internal processes that I saw as the root of their distress. Whilst these beliefs shifted and evolved over time, they strongly informed my initial framing of the research topic, the manner in which I engaged with participants, the way I interpreted and analysed the data, and the writing of this thesis.

Embedded in this paradigm, I initially applied these framings of mental distress to the concept of TRD. The early study documentation, such as the participant information sheet (Appendix A), frequently used the term “treatment resistant depression”. It described TRD as a “form of depression” the participants “have” that involved “several antidepressants having not worked for you as well as might be hoped”. In many of the interviews, especially those that occurred early in the research process, I continued this framing. For example, I opened one participant’s interview with, “I'm interested in your experience of having depression that hasn't responded to antidepressant treatments as doctors and psychiatrists and psychologists might expect and what that's been like for you”. This framing meant that, before the interviews began, the participants had been socialised to certain narratives of mental distress. TRD had been positioned as a phenomenon they *had* rather than experienced – as something internal to them, and antidepressants were positioned as generally effective. These framings, which I originally viewed as objective assessments, may have influenced the narratives that emerged in the interviews. Alternative framings, such as ‘the experience’ of ‘long-term depression' or 'persistent depression', may have created space for or encouraged other narratives.

My background as a trainee psychologist also deeply informed the manner in which I engaged with participants as the interviews progressed. At the time the interviews took place, I was working full-time as a psychologist at a private psychology clinic. Inhabiting the world as a psychologist, I found it challenging to shift roles when it came to conducting the research interviews. Sitting opposite the participants in the private practice consulting rooms that were being used for the interviews, I often found myself feeling, acting, and appearing like I was at work as a psychologist. As discussed in Chapter Four, at times, I also engaged and spoke like a psychologist. I frequently enquired about internal processes such as thoughts and emotions and through my questioning, which was at times not dissimilar to a clinical assessment, attempted to understand what had caused the participants' depression and what was maintaining it. In doing so, I contributed to ordered constructions of depression and, in placing value on the ability to be self-aware, encouraged narratives of self-surveillance and self-mastery.

In the interviews, I also contributed to the construction of narratives of self-labour through frequently enquiring about the participants' engagement and success with various health professionals, treatments, and lifestyle changes. These were approaches to managing mental health that I, as a psychologist, perceived to be important and helpful. I asked one participant, "So have you found the medications that [the psychiatrist] has given you and other psychiatrists have given you, have you found them helpful?" I asked another, "Have you been to many psychologists along the way?", another (after he referred to a self-help book he had read), "And are there other books that you found helpful too?", and another, "And do you think that DBT [dialectical behaviour therapy] helped with the depression?" Through this questioning I encouraged accounts of self-labour, discouraged potential stories of giving up trying, and reinforced the virtuous position of self-managing neoliberal subject. Imbued with narratives of personal responsibility for mental health, this was likely driven by my curiosity as a psychologist as to whether the participants really were doing all they could to get better.

Lastly, and perhaps most concerningly for me personally, I subtly reinforced narratives of personal responsibility throughout the interviews. I directly asked participants to account for their persistent distress and, often, my framing in this questioning placed emphasis on the individual. For example, I asked one participant “So do you have ideas about why it’s you that has had to go through this [treatment resistant] depression?” Here, I positioned the participant as different from people who recover as expected and asked them to explain what it was about them that rendered them treatment resistant. Additionally, when participants gave explanations for persistent distress that were rooted in personal characteristics, I frequently asked them to elaborate or, if time had passed, redirected them back to stories relating to this. For example, I directed one participant back to a previously told story about negative thinking potentially contributing to persistent distress - “And um earlier you mentioned that like thinking about whether it’s something about you, the reason why the medications aren’t working. Can you tell me more about that?”. Similarly, after one participant suggested that their personality may contribute to long-term depression, I promptly asked them to elaborate – “What sort of personality do you think you’d have to have, to feel like this?” I did not do this for all explanations of persistent distress storied by participants. Whilst I asked about the participants’ life circumstances, it was always in relation to ‘triggers’ occurring at specific time points, rather than about ongoing social or economic difficulties. For example, I asked one participant “so at that time where you first became depressed, what was going on in your life?” and another, “And what was going on at the beginning of the year when you started feeling low again?” Whilst these questions encouraged stories of specific precipitating events, they did not create space for stories of broader socio-structural contributors to persistent distress. This encouragement of certain narratives and discouragement of others likely reflected my professional beliefs (at the time) that personal factors were the cause of persistent distress.

This pattern of meaning-making continued to play out as I engaged with the data, began the analysis process, and wrote this thesis. In the early stages of analysis, I engaged with the transcripts as I had been taught to engage with clinical case studies as a psychologist. Rather than attending to the stories of the participants, I looked – through a psychologist's lens – for factors that could explain why these people were not experiencing resolution of symptoms. As a psychologist trained predominantly in cognitive behaviour therapy (a type of psychotherapy focused on the link between thoughts and mood), the factors I looked for and found often related to the participants' thinking. Again, this likely meant that I attended to certain narratives (such as internal attribution narratives) more than others. Throughout the research, I contributed to the construction of depression as a process playing out within the bounded individual separate from context, that could be controlled and resolved through engaging in a process of self-mastery and self-management. With another interviewer and researcher – someone who was not a psychologist or health professional – the narratives that emerged may not have been so strongly aligned with narratives of neoliberalism. More space may have been created for the creation of alternative narratives.

Although I have outlined my influence on the data collection and analysis, I was likely just one element in a constellation of factors that encouraged these particular narratives. The participants were existing clients of the psychiatry private practice, were long term antidepressant users, and the interviews took place at the site of treatment and recruitment. My position as a trainee psychologist – and the experiences and beliefs that came with that – corresponded seamlessly with this psychiatry practice setting and the framings of mental distress that were likely circulating within it. Combined, these factors created a very particular research landscape – one that closely resembled a clinical setting. With both researcher and participant enacting the positions that they usually adopted in these contexts, the research illuminated narratives of mental distress that may not have emerged so strongly had there been a different researcher or setting. This is a unique strength, as it allowed the research to demonstrate how the narratives circulating in these settings shape the participant accounts of mental distress.

This research, spanning several years, shaped me – as a person, a researcher, and a psychologist – just as much as I shaped it. I began the research firmly embedded in a mainstream scientific clinical training programme. As the research progressed, I began to question the concepts I had taken for granted in my study and work as a psychologist. I noticed the discipline's intent focus on the individual as the site of pathology and the source of change and felt ill-equipped when working with people experiencing significant social or economic adversity. I noticed my own tendencies to assign blame to the client when they were not improving or engaging with therapy as I had hoped, as well as negative constructions of these clients circulating in the clinical settings that I inhabited.

Just as the participants in this research navigated narrative tensions in making sense of mental distress, so too did I. For much of this research process, I inhabited these two worlds: one as a psychologist working at a private practice, teaching breathing exercises, strategies for challenging 'unhelpful thinking', and tools for managing difficult emotions, and one as a researcher critiquing these very practices. Spending one day shaping the perfect neoliberal subject and the next day reading and writing about the harms of doing so was uncomfortable. At times, this tension culminated in me struggling to imagine pursuing a career as a clinical psychologist and, at times, lead to me feeling unable to persist with my research.

With time, discussion, and a break from clinical work, I feel closer to being able to bridge these two worlds. This research project has illuminated unexamined assumptions inherent in my discipline and forced me to reflect on the type of clinician I wish to be. It has prompted a commitment to working, as much as possible, in a way that does not perpetuate a culture of individual responsibility and blame. It has also cemented my social justice leaning and commitment to considering and attending to social, economic, and political contributors of distress. It has instilled in me a desire to create space within clinical encounters for the creation of alternative narratives that are affirming of the individual, their complex experiences of mental distress, and their unique contexts. Whilst the tension of inhabiting these two worlds has been a challenge, I am grateful for the experience of it, as I feel it has shaped who I am as a person, a researcher, and a psychologist for the better.

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APPENDICES

Appendix A: Information sheet and consent form

MASSEY UNIVERSITY
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TE KURA PŪKENGA TANGATA

Participant Information Sheet

Experiences and Understandings of Treatment Resistant Depression

Location:	[Redacted location] Auckland
Ethics Committee Reference:	16/NTA/197
Lead Investigator:	Ella Kroch, Doctor of Clinical Psychology student
Contact:	ella.kroch1@uni.massey.ac.nz

You are invited to take part in a study exploring clients' experiences and understandings of treatment resistant depression. This study is a doctoral research project lead by a Doctor of Clinical Psychology student from Massey University. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can withdraw from the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of this Participant Information Sheet and the Consent Form to keep. Please make sure that you have read and understood all the pages.

WHAT IS THE PURPOSE OF THIS STUDY?

- In this study, we are exploring experiences and understandings of treatment resistant depression.
- Whilst there is some research looking at health care providers' views on and experiences of working with people with treatment resistant depression, there is limited research exploring clients' experiences and understandings of this form of depression. The goal of our research is to find out what it is like to have treatment resistant depression and how it is understood.

- The findings are likely to contribute to the development of more effective treatment approaches for treatment resistant depression.
- Our group is made up of one Doctor of Clinical Psychology student as well as clinicians and academics who are interested in improving outcomes for people with treatment resistant depression. We are based at Massey University, Auckland University of Technology, and [Redacted location].
- This study has been approved by the Health and Disabilities Ethics Committee (HDEC). Contact details for this ethics committee are at the end of this form.

WHAT WILL MY PARTICIPATION IN THIS STUDY INVOLVE?

- You have been invited to participate in this study due to your diagnosis of Major Depressive Disorder and the fact that several antidepressants have not worked for you as well as might be hoped.
- If you agree to participate, this study will take approximately 1-2 hours of your time and involve one trip to [Redacted location] for an interview.
- The interview will be informal and focus on your experiences and understandings of treatment resistant depression.
- The interview will take place at [Redacted location] and will be within normal working hours, so you will need to be available between the hours of 8.30am and 5pm.
- The interview will be audio recorded so that it can be transcribed and analysed. Your name or other identifying information will be removed from the transcripts and any written work, so you will not be identifiable.
- You will receive a petrol voucher to cover your transport costs for this interview and to acknowledge your contribution to the research.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

- There are no guaranteed benefits, however, you may value having the opportunity to share your experiences of depression with a supportive researcher in an informal setting. You will also be helping us to understand what it is like to experience depression that is resistant to treatment so that we can work to develop more effective treatments.
- In terms of risks, it is possible that talking about your experiences or understandings of treatment resistant depression makes you feel uncomfortable, upset, or distressed. Should this happen during the interview, we will stop and consider whether it is best to postpone or cancel the session. There is a list of services at the end of this information sheet should you feel you need support following the interview.

WHAT ARE MY RIGHTS?

- Your participation in this study is voluntary. It is up to you whether you take part or not. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. If you do not want to take part you do not need to give a reason. If you decide to take part but then change your mind, you are free to withdraw at any time without giving a reason. The decision to not take part or the decision to withdraw will not affect the standard of care you receive from [Redacted location].
- You have the right to access the information collected about you as part of the study. You have the right to request a copy of your interview transcript to read and alter before it is analysed. If you choose to do this, you will have two weeks to make changes.

- You will be told of any new information related to the study that becomes available during the course of the study that may have an impact on your health.

WHAT HAPPENS AFTER THE STUDY?

- Your treatment at [Redacted location] may continue as normal.
- At the end of the study, your audio recordings will be kept in a locked cabinet in a secure room at the School of Psychology, Massey University. Data relevant to our research will be entered into a password protected file on the lead investigator's password protected computer. This data will be identified by an identification code, not your name. Your name or other identifying information will never be used in any research reports or publications. Only members of the study team will be able to access your data. Your data will be stored for a period of 10 years and will be destroyed after this time.
- If you wish, we can send you a summary of the results after the completion of the study. The study findings may also be published in academic journals and presented at conferences.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study, you can contact:

Researcher

Ella Kroch
Doctor of Clinical Psychology student
School of Psychology
Massey University
Email: ella.kroch.1@uni.massey.ac.nz

Research and Clinical Supervisors

Dr Mary Breheny
Senior Lecturer
School of Health Sciences
Palmerston North
Massey University
Email: M.R.Breheny@massey.ac.nz
Phone: (06) 356 9099 ext. 83523

Dr Kirsten van Kessel
Senior Lecturer and Registered Clinical Psychologist
Department of Psychology
AUT University
Email: kvankess@aut.ac.nz
Phone: (09) 921 9999 ext. 769

If you want to talk to someone who is not involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Email: advocacy@hdc.org.nz

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

WHO DO I CONTACT IF I NEED SUPPORT?

If you are having difficult thoughts or feelings following the interview, there is support available to you.

[Redacted location]

National Helplines:

Lifeline
Free Phone (anytime): 0800 543 354

Suicide Crisis Helpline
Free Phone (anytime): 0508 828 865

Depression Helpline
Free Phone (anytime): 0800 111 757
Free Text (anytime): 4202

Mental Health Crisis Teams:

Waitemata DHB
Phone (working hours): (09) 4871414
Phone (after hours): (09) 4878900

Counties Manukau DHB
Phone (anytime): (09) 2613700

Auckland DHB
Free Phone (anytime): 0800 800 717

Maori Mental Health support:

Waitemata DHB Whitiki Maurea
Maori Mental Health Services
Phone: (09) 822 8555

Counties Manukau DHB Te Puna Waiora
Maori Mental Health Services
Phone: (09) 259 5099

Auckland DHB Manawanui Oranga Hinengaro
Maori Mental Health Services
Phone: 0800 845 308

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Consent Form

Experiences and Understandings of Treatment Resistant Depression

Location: [Redacted location] Auckland
Ethics Committee Reference: 16/NTA/197
Lead Investigator: Ella Kroch, Doctor of Clinical Psychology student
Contact: ella.kroch1@uni.massey.ac.nz

Please tick to indicate you consent to the following:

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this Consent Form and Participant Information Sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my care at [Redacted location].		
I consent to the research staff collecting and processing my information, including information about my health.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I understand that there may be risks associated with participation in this study.		
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.		
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I know who to contact if I have any questions about the study.		
I understand my responsibilities as a study participant.		

I agree to a researcher contacting my health provider at [Redacted location] for diagnostic clarification.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant’s name (printed): ______________________________

Signature: ________________ Date: ________________

Declaration by member of research team:
I have given a verbal explanation of the study to the participant, and have answered the participant’s questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher’s name (printed): ______________________________

Signature: ________________ Date: ________________

Appendix B: Demographic questionnaire

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Demographic Questionnaire

Experiences and Understandings of Treatment Resistant Depression

Please complete the following questionnaire honestly and return to the researcher. Your information will be confidential and will remain anonymous. If there are questions you do not wish to answer, you may leave them blank. Thank you.

1. What is your age? ________

2. What is your gender?
   - ☐ Female
   - ☐ Male
   - ☐ Other

3. What is your ethnicity?
   - ☐ NZ European/Pakeha
   - ☐ Maori
   - ☐ Pacific Nations
   - ☐ European (non NZ)
   - ☐ Asian
   - ☐ Other (please specify) ________

4. What is your relationship status?
   - ☐ Single
   - ☐ Married
   - ☐ De facto
   - ☐ Divorced
   - ☐ Separated
   - ☐ Widowed
   - ☐ Other (please specify) ________

5. What is your highest level of education?
   - ☐ No schooling
   - ☐ Primary school
   - ☐ Some high school
   - ☐ High school
   - ☐ Trade/vocational training
   - ☐ Some university
   - ☐ Bachelor's degree
   - ☐ Master's degree
   - ☐ Doctoral degree
   - ☐ Other (please specify) ________

6. What is your employment status?
   - ☐ Unemployed and not currently looking for work
   - ☐ Unemployed and looking for work
   - ☐ Self Employed
   - ☐ Employed for wages/salary
   - ☐ A homemaker
   - ☐ A student
   - ☐ Retired
   - ☐ Unable to work

7. Which mental illness(es) have you been diagnosed with?

____
____
____

Appendix C: Statements of contribution for doctorate with publications

DRC 16

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

GRADUATE
RESEARCH
SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Ella Kroch
Name/title of Primary Supervisor:	Dr Mary Breheny

In which chapter is the manuscript /published work: Chapter 4

Please select one of the following three options:

● The manuscript/published work is published or in press

- Please provide the full reference of the Research Output:

Kroch, E., Breheny, M., van Kessel, K., and Taylor, J. (in press). Navigating narrative tensions in the experience of treatment resistant depression. Qualitative Psychology.

○ The manuscript is currently under review for publication – please indicate:

- The name of the journal:
- The percentage of the manuscript/published work that was contributed by the candidate:
- Describe the contribution that the candidate has made to the manuscript/published work:

○ It is intended that the manuscript will be published, but it has not yet been submitted to a journal

Candidate's Signature:	Ella Kroch Digitally signed by Ella Kroch Date: 2020.12.12 17:30:38 +13'00'
Date:	12-Dec-2020
Primary Supervisor's Signature:	Mary Breheny Digitally signed by Mary Breheny DN: cn=Mary Breheny, c=NZ, o=Massey University, ou=School of Health Sciences, email=[illegible] Date: [illegible]
Date:	13-Dec-2020

This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis.

GRS Version 5 – 13 December 2019
DRC 19/09/10

DRC 16

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

GRADUATE
RESEARCH
SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Ella Kroch
Name/title of Primary Supervisor:	Dr Mary Breheny
In which chapter is the manuscript /published work:	Chapter 5

Please select one of the following three options:

○ The manuscript/published work is published or in press

- Please provide the full reference of the Research Output:

● The manuscript is currently under review for publication – please indicate:

- The name of the journal:

  Sociology of Health and Illness

- The percentage of the manuscript/published work that was contributed by the candidate: 80.00

- Describe the contribution that the candidate has made to the manuscript/published work:

  The candidate prepared the manuscript. The supervisory team provided support and guidance throughout this process, assisted with the analysis, and provided feedback on writing and guidance on conceptual and theoretical issues.

○ It is intended that the manuscript will be published, but it has not yet been submitted to a journal

Candidate's Signature:	Ella Kroch Digitally signed by Ella Kroch Date: 2020.12.12 17:30:38 +13'00'
Date:	12-Dec-2020
Primary Supervisor's Signature:	Mary Breheny Digitally signed by Mary Breheny [illegible]
Date:	13-Dec-2020

This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis.

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Appendix D: Research case study

Massey University

Clinical Psychology

CASE STUDY 6

“Am I one of those difficult people, am I?”

Narrative analysis of one woman’s experience of treatment resistant depression

Candidate: Ella Kroch

Clinical Psychology Programme Massey University

Student ID: [redacted]

Setting: Centre for Psychology, Albany

Research Supervisors: Dr Mary Breheny, Dr Joanne Taylor, Dr Kirsten van Kessel

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This case was completed during internship at the Centre for Psychology in 2018 and represents the work of the candidate

Abstract

A significant proportion of people with depression, approximately 20%, do not experience recovery even after several rounds of antidepressant medication. Such individuals are said to have a form of depression called treatment resistant depression. Health care providers have been found to frame these individuals as difficult and manipulative, and to attribute their pervasive low mood to social deviancy or personality disorders. In this single case study, I explored the ways that one woman, Pauline, made sense of her treatment resistant depression. By examining her account from a narrative analytic perspective, I found three overarching narrative tensions: '*Am I getting better or am I stuck?*' '*Am I good patient or a bad patient?*' '*Did my difficult life* or *my negative thinking cause my depression?*' More specifically, I found that Pauline drew on a number of competing narratives and cycled through telling numerous, context specific, and often conflicting stories in an attempt to make sense of her lived experiences. This analysis suggested that, faced with an experience that does not fit the mainstream public account of diagnosis with and recovery from depression, individuals with treatment resistant depression struggle to renegotiate their identities and restore any sense of coherence.

Keywords: treatment resistant depression; depression; narrative; identity; illness

Introduction

Depression is traditionally conceptualised as a condition that involves sad, empty, or irritable mood, and physical and cognitive changes that adversely impair an individual's functioning (American Psychiatric Association, 2013). Major depressive disorder (hereafter referred to as depression) is a clinical condition situated within the individual and objectively defined by symptom-based diagnostic classification systems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013; Lewis, 1995). Depression has been named the leading cause of disability in the developed world and a major public health concern (World Health Organisation, 2008). According to Te Rau Hinengaro, The New Zealand Mental Health Survey, depression is also highly prevalent in New Zealand, affecting approximately one in six New Zealanders (Oakley Browne, Wells, & Scott, 2006).

Pharmacological and psychotherapeutic treatments have advanced significantly over recent years improving outcomes for individuals with depression, however, a considerable proportion of people continue to struggle even after intervention (Berlim, 2007). This lack of expected treatment response, which is said to affect approximately 20% of patients with depression (Crown et al., 2002), is frequently termed treatment resistant depression. Whilst there is a lack of consensus on definitions, treatment resistant depression is most commonly defined as an episode of depression that has not responded to two or more trials of antidepressant medication at an adequate dose and duration (Berlim, 2007). The term treatment resistant depression is often used interchangeably with ‘chronic depression’ and ‘recurrent depression’, which leads to some confusion in both clinical practice and scientific literature. However, a growing body of research suggests that treatment resistant depression may be unique in its own right. In chronic depression, the vast majority of individuals have not received adequate treatment so cannot be considered treatment resistant (Gelenberg, Kocsis, McCullough, Ninan, & Thase, 2006) and in recurrent depression, individuals *do* experience recovery in between episodes and respond to treatment (Gelenberg et al., 2006). These factors suggest that people with treatment resistant depression differ from those with chronic and recurrent depression. People with treatment resistant depression often seek help from healthcare professionals and receive adequate treatment, yet do *not* experience recovery from depressive symptoms.

The experience of treatment resistant depression is thought to present additional challenges when compared to the experience of typical major depressive disorder. Individuals with treatment resistant depression can feel discouraged and hopeless after trialling multiple antidepressant medications without significant improvement and report high levels of self-injurious behaviour (Dunner et al., 2006). In addition to having considerable impact on the individual, treatment resistant depression is also thought to present a significant burden for support people, health services, and society at large (Thomas et al., 2012; Wiles et al., 2013), and to be a major challenge for clinicians (Wijeratne & Perminder, 2008).

Publicly availably narratives of depression

Personal narratives and accounts of single episodes of depression tend to fit a recognisable pattern. The typical sequence is of a) an initial realisation that something is wrong, b) a struggle to come to terms with and understand the new experience and identity, c) a period of help seeking, and d) a transition to recovery (Karp, 1994; Schreiber, 1996). During the phase of coming to terms with and understanding the depression, stories are told of painful paradoxes. People speak of the desire to engage, take control, confront their issues, form relationships, recover, and make plans for the future, but simultaneously, feelings of powerlessness, the desire to withdraw, and the desire for things to stay the same (Danielsson & Rosberg, 2015; Rapmund & Moore, 2000; Sarkohi, Frykedal, Forsyth, Larsson, & Andersson, 2013).

These accounts and narratives of depression include a recovery phase, which tends to come after a period of help seeking and introspection. Once feeling better, individuals attribute their recovery to becoming more aware of the factors contributing to their depression, learning to trust their instincts, and becoming more active participants alongside their health providers (Steen, 1996). Individuals also speak of experiencing shifts in the way they view themselves, the world, and the future (Ridge & Ziebland, 2006; Steen, 1996). For example, they cease to see depression as *part* of themselves and, instead, view it as an *experience* that is distinct from the self (Ridge & Ziebland, 2006). After recovering, many individuals appear to rewrite depression in more helpful ways. For example, they reconstruct their depression as a spiritual journey, as an experience that led to increased self-awareness, as motivation to find meaning in life or a more authentic self, or as a chance to stop and rethink their lives and what is important (Ridge & Ziebland, 2006). These stories place value on gaining insight and taking responsibility as key parts of the process of recovering (Ridge & Ziebland, 2006; Steen, 1996).

As the media both constructs and reflects socio-cultural realities, analyses of media portrayals of depression can also provide insight into public understandings of depression. Since the 1990s there has been a shift in the media to portray depression as a largely biomedical phenomenon (Clarke & Gawley, 2009). Despite the lack of consensus on causes of depression, depression is presented almost exclusively as a malfunctioning of the biological body. It is defined in these media portrayals using biological, biochemical, and genetic terms and explanations, and is closely associated with the domains of medicine and biology. This representation of depression leads to a focus on medication as the appropriate treatment (Clarke and Gawley, 2009). There is also an emphasis on the importance of consulting with mental health professionals and seeking expert opinion. Today, the dominant metaphor portrayed in the media is that depression is the "common cold of mental health" and that the appropriate response is antidepressant medication, the "aspirin for the psyche" (Clarke & Gawley, 2009).

These personal narratives and media portrayals of depression appear to be in keeping with narratives of illness more generally. For example, they are consistent with Frank's (1995) restitution narrative of "yesterday I was healthy; today I am sick; tomorrow I will be healthy again". This is the culturally dominant narrative of illness and the story that is told by the majority of people who have recently become ill (Frank, 1995). Behind this narrative is the modernist expectation that behind every suffering there is a remedy, and that health is the normal condition that people ought to have restored (Frank, 1995).

Counter-narratives of depression

Some people with depression, however, do not experience recovery in the expected timeframe or manner. For these individuals, the publicly available illness and depression narratives may not accurately frame their experiences. Instead, accounts of those who have 'chronic depression' or 'recurrent depression' describe feeling stuck, feeling like a failure, dreading future recurring episodes, and contemplating suicide (Ridge & Ziebland, 2006). Unlike those whose experiences fit with the dominant narratives, these people struggle to establish, or even imagine, a recovery narrative (Ridge & Ziebland, 2006). Understandably, these stories have profound themes of hopelessness (Stigsdotter Nyström & Nyström, 2007) and fatalism (Gask, Aseem, Waquas, & Waheed, 2011). This sits in stark contrast to the cautious sense of hope evident in dominant narratives of depression (Rapmund & Moore, 2000; Sarkohi et al., 2013). In contrast to those who experienced single episodes of depression, those with 'chronic depression' or 'recurrent depression' were unable to situate their experiences within a broader process of meaning-making (Stigsdotter Nyström & Nyström, 2007).

Instead of drawing on dominant narratives of illness, these accounts have links to chronic illness literature. Chronic illness has been likened to a "biographical disruption" due to the illness' significant impact on the individual's expected life course (Bury, 2001, p. 169). When a biographical disruption occurs, the individual is faced with the challenge of reconstructing their identity and life story in order to maintain a coherent sense of self (Crossley, 2000). In keeping with this, Frank (1995) argues that when people experience significant changes in life circumstances, such as chronic illness, "narrative chaos" may ensue. The same has been said for chronic mental illness, with the suggestion that these individuals are suffering from "an incoherent story" or "an inadequate account of oneself" (Polkinghorne, 1988, p. 179). In these cases, Frank argues that 'narrative wreckage' may ensue where individuals draw on a chaos narrative: uncertainty about the future, lack of order, and life never getting better (1995). Unlike the culturally favoured restitution narrative, there is a widespread discomfort in hearing and telling the chaos narrative, perhaps due to the fact that it reminds us of the fragility of the human body or mind (Frank, 1995).

When individuals experience depression that does not align with dominant narratives of illness and recovery, there are implications for health service experiences (McPherson & Armstrong, 2009; McPherson, Byng, & Oxley, 2014; McPherson, Walker, & Caryle, 2006). Counsellors' reactions towards these clients have been found to be predominantly negative, with counsellors describing feeling powerless, a failure, deskilled, drained, finding the work painful, and experiencing 'heartsink' moments when these clients entered the service (McPherson et al., 2006). Among GPs, there was a general loss of empathy when patients did not demonstrate improvement over time. Patients were described as burdensome, manipulative, or difficult people with generally unpleasant characteristics (McPherson & Armstrong, 2009). When patients did not respond to antidepressants, GPs attributed their problems to social deviance rather than depression (McPherson & Armstrong, 2009). Whilst these medical professionals typically draw on medical explanatory models of depression, this was not the case for patients with treatment resistant depression. Instead, GPs used psychosocial explanations, such as previous trauma or abuse, problematic attitudes or personalities, and deficits in social skills and coping skills (McPherson & Armstrong, 2009; McPherson et al., 2006). This suggests that when individuals respond to treatment as expected, GPs label them as depressed and situate their experiences within a medical framework. However, when patients do not respond to antidepressants, the medical model is no longer used to explain their symptoms and instead responsibility is attributed to the client for not recovering due to the fact they are 'difficult', 'resistant', 'manipulative', 'unpleasant' and 'socially deviant' (McPherson & Armstrong, 2009).

Rationale for the current study

There is evidence to suggest that the experience of treatment resistant depression may be significantly different from other forms of depression, in that affected individuals *are* receiving adequate intervention, but are *not* experiencing recovery. Drawing on publicly available narratives, people diagnosed with depression are likely to expect recovery and make sense of their situation in terms of a restitution narrative (Frank, 1995). However, a person with treatment resistant depression does not recover. Instead, they trial many medications without significant improvement. When recovery does not occur, they may be constructed as “difficult” or “socially deviant” patients by medical professionals (McPherson & Armstrong, 2009). As a result of this, people with treatment resistant depression cannot successfully draw on dominant or publicly available narratives of depression to make sense of their experiences. These people must search for new ways of making sense of their experiences. There is no known research exploring how these individuals experience, understand, or make sense of depression that is treatment resistant. This study will address this gap in the literature by conducting an in-depth narrative analysis of the experiences of one woman with a decade long history of treatment resistant depression.

Method

Narrative Psychology

This single case study used a narrative research approach to explore how one woman has experienced, understood, and made sense of her treatment resistant depression. Narrative psychology is concerned with the ways in which humans organise, make sense of, and interpret their lived experiences through storytelling (Murray, 2008; Silver, 2013). Narratives also play a central role in the way humans construct and maintain their identities (Hiles & Cermak, 2008). Through the process of telling stories, individuals not only come to *understand* themselves, but also *create* themselves (Crossley, 2000). However, rather than revealing an ‘essential’ self, stories present certain versions of the self (Riessman, 2003). Narrative approaches, therefore, are well suited to the study of how people present themselves in certain ways, for example, often in a favourable light (Stephens & Breheny, 2013). Narrative approaches are also concerned with the surrounding socio-cultural context, which informs the stories people tell (Murray & Sools, 2015).

Storytelling is particularly evident in situations where people's expected life courses have been disrupted, for example by illness (Stephens, 2011). Storytelling is used to make sense of changes in life circumstances, as it facilitates understanding of why and how an event happened and who the individual was before this event occurred, as well as helping the individual to renegotiate their identity and restore a sense of coherence (Crossley, 2000; Murray, 2008; Sarbin, 1993; Stephens, 2011). Examining such narratives provides insights into the effects of an illness on the person's life, including their day-to-day activities, their relationships, and their experiences within medical settings. Narrative approaches also provide insight into how people take up and negotiate identities, such as 'mentally ill', 'patient', or 'treatment resistant'.

Study Context and Location

The study took place at a private psychology and psychiatry practice in Ponsonby, Auckland. Ponsonby is a predominantly upper middle class suburb in central Auckland that has undergone significant gentrification over the last 20 years. The private practice is located in a renovated villa on a residential street off Ponsonby Road. It offers the services of four psychiatrists and two psychologists and, according to its website, combines these two disciplines in order to best support clients. The private practice receives self-referrals and referrals from general practitioners and other specialists in the Auckland region.

The current study was part of a larger qualitative study exploring experiences of people with treatment resistant depression. This larger study had a target sample size of approximately

12 participants and, at the time of writing, I had interviewed nine individuals. During the recruitment phase, the psychiatrist identified individuals on his caseload treatment resistant depression and asked them if they were interested in participating in a “study on depression”. If the individuals were interested, they were given information sheets outlining details of the study and asked for permission to be contacted. I then contacted these individuals, gave a brief overview of the study, answered any questions, and, if they were willing, set a date and time for the interviews. Ethical approval for the study was gained through the New Zealand Health and Disability Ethics Committee.

Participant

From the larger qualitative study, I selected one participant for this single case study due to the rich and detailed accounts of depression that she gave. Pauline (name and identifying details changed) was a single 48-year-old woman of New Zealand European descent. At the time of the research she was living in Auckland, New Zealand and was employed in a sales role at a retail company. Pauline had been experiencing depression for approximately nine years in total and had been diagnosed with major depressive disorder and generalised anxiety disorder. Over the course of her depression, Pauline estimated that she had been treated with up to 20 medications, each only providing short-term or minimal relief from symptoms. She had returned to the psychiatrist for medication reviews as required. Pauline had also received psychological treatment from a registered clinical psychologist for seven years.

Interview Procedure

Data was collected through a semi-structured interview. Prior to the interview Pauline gave informed consent and completed a demographic questionnaire. The interview took place in an office at the private practice in Ponsonby where she had been recruited. Upon meeting, I introduced myself and shared some information about my background and my roles as a clinical psychology trainee and a doctoral researcher at Massey University. I explained that the purpose of the study was to explore people's experiences and understandings of depression that had not responded to medication or treatment as expected. In contrast to the Participant Information Sheet, I avoided use of the term treatment resistant depression, and instead referenced 'depression' more generally. This was aimed at keeping the interview broad rather than narrowing the focus to a specific type of story. I told Pauline that there was no right or wrong account and that I would be interested in anything that she would like to share about her experiences of depression. I then asked whether Pauline would like to start with the story of when her depression first began.

Following this, the interview had an open structure with no fixed interview schedule and was largely led by Pauline. I did, however, keep the general aim of exploring how people experience, understand, and make sense of their treatment resistant depression in mind throughout the interview. As suggested by Murray (2003), I attempted to elicit narrative accounts and rich descriptions by, firstly, simply asking for them, for example, by saying "could you tell me the story of when you first sought help?" and, secondly, by encouraging them through reference to times and places, for example, "could you tell me more about the *time* the doctor told you that you have depression?" This approach allowed for both flexibility of conversation and the covering of points relevant to the research questions. The interview with Pauline lasted approximately 80 minutes and was audio recorded. Following the interview, I offered Pauline a $50 petrol voucher to thank her for her time and willingness to share her story.

Analysis

Following the interview with Pauline, I transcribed the interview and cross-checked the transcription for accuracy. In terms of transcription conventions, words are underlined to show emphasis and ellipses are used to indicate pauses. Analysis was guided by the narrative approaches of Murray (2000) and Stephens and Breheny (2013). This involved focusing on multiple levels of meaning: personal stories, co-constructed stories, and publicly available narratives, as well as the intersection between these levels. First, I analysed the transcript for personal stories told by Pauline about her experience of depression. These were identified by searching for mini-accounts that Pauline told with a beginning, middle, and end. Secondly, I paid attention to the ways these stories reflect co-construction between Pauline and myself. I considered how my position as a clinical psychology trainee and the setting of a private psychiatry practice may have influenced how Pauline told her stories. Lastly, I considered publicly available narratives of depression, mental illness, and illness more generally that Pauline and I drew on during the interview in our co-construction of stories.

Findings

Am I getting better or am I stuck?

"I, you know, am now getting better". Pauline described being able to "pinpoint" the onset of her depression to 2009, approximately nine years before the interview. She described having worked hard in her sales role for several years without breaks, and beginning to experience a lack of enthusiasm and enjoyment. She thought she might be *"worn out"* and, as a result of this, decided to go on holiday. On return, however, Pauline realised that she felt no better and, as the weeks passed, she deteriorated. She described seeking help from her GP then being referred to a psychiatrist in private practice and beginning pharmacological treatment.

At this stage Pauline's story of depression did not differ significantly from publicly available narratives of depression and a certain hopefulness was evident in her accounts. Publicly available narratives of depression include some key elements: realising that something is wrong, seeking help from qualified mental health professionals, being diagnosed with depression and provided with treatment, diligently following the health professional's advice and treatment protocol and, lastly, experiencing symptom reduction and return to previous level of wellbeing. This narrative clearly encourages certain expectations around recovery and, in keeping with this, Pauline told a story of her initial experiences of depression which was characterised by expectation of return to wellness. This restitution narrative (Frank, 1995) was evident in Pauline's account of explaining her situation to her colleagues at work, as means of understanding her situation as 'yesterday I was a high functioning and healthy working woman, today I am depressed, tomorrow I will be a high functioning and healthy working woman again'.

> *Pauline:* *...there was a point at the first couple of years where I was very depressed and then I had something that was making me better and I went to, ah, a sales conference that we had for our staff and said "oh look, I know that I haven't been very well and helping you guys very much and that, that's because I've been sick and I just want to tell you that I, you know, am now getting better".*

Even when Pauline did not have immediate success with medications, she continued to draw on the restitution narrative, and told a story characterised by the possibility of return to wellness, even if it this takes a while:

> *Pauline:* *'cos I know that sometimes it can take time to find something that works for you... Like we make skincare, so it doesn't work for everybody, and, or some people have reactions to certain things and so, you know, some people cannot drink dairy or gluten so, you know, it's a matter of your body adjusting to it.*

Pauline suggested that, just like "skincare", an individual may need to try several antidepressants before finding one that suits them, or, just like "dairy or gluten", an individual may react badly to one antidepressant and need to try other options. In making this analogy, Pauline drew on the publicly available narrative that depression is a biological dysfunction that needs to be rectified through medication. As medical explanatory models are less stigmatizing (Frank, 1995; Schreiber, 1996), drawing on this conceptualisation of depression allowed Pauline to attribute her difficulties to biology, and provided her with a comfortable way of storying her experiences to her colleagues. Pauline found a way to hold on to the restitution narrative and, resultantly, hope. Her explanation of the fact that "it can take time to find something that works" and her motivation and willingness to continue attending appointments and trialling new medications were likely grounded in expectations of finding a cure, which were informed by the restitution narrative.

"No end to the tunnel". Pauline described an event that functioned as a major turning point in the way she made sense of her experiences. She described a discussion with her psychiatrist during a routine appointment, during which she received some new information:

> *Pauline:* *And so it wasn't until a couple of years in that [the psychiatrist] said "oh well, um those people with major depression like yourself", and I'm going "okay, I didn't know there was <u>different types of depression</u>". So, so that's when it sort of clicked, okay, that there's more than just trialling a couple of different things, that these, um, are people who have, um, the inability to find something.*

Pauline spoke of being told by the psychiatrist that she had a different type of depression. Pauline called it "major depression" but the way she described it as "people who have, um, the inability to find something" suggests that she was describing treatment resistant depression. Pauline continued this account by describing going home and doing some research to try to make sense of this information.

> *Pauline:* *And then I read online in a couple of forums and there's this one lady who started up a group called blue something or other and she's had major depression and a lack of finding a drug for about 15 or 20 years. So that's a <u>really long</u> time. And she is worse than me that she has some times where she can't get out of bed. I've never really had that issue. I've*

had times where I can't get out of the house. Um, but to recognise that, you know, it could go on for that long is, um, frustrating and upsetting because you sometimes get to the end of your tether and you think how do I go on? (laughs).

Ella: *Yeah. Yeah. That's completely understandable.*

Pauline: *Yeah. And where at the moment I'm probably a lot more positive because what I'm on at the moment has lifted me a little bit to where it's, um, where I'm able to cope with everything a lot better…*

In the first section of this excerpt, Pauline described the time she first became aware of a counter-narrative of depression: that there are some people who do not recover despite treatment. She then began to present an account of her depression as a long-term struggle. However, following this, Pauline very swiftly abandoned the "no end to the tunnel" story (drawing on counter-narrative of depression) and resumed the previously outlined "I am now getting better" story (drawing on the restitution narrative), where she began to talk about a medication that has "lifted [her] up a bit". Pauline had a tendency to (re)focus on the restitution narrative by highlighting stories of new and alternative treatments, possible outcomes, and opinions of medical professionals. As restitution narratives are the favoured and dominant accounts of illness in Western culture and offer concrete hope, it is unsurprising that Pauline was drawn to this. I did not, however, subscribe to this and, informed by my personal agenda, repeatedly directed Pauline to the "no end to the tunnel" story.

Ella: *Oh gosh. What about the time you mentioned earlier when you did the research and you found, uh, was it the blog of the lady? Can you tell me about that time and when you…it sounded like you sort of realised that there were people out there who had depression like yours for a long time?*

Pauline: *It made me sad and upset me mainly because, ah, I don't want to be. It depends on what frame I'm in too. So if I'm quite low it can make me, um, seem that there's no end to the tunnel. Um, but if I'm a little bit more positive it can also make me feel down and there's no end to the tunnel (laughs). Um, but also the fact that she does live with it so that, you know, even though it is hard, um, ah, and it's a struggle that she can… she's spent that long a time so she can live with it. But the other end is that when I am very depressed, it is, I don't know how to, how I would cope for that length of time to deal with it. 'Cos it is a very long time, and I hate… I mean, going from being positive to having depressive state, it's such hard work. Yeah (in pained voice, sighs).*

Ella: *So do you think when you read that things changed in terms of the way you understood what was going on for you?*

Pauline: *I think it did a little bit. When I read it I was quite depressed and it did upset me. A lot. Um, so that, um, at that point it was… how the… I don't know if I can cope for that long without… without, with finding, um, something that was helpful, um, but, when I'm up a little bit, it's like well I'm not the only one who is going through that and she has coped. So there's two sides of it. So when I'm depressed it's like oh my god, how do I cope, I can't see the end of… I can't see any light, and you know to think that all those years and you still can't find something that's helpful, and knowing that, you're in a such an up and down state all the time. Like even just this last year I think I'm on my third or fourth set of drugs.*

After I made several attempts to direct Pauline back to the "no end to the tunnel" story, Pauline, obligingly, began to present an account of her depression as a struggle with no end in sight. Whilst telling this story, Pauline began to draw on narratives of chronic illness and to frame her depression as something that would affect her for the rest of her life. This occurred to the extent that feeling “more positive” was no longer viewed by Pauline as being suggestive of movement towards recovery (as it was in her “I am now getting better” story), but rather as a transient phase of the illness. When individuals with chronic conditions experience a reduction in symptoms, they do not assume that they have recovered. Instead, they conceptualise this improvement as a short term reprieve from long term illness. Likewise, in this account, Pauline no longer attempted to draw on restitution narratives, and instead despaired that hope was lost and that there was “no end to the tunnel”. Many people with chronic illness accept their circumstances, carry on with life, and make the most of asymptomatic moments. However, Pauline told of feeling “down” and like there is “end to the tunnel” even when she is feeling “more positive”. For Pauline, feeling better some of the time was not enough. Instead, she alluded to living life only being possible when she found a cure.

Bad patient or good patient?

When recovery begins to feel unlikely or impossible, Frank (1995) argues that the cause of the illness becomes of interest. When publicly available narratives no longer accurately frame people’s experiences, they are encouraged to find new ways of making sense of these experiences. Accordingly, later in the interview, Pauline began to recount stories of hypothesised causes with the narrative purpose of explaining and accounting for her long-term depression. Pauline provided an account of her psychiatrist saying to her that she was “…one of those patients that have been around for a long time”. At this point in time, lack of response to medication troubled explanations of depression as a malfunctioning biological body. Instead, in this story, Pauline began to explore the idea that something about her personality or character may be to blame for the long-term nature of her depression.

Ella: *I'm wondering, I'm interested in the, the time that you mentioned earlier when [the psychiatrist] said "people like you with major depression". Can you tell me more about that situation and what happened and how you were feeling when that happened?*

Pauline: *Um, I think I was surprised that I had ended up in that area, and then I like to do research so I went and had a look and see what major depression was or what it was. Um, and the different types of depression, so it was, um, it wasn't, um, I think it was just a general talk, so it didn't make me feel negative. It was just a surprise that, um, there was different types of depression and I ended up there sort of thing. And, I mean he made a comment the other day actually where I went "um, am I one of those difficult people am I?" (laughs).*

Ella: *You asked that?*

Pauline: *No, he said something along the lines "well um, you're one of those patients that have been around for a long time" and I went "um, ok, I'm one of those people" (laughs).*

Pauline had an impression of the type of people who "end up in that area" and she resisted being positioned in this group. As McPherson and colleagues note, individuals with treatment resistant depression have been viewed as "manipulative", "difficult" people with "generally unpleasant characteristics" by primary care clinicians such as GPs (McPherson & Armstrong, 2009, p.1139). Pauline was aware of the possibility of being viewed as a difficult patient. Pauline repeatedly stated that she was surprised by the psychiatrist's comments and, in doing so, attempted to position herself as *not* one of "those patients". Pauline used humour to diffuse the tension of me prompting, in a somewhat surprised manner, "you asked that?" Her laughter and humour smoothed over the awkwardness of her simultaneously questioning whether this could be the reason for her long-term depression, whilst also distancing herself from “those patients”.

Pauline provided an account of herself as a good patient willing to try a range of prescribed medications. Cutting across this narrative was an alternative account of struggling to adhere to her treatment regime at times. Pauline suggested that her depression may have persisted due to her withdrawing from treatment:

Pauline: *Um, but I find that when I get quite depressed I tend to withdraw into myself and I will miss, not miss [psychology] appointments, cancel appointments, and the same as I’ll do the same thing with [the psychiatrist] as well that I’ll cancel appointments as well. So I tend to withdraw into myself. Yeah.*

Ella: *And is that because you just don’t feel like going out and talking to people and having to…?*

Pauline: *No, it’s more probably that, um, I feel… ashamed. Well, I was going to say ashamed that things haven’t worked (begins to cry).*

Ella: *(offers tissues)*

Pauline: *It’s alright I’ve got some. And upset that (sighs) I have to go through it again (blows nose).*

Ella: *Yeah. That makes sense.*

Pauline: *But yeah, or… which I tend to do a lot, stick my head in the sand and it will go away. Yeah.*

Ella: *Yeah.*

Pauline: *Yeah.*

Ella: *Do you feel comfortable talking more about what you mean when you say ashamed?*

Pauline: *That my mind or my body have, um, failed me, that, um, that, ah… I don't know (cries).*

Rather than accepting the interviewer's suggestion that this withdrawal from treatment reflected symptoms of her depression (not wanting to go out and talk to people), Pauline provided an alternative explanation based in shame. In this excerpt, Pauline stated that she withdraws from treatment as she feels ashamed that she must engage with treatment again. Her lack of recovery was shameful for her. . At the same time, her lack of recovery was attributed to her avoiding treatment and cancelling appointments. Whilst providing another way to make sense of her lack of recovery, this account positioned Pauline in the subject position that she had been tirelessly trying to avoid – one of "those difficult people" who clinicians dread.

To counter ideas about her potentially being "one of those difficult people" or "one of those patients that have been around for a long time", Pauline often returned to a story that, in contrast, positioned her as a good patient. In these moments, she spoke enthusiastically about attending appointments with her psychiatrist and clinical psychologist and trialling new, infrequently used, and often very expensive medications. She also alluded to a positive relationship with her psychiatrist, in which he disclosed his own personal experiences of depression and chose her to be the first patient to trial a new American drug.

Ella: *What was that like for you that time when he said that?*

Pauline: *Um, nothing, it didn't worry me. Um, no that didn't worry me. Um, because I know it's said in a safe place, so it's never ever anything that's said, um, in a negative fashion or something to put you down. Where other people can do that, but with [the psychiatrist], you know that it's... you know he's been through it so he knows what it's like, so yeah, and I know that I'm a bit of a… um, because 3 or 4 months ago when we went onto a trial drug from America and I'm the first one to try it of his* *patients (laughs). It didn't work, but I was the first one of his patients to try it! (laughs)*

Ella: *Oh that's exciting. Sounds like he's doing everything he possibly can. He's got the trial drug and you were the first person.*

Pauline: *Well it's not, it's not, it's trialling in New Zealand. They've never had anyone trial it, have it, use it in New Zealand. Um, and it was $600 a month, so we tried it for six weeks to see if it did anything, so yep.*

Ella: *And so that one wasn't effective?*

Pauline: *No.*

In drawing attention to these experiences, Pauline presented herself as a person doing everything possible to recover. In telling this story, Pauline was able to distance herself from "those difficult people" as well as the idea that her long-term depression may have been occurring as a result of her character or personal choices. This story also countered the previously told "there's no end to the tunnel" story. Instead, it drew on the publicly available narrative of depression and illness that suggests that good patient behaviour will lead to recovery. As a result of this, Pauline asserted that there was still hope of recovery.

In presenting herself as someone who continued to persist in pursuing recovery, Pauline's story aligned more closely to accounts of terminal illnesses such as cancer. Cancer sufferers often tell stories of tirelessly battling, drawing on inner strength and bravery to fight on and on, and trying any type of treatment at any cost (Ellingson, 2017). In telling a story that likened her experience to that of cancer sufferers, Pauline positioned herself as a tireless battler against a persistent illness, demonstrating her strength and bravery. Narrating her experience of depression in this way suggests that recovery is the only resolution for depression. .

Throughout the interview, a narrative tension emerged with Pauline switching between the two competing stories of bad patient versus good patient. She appeared to need both stories to make sense of her experiences.

Did my difficult life or my negative thinking cause my depression?

"You deserve that pain". Pauline provided another account of her reluctance to engage with treatment, that she felt that deserved the pain of depression. This story was told to account for her withdrawal from treatment, that she was not good enough to be well and not well enough to go to the doctor:.

Pauline: *I suppose part of that is, why I haven't gone to the doctor, is that, is part of that is the depression, is that I feel that… it feels difficult to say… I deserve the pain (cries). That not that I'm a bad person, but I'm, that's the negative thoughts that I'm a, not a good, not a good person, not good enough or well enough that I can go to the doctor. Yeah, that that pain is part of just living with everything and that it's, I live with pain a lot of the time, and I just ignore it, and that, is both physical, and then when I get a depression, that's also emotional. So you get used to the pain and you get used to thinking that you deserve that pain. Yeah.*

Ella: *I wonder where that comes from? Like the feeling that you deserve it?*

Pauline: *Um… (cries) from… younger and negative things that have happened in my life. Um, and they get reinforced and that's the spiral that leads down to the depression as well, is that you think that you're not good enough and so that's part of the spiral down into the depression and then when you're there you think all those thoughts all the time so it's really hard to find anything to grab onto to lift you back out, yeah.*

Ella: *Yeah, yeah. So those negative thoughts get you there and then when you're there it's happening so much and you sort of start thinking, 'well, I don't deserve to be getting any better'?*

Pauline: *Yeah.*

In this account, Pauline appeared to be suggesting that it her long-term depression may be warranted due to her previous experiences or qualities. In telling this story, Pauline reconstructed her depression, not as an illness with a biological basis, but as punishment. This story likened the depression to a punishment for "negative things that have happened in [her] life" and positioned Pauline not as someone with malfunctioning brain biology, but as someone deserving the pain of depression. Essentially, the story went: I am a bad person, which is why bad things happened to me when I was younger and why bad things are happening to me now. In this account, Pauline was employing the same meaning making process that she used in her earlier life to make sense of and explain why she was not recovering from depression in the present day.

This type of account was not unfamiliar to me as a clinical psychology trainee and not unfamiliar to Pauline, who had likely told this story many times to psychiatrists and psychologists in the months and years prior. This section of the interview took on a strong therapy flavour, with me inadvertently positioning myself as therapist and using phrases such as "I wonder where that came from" and "it makes me feel happy to hear that…", and Pauline assuming the position of client/patient. As a result of this dynamic, the adopted roles, and the shared familiarity, Pauline and I co-constructed a rich and detailed narrative of depression as the culmination of a series of difficult or traumatic life events.

"Negative thoughts". As well as storying depression as an inevitable consequence of difficult life events, Pauline also presented an alternative story. This account suggested that her depression had occurred as a result of negative thoughts or interpretations of life events, rather than the life events themselves. This cognitive conceptualisation is a dominant narrative of depression and mental illness more generally within the world of clinical psychology. It is likely, therefore, that Pauline learned to account for her depression in this way through her seven years of psychological therapy. Within this excerpt, Pauline frequently switches between the "you deserve that pain" story and the "negative thoughts" account. The psychologised language that Pauline employed to narrate the "negative thoughts" story almost made it seem that her psychologist was present in the room, reframing Pauline's statements and helping her "have another way of looking at it".

Pauline: *Yes, but since [the negative thoughts] happened when I was younger, I've had them for such a long time and what I've learnt over… is that it is hard to let them go and it's only in the last two or three years that I've managed to say "well, that was then, that is, um, quite often that person reflecting or doing something that's negative to me but I didn't do anything, ah, that I knew of and I can't change that". But that's been really hard to, um, get past… Yeah. And to not, when I'm depressed, not to grab onto those thoughts that, you know, "I'm such a bad person, that's why people don't like me or that's why they did that to me" when it's quite often themselves doing it because they are angry or upset or something or other and then that's deflecting onto you. But that, at the very beginning, those thoughts would be there, and it's only the last couple of years that I've managed to try and turn that around and have another way of looking at it. Yeah, yeah.*

Conclusion

This single case study used a narrative research approach to explore how one woman experienced, understood, and made sense of her treatment resistant depression. In the analysis, three main narrative tensions emerged: '*Am I getting better or am I stuck?*' '*Am I good patient or a bad patient?*' *Did my difficult life or my negative thinking cause my depression?*' Each of the stories told by Pauline, whilst often conflicting, had advantages and disadvantages in the way that they positioned her and accounted for her experiences.

The "I, you know, am now getting better" story, which drew strongly on Frank's (1995) restitution narrative and other publicly available narratives of depression and illness, provided Pauline with a socially acceptable way of storying her experience of depression to others. It also allowed her to conceptualise her depression as a temporary biological malfunction, to hold onto hope, and to maintain her position in society as a worthwhile human being. Over time, it became increasingly difficult for Pauline to narrate her experiences using this account as her depression did not resolve. Instead, Pauline narrated her ongoing struggles with depression through the "no end to the tunnel" story, which linked depression to chronic illness. This narrative was difficult for Pauline, however, as it required her to accept that her depression may not be resolved.

The conflicting good versus bad patient stories also each had advantages and disadvantages for Pauline. The bad patient account provided Pauline with a way of making sense of her long-term depression, as it made intuitive sense to her and others that someone who does not follow treatment advice would remain unwell. However, her lack of recovery contributed to her being positioned as one of the "manipulative", "difficult" people with "generally unpleasant characteristics" who health professionals dread (McPherson & Armstrong, 2009), and attributed her depression to flaws within her character. The conflicting good patient story allowed Pauline to counter the bad patient story and present herself in a positive and virtuous light to me, the interviewer. It also allowed her to hold onto the publicly available narrative that good patient behaviour leads to recovery and, resultantly, hope. However, leading on from this, the good patient story meant that Pauline had to grapple with a confronting question: *what does it mean that I am being a good patient and still not getting better?*

Lastly, the stories situated within '*did my difficult life or my negative thinking cause my depression?*' tension, also both had advantages and disadvantages. Pauline's account of depression as inevitable punishment for a life of trauma fulfilled the narrative function of accounting for her long-term depression. It was narrated and received as a rehearsed and familiar story. Conversely, however, this particular story framed depression and suffering as her inescapable fate. The conflicting and more recently adopted "negative thoughts" account also provided Pauline with a way of accounting for her experiences of depression. To some extent, this account also drew on the restitution narrative so offered some degree of hope to Pauline that, if she fixed her negative thinking, she would recover.

Pauline drew on a number of competing illness and mental health narratives and cycled through telling numerous, context specific, and often conflicting stories in an attempt to make sense of her lived experiences. This analysis suggests that, faced with a lack of public narratives that accurately frame their experiences, individuals with treatment resistant depression struggle to renegotiate their identities and restore any sense of coherence.

Clinical Reflection

Pauline was the first person I met with treatment resistant depression. As treatment resistant depression is the topic of my doctoral research, I had spent many hours reading scientific literature and thinking about this form of depression as a theoretical concept. It was an entirely different experience, however, to meet Pauline and to hear about the experience of treatment resistant depression from her perspective. It was both fascinating and heart-breaking to hear Pauline's story. I could not believe that she had been depressed for nine years, had trialled upwards of 20 antidepressant medications, and had attended endless appointments with her psychiatrist and psychologist. I could not begin to imagine the degree of strength that it would take to carry on with life. The 80 minute unstructured interview with Pauline produced vastly different information to an initial clinical assessment and gave me new insights into the nuances of the pain that our clients feel. Following the interview, Pauline remarked that she had enjoyed being able to share her story of depression and had found it therapeutic. This made me realise the importance of achieving a balance between information gathering, “box ticking” and agenda following, AND allowing clients to tell their stories in a way that makes sense to them.

Faced with her experiences not fitting the ‘standard story’ of depression, Pauline had significant difficulty making sense of what was going on for her. In clinical terms, she explored many possible predisposing, precipitating, and perpetuating factors of her depression. For example, she spoke about difficult and traumatic life events, being a bad patient, deserving the pain, and having negative thoughts. None of these explanations were sufficient alone so Pauline cycled through them all, often abandoning one story/explanation in favour of another. Following this analysis, I began to reflect on how a large part of our role as clinical psychologists is helping people understand what is happening to them. Humans are constantly storying their experiences in an attempt to make sense of their lives and this is particularly evident after “biographical disruptions”, such as mental illness (Frank, 1995). It has been interesting to see how this plays out in clinical practice. On the one hand, some clients have rehearsed explanations for why they are mentally unwell, for example, “my mother died” or “there is a chemical imbalance in my brain”. On the other hand, many clients tearfully despair “I don’t know why this is happening to me!” and are very unsettled by this lack of understanding of causation. As clinical psychologists, we have a useful and powerful tool for assisting clients in making sense of and understanding their experiences: formulation. In many cases, after discussion of a formulation in session, clients have stated that it is a relief to know what is going on for them. This has prompted me to be more explicit in sharing my formulations with clients.

It was very interesting to read the literature on healthcare professionals' reactions to people with treatment resistant depression (McPherson et al., 2006; McPherson et al., 2009). Since reading these articles, I have become more aware of my own reactions to clients and the way that certain clients are spoken about and constructed in the workplace. At times I have noticed my own "heart sink" feelings when I am seeing a client who is not improving despite my efforts. I have also occasionally noticed clinicians attributing clients' long term difficulties to 'personality disorders' or the fact that they are 'interpersonally challenging'. Learning that Pauline was privy to the way she was positioned by healthcare professionals has prompted me to explore my own feelings of frustration or dread associated with some clients, and to consider what I can do about these feelings to prevent them from interfering with treatment. For me, as a novice therapist, I have found that my clients' lack of improvement tends to trigger thoughts such as "I'm not good at this job", "this client would have benefited more in seeing someone else", and "I must be doing something wrong". This exploration has been useful – it has helped me understand where these feelings originate and has prompted me to be mindful and challenge this thinking when appropriate. I have also found discussions in supervision to be very helpful when I notice these feelings.

Whilst grounded in a different epistemology to mainstream clinical psychology, the process of meeting Pauline and analysing her data has deeply informed my clinical practice. It has expanded my understanding of depression, treatment resistant depression, and mental illness, provided me with insight into the lived experience of the pain of treatment resistant depression, and has prompted me to consider my own reactions to "difficult" clients. This process has been an invaluable experience and I now feel much better equipped to work with people with persistent forms of mental illness.

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