Disability grant utilisation and barriers to access for patients with personality pathology: A multi-method study

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DECLARATION

I, Hayley Julius, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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ABSTRACT

Background

Personality disordered (PD) patients suffer the misnomer of “difficult to treat”. Difficulties in interpersonal style attendant with this diagnosis can impact on clinician attitude. This suggests that negotiating access to government health and social services, including the disability grant, might be a process with unique barriers for this group of patients. This study aims to investigate barriers that patients with PD (disorder or traits) experience in accessing the government disability grant.

Methods

A multi-method approach was used to identify barriers and facilitators to accessing the government disability grant in a group of psychiatric patients attending the Ward 1 therapeutic programme at Valkenberg hospital, South Africa. In the first phase, files of patients attending the programme in 2018 and 2019 were reviewed. Variables related to PD diagnosis, disability grant and others of interest were analysed using SPSS. In the second phase, purposive sampling for patients with PD and disability grant was done to conduct semi-structured interviews. Nvivo software was used to categorise and assist with analysis of themes. In the third phase an online clinician survey was conducted amongst psychiatrists and psychiatry registrars within the Department of Health, Western Cape who are tasked to assist with disability grant applications for this patient group. This was done to determine clinician beliefs and attitudes to making disability grant applications for patients with PD that may serve as barriers.

Results

File review: Valid data from 237 patient folders indicated that a total of 53 (22.4 %) patients had ever-access to the government disability grant (DG) and 6 (2.5 %) to private disability pay-out (Total: n = 59, 24.9 %). Half of patients admitted over the two years had a PD diagnosis (n = 122, 51.5 %). Borderline personality disorder was the most diagnosed PD (n = 68, 29 % of the sample). Although the majority of those with disability grant access had a PD diagnosis (n = 31, 52.5 %), there was no significant association between having a PD and receiving DG support.

Patient interviews: Framework analysis was used to derive at 5 themes that related to *Knowledge and beliefs* about impairment and the disability grant, *Course and access* to the grant, *Barriers to access*, the *Psychosocial impact of the disability grant*, and *Participant service needs* related to recovery and possible sustained economic participation. Sub-theme findings related to the relationship with mental health professionals as facilitators to access, the impact of disability grant lapse on mental well-being,

and three-way stigma related to having a 1) disability grant, 2) psychiatric diagnosis and 3) disability grant access for a psychiatric diagnosis. Internalised stigma was a significant finding and stigmatising judgement was experienced in interaction with general health professionals and may serve as a barrier to first access .

Clinician survey: Respondent rate to the survey was low (n = 12, 21.8 %). Clinicians had much experience working with adult patients with PD, but most did not consider disability grant assessments with PD patients a routine part of their work. Confusion about how to make disability assessments for this group, compared to those with a primary common mental disorder or a serious psychiatric disorder, was salient. Most clinicians experienced dual role conflict in treating the PD patient and assessing them for a disability grant application, endorsing that the task should be delegated to another professional. Interpersonal interaction with PD patients was a challenge for clinicians but they did not believe this prevented them from considering treatment options for the patient that could support recovery and more sustained economic participation.

Discussion and Recommendations:

Barriers to initial access to the disability grant related to internalised stigma and patient readiness, as well as general health professional attitude. Recipients of disability grants motivated for access based on impaired functioning, in keeping with recommendations by the Department of Social Development (DSD). Functional impairment related to instability of affect, mood dysregulation that contributed to inconsistencies in behaviour, and interpersonal difficulties. These were implicated in difficulties returning to work and continuation of the disability grant. The disability grant was experienced as a significant source of support and relationships with mental health practitioners were an invaluable source of mental health support. Stigma was experienced from communities and general health professionals. The DSD mandate to routinely review access to the disability grant was a barrier contributing to distress, deterioration in mental health and socioeconomic well-being, and avoidant engagement with employment options. Recommendations to the DSD are highlighted to address realignment of the ‘temporary’ grant with incentivisation for recovery and economic participation. Government multi-sectoral coordination to address stigma is highlighted. Recommendations for clinician training and practice for more confident assessment of impairment in PD patients, and to support mental health in this patient population, are made.

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CHAPTER 1 INTRODUCTION

1.1 Rationale for Study

Data from the 2019 Global Burden of Disease Study suggest that mental disorders contribute to a large proportion of the global all-cause disease burden. In 2019 this category included depressive and anxiety disorders, bipolar disorder, schizophrenia, autism spectrum disorders, conduct disorder, attention-deficit hyperactivity disorder, eating disorders and idiopathic developmental intellectual disability. Personality disorder was included in an other mental disorders residual category included under mental disorders. These accounted for 125, 3 million disability-adjusted life years (DALYs) (4.9% of global all-cause DALYs), and 14.6% of global years lived with disability (YLDs) (Ferrari et al., 2022). This excluded substance use disorders that, together with mental and neurological disorders contributed to 10.4 % of global (all-cause) DALYs, and 28.5 % of global YLDs in 2010. Within that 2010 grouping of mental, neurological and substance use disorders, mental disorders contributed 56.7% to DALYs (Whiteford, Ferrari, Degenhardt, Feigin, & Vos, 2015). Personality disorder has been found to be highly comorbid with common mental disorders (CMDs) namely, mood disorders, anxiety disorders and substance use disorders (Friborg, Martinussen, Kaiser, Øvergård, & Rosenvinge, 2013; Gabbard et al., 2000), and has been implicated in their recurrence (Friborg et al., 2013; Tyrer, Reed, & Crawford, 2015). International literature suggests that personality disorder, in its relation to lifestyle problems, poor physical health, effects of psychotropic medication, and death arising from suicide, homicide or accident, is associated with poorer health overall and raised mortality (American Psychiatric Association, 2013; Bender et al., 2001; Friborg et al., 2013). Personality pathology carries both direct and indirect cost to mental health services (American Psychiatric Association, 2013; Bender et al., 2001; Friborg et al., 2013; Ro & Clark, 2013).

Disability grant disbursement by the South African government forms part of a broader social security programme, administered by the Department of Social Development (DSD), to individuals who fulfil certain criteria (South African Government, 2022). The disability grant (pension) is a cash payment made on a monthly basis to an individual who permanently or temporarily is unable to work due to an illness, injury or medical condition. Whilst cash pay-outs to support disability is exercised for CMDs (Lund et al., 2011), an observational study in South Africa suggests greater clinician challenges in the process of disability grant applications for psychiatric patients (Kelly, 2016), and anecdotal report from mental health professionals considering disability grant applications suggests this may be a particularly difficult process with patients with personality pathology in a psychiatric setting in South Africa. Assessment of functional impairment on a continuum is made in an encounter between the patient and clinician. Because individuals with personality pathology usually present for support when pathology is exacerbated due to an increase in stressors, this encounter might be constrained. Further, the DSD language of ‘permanent’ or ‘temporary’ disability is different to the medical language of impaired functioning that is assessed to varying degrees across several spheres of living. This can serve as a barrier for doctors talking about disability grant support with patients who identify with the mainstream DSD language of disability. Taken together, clinicians may feel uncertain about the adequacy of their assessments and uncertain if treatment and rehabilitation can or should be pursued in mitigation of a claim to disability. The state health system plays a role in gate-keeping access to the disability grant for patients with personality pathology, while also attempting to optimally assess, treat and provide rehabilitation for these individuals. Psychiatrists within the public mental health sector, may be particularly hampered by these concerns, in a confusing dual role as treating clinician and assessor for the disability grant.

Systemic, interpersonal and attitudinal barriers to patient mental health care are well documented internationally, and evidence suggests that these are similar for the mental health care of patients with personality pathology (Dadi, Miller, Azale, & Mwanri, 2021; Koekkoek, van Meijel, Schene, & Hutschemaekers, 2009). Additionally, barriers to clinicians that include patient interaction, clinical and mental health system factors, and the clinician’s personal beliefs and values (Chartonas, Kyratsous, Dracass, Lee, & Bhui, 2017), may hinder more confident engagement with cash pay-out support for personality disordered individuals. Little is known about the benefits accrued to patients with personality disorder who receive disability grant support, or about the challenges of accessing disability grants for patients with personality disorder. The above require consideration, as factors that contribute to mental health for this patient group in a low- and middle- income country (LMIC) such as South Africa.

1.2 Aim

The aim of this study is to explore the experiences of accessing disability grant support for patients with personality pathology (disorder or traits), and clinicians tasked with intervening on their behalf. The aim will be met by achieving three objectives:

1.3 Objectives

1. To report on disability grant support utilisation by patients with personality pathology (disorder or traits) admitted to Valkenberg psychiatric hospital in Cape Town, South Africa.

2. To report on these patients’ experiences of access to state-issued disability grant support, possible barriers to access and impact of disability grant support on their psychosocial wellbeing.
3. To identify clinician opinions and possible barriers in making disability grant applications for patients with personality pathology, and to identify what would assist clinicians in the consideration of disability grant support to this population.

CHAPTER 2 LITERATURE REVIEW

2.1 Personality Disorder and Traits: The Diagnostic and Statistical Manual 5th edition Categorical Approach

The Diagnostic and Statistical Manual, 5th edition (DSM-5) defines personality disorder as “an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment” (American Psychiatric Association, 2013, p. 645). This pattern cannot be accounted for by another mental disorder or the physiological effects of a medical condition or a substance. Clustering of the different personality diagnoses is made according to shared descriptive features, namely, cluster A represents disorders with marked oddness or eccentricity, and includes paranoid, schizoid, and schizotypal personality disorder. Cluster B personality disorders of antisocial, borderline, histrionic, and narcissistic personality share features of being dramatic, emotional, or erratic. Cluster C avoidant, dependent, and obsessive-compulsive personality disorders share similarities of appearing anxious or fearful. Traits that are present but where there are insufficient criteria to warrant the diagnosis of a disorder, are subsumed under the categories of Other Specified Personality Disorder, or Unspecified Personality Disorder (American Psychiatric Association, 2013). The diagnosis of any of the ten personality disorders requires specific criteria that are cognitive, affective, behavioural and interpersonal manifestations of traits, resulting in a categorical present or absent conceptualisation of personality pathology. Personality traits are considered “enduring patterns of perceiving, relating to, and thinking about the environment and oneself that are exhibited in a wide range of social and personal contexts”; with personality disorders manifesting when traits are “inflexible and maladaptive and cause significant functional impairment” (American Psychiatric Association, 2013, p. 647).

While the DSM is the nosology commonly used in the training of psychiatrists and clinical adjunctive health service professionals in psychiatric settings, the World Health Organization (WHO) International Classification of Diseases (ICD) 11 ((WHO), 2019/2021) offers a dimensional system for the diagnosis of personality disorder, supporting empirical evidence that levels of severity of personality impairment should be considered in the diagnosis. Thus, diagnosis of personality disorder in the ICD-11 is made by determining the severity of impairments in self (identity, self-esteem, self-directedness), interpersonal functioning (intimacy and empathy), emotional, cognitive, and behavioural regulation, as well as assigning one of 3 levels of severity of impairment. ICD-11 also allows for the optional coding of the presence of up to 5 prominent personality domain traits (negative affectivity, disinhibition, detachment, dissociality, anankastia) (Tyrer, Mulder, Kim, & Crawford, 2019).

The DSM has attempted to address long-standing arguments for a transdiagnostic approach that elucidates impairment in personality and functioning on a continuum, rather than in a binary, absent-present construction, by including their own hybrid model in Section Three, but only as an alternative diagnostic approach requiring further investigation (American Psychiatric Association, 2013). Both ICD-11 and the DSM-5 Section Three approaches, however, bring focus to clinical practice experience and research evidence that severity of impairment increases with an increase in pathological personality domain presentation (Tyrer et al., 2019).

2.2 Personality Disorder Comorbidity with other mental disorders

Personality disorder has been shown to be highly comorbid with other mental disorders (Friborg et al., 2013; Gabbard et al., 2000), with a prospective study of treatment outcomes for patients with personality disorder at two inpatient programmes in the United States of America estimating that affective disorders — (major depression, bipolar disorder, and dysthymia) were comorbid with most participants in the study (82.9 %) (Gabbard et al., 2000). Personality disorder complicates the syndromal picture of other disorders, and is implicated in the recurrence of CMD, making those more difficult to treat (Friborg et al., 2013; Tyrer et al., 2015). Data from the United States of America National Epidemiologic Survey on Alcohol and Related Conditions (NESARC), showed that borderline personality disorder (BPD) had the highest prevalence of the personality disorders in a community sample (estimated at 2.7 %, based on a sample of 34, 481 participants), with high comorbidity of life-time mood, anxiety, substance use disorders, and other personality disorders (Tomko, Trull, Wood, & Sher, 2014).

The diagnosis of BPD has also been shown to be highly comorbid with posttraumatic stress disorder (PTSD) (Zeifman, Landy, Liebman, Fitzpatrick, & Monson, 2021) and that in many of these individuals there is a childhood or recent relational history of emotional abuse or neglect (trauma). Complex posttraumatic stress disorder (CPTSD) has been included in the ICD-11 as distinguishable from PTSD in that the history of traumatic events is likely of a prolonged or repetitive nature, that the criteria for PTSD is met and that disturbances of self-organisation (DSO) are also present. DSO criteria are met by symptoms that fall under 1) problems with affect regulation (including numbing), 2) that individuals' self-perceptions are as defeated, diminished or worthless and with attendant shame, guilt or failure related to the trauma event, and 3) individuals have difficulties of emotional detachment in relationships and sustaining relationships ((WHO), 2019/2021). These overlap with BPD criteria of affective dysregulation, distorted self-perception, and of unstable/difficulty maintaining interpersonal relationships, and contributes to arguments that comorbid BPD and PTSD (BPD-PTSD) can be better understood as CPTSD (Nestgaard Rød & Schmidt, 2021). However, a recent review of the literature on CPTSD and BPD suggests that CPTSD is not a sub-type of PTSD or BPD (Ford & Courtois, 2021), and this appears to be supported by treatment outcomes in BPD-PTSD where BPD-specific treatments demonstrate some relief of PTSD symptoms but are not adequate for sustained remission (Nestgaard Rod and Schmidt, 2021). Comorbidity of BPD with a post-trauma reaction warrants further understanding in order to inform treatment approaches and to have impact on public mental health interventions, particularly in South Africa, a country with high levels of trauma.

2.3 Barriers in the Treatment of Personality Disorder

Koekkoek et al (2009) explored clinical problems in the community care of patients with severe BPD using a modified Delphi method, which is an accepted strategy to generate knowledge in an area that is under-researched (Grime & Wright, 2016; Jorm, 2015). Patient-, professional-, interaction-, social system-, and mental health care-related areas of difficulty were identified (Koekkoek et al., 2009). A prominent problem was the pessimistic attitude of professionals regarding the treatment outcomes for this group of patients. Professionals' perception of the severe BPD patient as non-compliant and thus wasting the professional's time was salient, as was differing treatment expectations between the professional and the patient. Lack of organisational support within community mental health settings, lack of reflection amongst colleagues regarding personal feelings and attitudes, and lack of structured treatment in the management of these patients, were identified as problems within the category of the mental health system. Another study notes a perceived lack of purpose amongst trainee psychiatrists working with personality disorder patients as compared to their interactions with depressed patients (Chartonas et al., 2017). It is unclear why these barriers exist for patients with personality disorder, given a growing body of research that suggests that personality disorder symptoms are not as stable as previously thought. Treatment options for the most researched personality disorder – borderline personality - would include one, or a combination, of general psychiatric management and evidence-based psychotherapies such as Dialectical-behavioral therapy, Mentalization-based therapy, Schema-focused therapy and Transference-focused therapy which is likely to include both inpatient and outpatient possibilities (Choi-Kain, Finch, Masland, Jenkins, & Unruh, 2017). Medication adjuncts would not be indicated for a personality disorder but might assist with symptoms of other clinical syndromes that usually present comorbidly, such as major depression or generalised anxiety, or as a feature of a certain personality disorder, such as for perceptual disturbance in schizotypal personality disorder. There is some evidence that both personality disorder and personality disorder symptoms show inter-individual variability in rate of change, direction of change, differences over lifetime and in remittance, and are highly treatable. Personality disorder symptoms have been shown to decrease with maturation, and concomitantly, to develop where maturation stagnates or regresses (Wright, Pincus, & Lenzenweger, 2011).

2.4 Cost of Personality Disorder

It is reported that "(m)ental disorders cost low-income and middle-income countries US$870 billion every year, a cost that is estimated will more than double to US$2.1 trillion by 2030" (Jack, Stein, Newton, & Hofman, 2014). Literature suggests that patients with personality pathology take longer to improve than those with an acute CMD without personality pathology and that pathological personality presentations should be considered as critical in diagnosis and treatment planning of psychiatric patients, as they are associated with extensive use of mental health resources (Hengartner, 2015; Tyrer P., Reed G.M., & Crawford M.J., 2015). Most information about the direct and the indirect costs such as the inability to work, receive education, or the impact of the inability to care for family (Patel et al., 2007) for patients with personality pathology has come from high income countries. Whilst evidence-based interventions (Choi-Kain et al., 2017) for personality disorder are offered in the South African context both the dearth of epidemiological information on personality disorder, of information about cost to healthcare services to treat the disorder, as well as the cost of support services in the care of these patients, means that the cost to the economy of personality pathology is unquantified. Disability grant support would contribute to the cost of having a personality pathology.

2.4.1 Direct cost of personality disorder

Direct costs refer to the costs of providing health care to the person living with a disease, such as direct labour and intervention, and inclusive of costs to the provider, recipient or a third party. In a Norwegian randomised controlled trial assessing health service use and cost across day-hospital step-down treatment, and specialist outpatient services for borderline personality disorder and avoidant personality disorder patients, overall cost of treatment was higher for step-down treatment (defined in the study as consisting of different phases including a day-hospital programme with psychodynamic and cognitive behavioural group therapy, outpatient therapy, weekly individual and group psychotherapy and finally, only outpatient group psychotherapy in the final year) (Kvarstein et al., 2013). However, the cost of step-down treatment was not different between the borderline personality disorder and avoidant personality disorder groups over the course of the 36-month trial. In the outpatient service treatment, patients with avoidant personality disorder had more individual sessions, additional consultations, other day-hospital treatment, and addiction treatment in the initial phase of treatment than those with borderline personality disorder. For patients with avoidant personality disorder in the initial phase of treatment, emergency service costs were higher, with more frequent use of inpatient psychiatric services and higher number of inpatient days. When other-CMD comorbidity was controlled for, medication, general practitioner (GP) and community health service costs were higher for avoidant personality disorder. Both psychosocial and clinical improvements were noted for both groups with longer-term treatment (Kvarstein et al., 2013). In another study using the

International Personality Disorder Examination ICD-10 Screener in an Australian National Mental Health and Well-Being Survey, it was established that of the personality disorders, borderline personality disorder was more often associated with mental health consultation-seeking from GPs, psychiatrists and psychologists than other personality disorders (Jackson & Burgess, 2004). It has been noted that poorer Global Assessment of Functioning-F (GAF-F) (which refers to the portioning out of the functioning indicators, from the symptom indicators in the GAF) and current unemployment increased the probability of longer and more intense treatment in specialised hospitals services for personality disordered patients (Simonsen, Heinskou, Sørensen, Folke, & Lau, 2017).

2.4.2 Indirect Cost of Personality Disorder

Indirect cost is often considered to be cost associated with lost productivity due to a disease. In a nationwide assessment of personality disorders in the Netherlands between 2003 and 2006, lost productivity included absence from work, reduced efficiency at work, and difficulties with job performance, using the Health and Labor Questionnaire short form (Soeteman, Hakkaart-van Roijen, Verheul, & Busschbach, 2008). Results for personality disordered patients who had a paying job indicated that 47.6 days, or 7088 euros, per year were lost per patient, due to absence from or inefficiency at work. In a matched-controlled nationwide study of borderline personality disorder patients and spouses in Denmark, total direct healthcare cost and lost productivity cost was 16 times higher for borderline patients than their matched controls (Hastrup, Jennum, Ibsen, Kjellberg, & Simonsen, 2019). In the Jackson et al (2004) study, using the Brief Disability Questionnaire (BDQ), the 12-Item Short Form Health Survey (SF-12) and the total days and partial days out of role functioning in the preceding four weeks, borderline personality disorder was associated with increased disability.

Most literature on the indirect cost of personality disorder has focussed on BPD, due to an already extensive body of knowledge on the disorder, and its notable impact on functioning (Chanen, Sharp, & Hoffman, 2017). In the Hastrup et al (2019) study, lower earned income was noted for BPD patients before diagnosis was made, compared to controls. Earned income decreased even further after diagnosis was made. For the spouses of BPD patients there appeared to be a significant burden: lost productivity was 84 % of the total direct and indirect cost for spouses of BPD patients, and the earned income of spouses of BPD patients was one-third lower than that of controls. Of interest, unemployment benefit and disability pension were higher for spouses of BPD patients both before and after patient diagnosis was made, than in controls. The authors suggest that this may be related to non-random mating that has been observed to occur within and across psychiatric disorders, namely that personality disorder patients possibly select partners who also have personality disorder or another psychiatric condition (Hastrup et al., 2019). This suggests that personality disorder diagnosis, the presence of pathological personality traits (not meeting DSM-5 threshold criteria for a specific personality disorder diagnosis), and its interaction in cohabiting relationships should be considered in impaired functioning, and its cost implications.

2.5 Personality, Impairment and Psychosocial Dysfunction

Personality disorder traits can be considered on a continuum with normal personality traits. The Five-Factor Model (FFM) is a dimensional model of normal personality traits, developed using factor analysis to derive five broad trait domains of Neuroticism, Extraversion, Openness to Experience, Agreeableness and Conscientiousness (Costa & McCrae, 1992, cited in (Saulsman & Page, 2004)). Where personality traits occur towards the pathological side of the continuum, individuals may be at higher risk for psychosocial impairment that includes vocational impairments. Personality traits based on the FFM, and the association with disability has received research attention in the area of life satisfaction (Boyce & Wood, 2011; Ropponen, 2012). A study found that individual differences in pre-disability personality had an influence on adjustment and life satisfaction after disability occurred, with an agreeable pre-disability personality adapting more quickly and fully to disability (Boyce & Wood, 2011). A twin study aimed at investigating personality traits and life dissatisfaction as predictors for disability pensioning due to a low back diagnosis (as a mild, somatic symptom) suggests that prior life dissatisfaction and neuroticism may be risk factors for disability pensioning in low back disorder (Ropponen, 2012). There is support for significant correlation between social impairment, vocational impairment and distress in psychiatric patients, and the FFM of personality traits (Mullins-Sweatt & Widiger, 2010). In a cross-sectional study including 131,195 participants from high-income countries (Australia, Germany, the United Kingdom, and the United States), it was found that there was a higher mortality and disability risk where conscientiousness as a personality trait was below the median level of the sample (Jokela et al., 2020). Life expectancy was estimated to have been 1.3 years longer and disability-free life 1.0 years longer if excess risk associated with low conscientiousness was absent, whilst low emotional stability was also associated with loss of disability-free life years (Jokela et al., 2020).

Exploring the FFM of personality traits and the association with disability pensioning in a non-clinical sample of women aged 34 - 67 years in Norway, women scoring low on the trait domains of conscientiousness, extroversion, and high on neuroticism were found more likely to receive disability pensioning, defined as permanent (long-term) disability in the Norwegian welfare system (Østby, Mykletun, & Nilsen, 2018). The authors surmise that if low conscientiousness is also associated with poorer organization and structuring of behaviour, contributing to carelessness and unreliability, then it is likely to increase the difficulty of retaining employment (Østby et al., 2018). Thus, notwithstanding a mental health diagnosis of a personality disorder, personality traits towards the pathological end on a continuum with normal personality traits may be associated with disability pensioning.

The level of personality functioning appears to demonstrate a relationship with psychosocial functioning in individuals with psychiatric disorders. Level of personality functioning using the Level of Personality Functioning Scale (LPFS) was assessed with bipolar disorder type 1 (BD-1) patients to determine the relationship between global functioning and personality functioning, during a period of remission (Kizilkurt, Gulec, Giynas, & Gulec, 2018). It was found that lowered personality functioning (impairment) was correlated with impaired global functioning, using the Global Assessment of Functioning (GAF) score. Mild to moderate impairment in personality functioning was noted in patients with BD-1 (Kizilkurt et al., 2018). Ro and Clark (2012) argue for a study of the three-way interaction of psychosocial functioning, personality and psychopathological symptoms (read clinical syndrome) to understand this relationship better. Using the Short-Form 12 Health Survey – Version 2, general functioning in the areas of mental health, social functioning, role emotional functioning, physical functioning, bodily pain, vitality, general health, and role physical functioning, was assessed in a community sample of individuals who met BPD criteria in the NESARC study (Tomko et al., 2014). In this group, a lifetime diagnosis of BPD predicted significant impaired social functioning and impaired mental health. Having BPD was also associated with report of "having significant trouble with one's boss or employer" (Tomko et al., 2014, p. 744).

2.6 Psychosocial Impairment and Disability

Research suggests that while psychosocial improvements can occur for personality disordered patients, that this might happen to a lesser degree where there is no concomitant remission in personality disorder symptoms (Skodol et al., 2005; Zanarini, Frankenburg, Hennen, Reich, & Silk, 2005). The decision to apply for or suspend a state disability grant for impairment or disability based on personality pathology could possibly be assisted through understanding how level of personality impairment and level of psychosocial functioning interact. Psychosocial functioning is important for mental health and recovery but appears to be poorly understood. Along with the availability of numerous psychosocial functioning measures, functioning takes place in diverse areas of life, for example, work, parenting and socialisation; and functioning level in one area can be widely divergent from functioning in another (Ro & Clark, 2013). Impaired functioning in a work environment significantly affects the decision to issue a state disability grant, and individuals with personality disorders appear to continue to have poor occupational functioning despite treatment and remission in symptoms (see Bateman, Gunderson and Mulder, 2015, cited in (Juurlink et al., 2020)). Stigma for having a psychiatric diagnosis, leave from work to seek and follow up with psychiatric and psychological care, and the fact that individuals with a psychiatric diagnosis may lack support in the workplace, leading to continuing or even worsening occupational functioning, may be implicated in the above observation.

Research in a clinical sample in the United States of America suggests that BPD was the diagnosis most likely of the personality disorders to have ever received a social security disability income (SSDI). At baseline 40.7 % (n = 118) of a total of 290 BPD patients were on social security benefits, with 60 % eventually utilising social security support at least at one timepoint in the 10-year study (M. C. Zanarini, Jacoby, Frankenburg, Reich, & Fitzmaurice, 2009). Forty per cent of the 118 BPD patients at baseline were able to suspend disability income support, but 43 % of those suspending support subsequently returned to disability income support. Of the BPD patients who were not on disability support at baseline, 39 % of them initiated disability support for the first time during the ten-year period. In the larger group of BPD patients ever on disability support during the 10-year period, psychosocial strengths in the last two years were noted. This was in the areas of engagement with work or schooling (for at least 50 % of the time), having a supportive relationship with at least one friend, or a good relationship with a romantic partner (M. C. Zanarini et al., 2009). This suggests that the interaction between disability grant utilisation and improvements in psychosocial functioning may be bi-directional and requires further elucidation.

Within the South African disability assessment process, psychiatric disability directs focus to the medically identifiable symptoms that are related the mental health diagnosis and less so to the psychosocial sequelae thereof. These psychosocial difficulties, within the arena of disability advocacy often go ‘unseen’ and further sets psychiatric disability apart from the sensory, physical or intellectual disabilities. As such psychosocial disability due to a mental health condition is considered “harder to ‘see’ or understand” ((MHCC), 2022). It is likely that receipt of a disability grant for an ‘unseeable’ mental health condition may intensify stigma, possibly making access to psychosocial support, including in the workplace, more difficult. For example, stigma may work to restrict opportunities to supplement income through informal job opportunities or to access comprehensive state support with complementary subsidies through the mechanisms of self- and other- stigma (Thornicroft et al., 2022). Mental ill-health and psychosocial disability can present comorbidly with physical health conditions. Both these states contribute to disability, yet those affected by both are notably reluctant to also ascribe disablement to mental health symptoms (Ringland et al., 2019).

2.7 Psychiatric Disability and Civic Participation

Marrone and Golowka wrote in 1999 (p. 192) that “(p)sychiatric disability is a disease of losses” and argued for retaining the right and responsibility of persons to contribute through formal employment, citing social connection, housing, income, appearance, skills, self-respect and hope as attributes that become casualties in the trajectory of mental illness. These losses could be curtailed through involvement in meaningful employment that provides the opportunity to enjoy more experiences in life (Marrone & Golowka, 1999). In certain psychotherapy treatments, such as transference-focused psychotherapy, engagement with the world outside of the therapeutic encounter is monitored and used in transference interpretations to promote psychological integration and functioning (Radcliffe & Yeomans, 2019). The return to work is viewed as a necessary contractual undertaking to promote mental health. Tumbo (2008) argues that healthcare providers may have a pitying response towards patients with mental illness. Together with healthcare practitioners suspending the expectation that patients engage in meaningful work, this contributes to favourable disability grant assessments for patients with mental illness. Within the disability advocacy field, however, this approach is viewed as a form of oppression that is misaligned with acceptance and tolerance of disability in the workplace (Marrone & Golowka, 1999). The relationship between psychiatric illness and poverty is elucidated further in an editorial by Cook and Mueser (2016) who argue that psychiatric patients are in danger of giving up on attempts to lift themselves out of poverty or to accumulate needed resources provided for by their ‘indigent’ status. These resources are usually made available supplementally to individuals already on social support programmes (for example, rebates on municipal rates). Recipient delays in accessing these supplemental social support measures may occur due to myths and misinformation about, for example, limits on work and income thresholds (Cook & Mueser, 2016).

2.8 Impact of Disability Grant Utilisation

Whilst disability grants are meant to serve a social protection function in individuals where economic participation is constrained due to physical or mental reasons, the beneficial and detrimental impact in outcomes of psychosocial functioning and mental health is complex (Lund et al., 2011). Indications are that the relationship between poverty and mental health is likely bi-directional in the relationship between poverty and depression, as theorised through social causation and social drift theory (Lund & Cois, 2018). A recent systematic review and meta-analysis of the impact of cash transfers on subjective well-being and mental health suggests significant positive effect in low- and middle-income countries (McGuire, Kaiser, & Bach-Mortensen, 2022). With regard to personality disorders it might be necessary to understand: whether 1) personality disorder leads to increased presentation for health care, poor vocational and social functioning, loss of employment, and thus the initiation of social grant use and the drift into poverty, or 2) high levels of unemployment, poverty, the increasing normalisation of social grant use in South Africa and the attendant factors of stress, violence and exclusion contribute to exacerbation of (pathological personality) trait expression and impaired functioning. Whilst distress can be considered to likely be present at the time that a disability grant is applied for, the initiation and course of disability grant utilisation may also have unforeseen and unintended negative consequences, such as a depreciation in the financial position of the individual and the household, increased socio-economic difficulties, and an increase in emotional distress in the form of regret, resentment, and helplessness (Mokoka, Rataemane, & dos Santos, 2012). Loss of role identity and self-esteem may also be attendant. As far as it is known, no research related to the intersection of mental health, personality functioning, psychosocial impairment and the deleterious or protective functions of social grants has been undertaken in the context of a LMIC. Access to disability support for this group as well as understanding the ease of access will assist in considering the impact of disability support for this patient group.

2.9 The South African Context

2.9.1 Prevalence of Personality Disorder in the South African Context

There is limited research on disordered personality functioning either in the general population or in patients accessing treatment to mental health care services in the South African context. A retrospective epidemiological study undertaken to identify patterns of admission to three psychiatric hospitals concluded in 1999 that more women were diagnosed with mood, anxiety, adjustment disorders and with avoidant, dependent, histrionic, and borderline personality disorders, whilst more men were diagnosed with substance abuse, schizophrenia, cognitive disorders, and antisocial personality disorders (Strebel, Stacey, & Msomi, 1999). Suliman, Stein, Williams, and Seedat (2008), used multiple imputation to estimate the occurrence of personality disorders, and found a prevalence of 6.8 % in a nationally representative sample in the South African Stress and Health Study. Applying categorical diagnoses from the DSM-IV, it was estimated that the three personality clusters were comorbid with each other and that there was high comorbidity of personality disorders with axis I disorders. Cluster A disorders were estimated to be more prevalent than cluster B or C, with just under 20 % of those with a possible personality disorder diagnosis receiving treatment for a mental health or substance problem in the preceding 12 months (Suliman et al., 2008).

2.9.2 The South African Social Support System

Cash pay-outs for disability on mental or physical grounds forms part of the social protection response of the South African government to mitigate against vulnerability and poverty in a country with high population unemployment rates of approximately 40 % (Webb & Vally, 2020). Compared to other African countries, a significantly large proportion of social spending happens in the disbursement of social grants, with an estimated monthly pay-out of more than 18 million social grants (Webb & Vally, 2020). This social protection response seeks to be comprehensive and includes free health care and the option to apply for “indigent status”, which allows for rebates on expenses related to water, electricity and sanitation services (International Labour Office, 2016, p. 2).

Disability grants may be applied for when individuals are unable to work for longer than 6 months, as a result of a stated physical or mental disability (South African Government, 2022). Disability assessed as lasting longer than a year would qualify for a “permanent grant”, though this does not mean that it is lifelong. Disability not lasting continuously for more than 6 months would be considered temporary. Further criteria include:

- South African citizenship, residency or refugee status
- Age between 18 and 59
- Should not be in state institutional care
- Should be in possession of a 13-digit, bar-coded identity document
- Earnings should not be more than R86 280 per annum (unmarried), or R172 560 (married)
- Assets should not be valued at more than R1 227 600 (unmarried) or R2 455 200 (married)
- Should subject oneself to a medical examination by a state-appointed doctor to assess degree of disability
- Should make available any previous medical records and reports.

Furthermore, the grant is subject to review, and is also subject to a reduction in the fourth month after a recipient’s admission into the care of a state institution, that can be reinstated from the date of discharge. The current maximum pay-out amount of a disability grant is R1980 per month (South African Government, 2022) and the South African Social Security Agency (SASSA) on behalf of the DSD is responsible for the disbursement of cash pay-out to successful applicants.

The South African government makes provision for the war veterans grant, care dependency grant, foster child grant, grant-in-aid, child support grant, disability grant and the old age pension grant and, since the covid-19 pandemic in 2020, the relief of social distress grant. Of the 17.2 million social grant beneficiaries in South Africa in 2017, the vast majority were recipients of the child support grant (12,039,444), the old age pension (3,283,286) and the disability grant (1,069,802) (Chagunda, 2019).

2.9.3 Psychiatric Health Care and Disability Grant Utilisation in South Africa

In the 2016/2017 financial year, country-based expenditure on mental health care in South Africa was 5 % (ZAR 615.3 million) of the total public health budget, with 86 % of this expenditure being directed to inpatient treatment of mental health conditions (Docrat, Besada, Cleary, Daviaud, & Lund, 2019). An audit of patients presenting for acute admission at the Western Cape’s largest psychiatric hospital over a 6-month period in 2016, showed that 37 % received disability grants, and only 12 % of the 573 patient files audited documented that the patient was in employment (Franken, Parker, Allen, & Wicomb, 2019). Whilst most admissions were men (67 %), women were more likely to be in receipt of disability grants (44 % vs 34 % of males). Findings also suggest that a third of those in receipt of disability grants were also misusing substances (Franken et al., 2019). In a study of factors associated with psychiatric patients' completion of a substance rehabilitation unit programme at Weskoppies hospital in South Africa, it was found that patients who had never received a disability grant were significantly more likely to complete the substance rehabilitation programme (Dreyer, Pooe, Dzikiti, & Krüger, 2020). Re-instatements of disability grant has also been cited as a reason given by patients for their non-compliance with psychiatric treatment in a rural district of South Africa (Sharif, Ogunbanjo, & Malete, 2003). The relationship between mental health, substance use rehabilitation and disability support requires further exploration.

2.9.4 Sequelae of cash transfer in South Africa

In South Africa, there is some evidence that cash transfers not only meet the primary effect of poverty alleviation but that it can have downstream consequences such as enabling women to exercise assertive control over resources, contributing to the exit from abusive intimate partnerships (Chagunda, 2019). Cash transfers in the form of disability grant specifically has more far-reaching consequences than for the individual who receives it, and impacts dynamics in the households where the recipients reside. Kelly (2019) draws from two qualitative studies on disability grants in the Western Cape province of South Africa and shows how grant recipients' familial support, household compositions, and economic stability can be influenced by the access to, or exclusion from the disability grant. Kelly (2019) demonstrates that grant recipients in households share these financial resources with those who are not employed and that periods of temporary grant lapse require loans to be made, with long-term financial impact. The dynamic of pathological interpersonal interactions in these households is alluded to. With the 'incentivisation' of disablement to ensure continuance of disability grant receipt and economic survival, the health and wellness recovery of the individual is compromised (Kelly, 2019). It may be necessary to determine whether this encourages the 'performance' of disablement that leads to medical help-seeking, in order to mitigate what Tumbo (2008) argues is a social and economic system issue.

2.9.5 Psychiatric Applications for the Disability Grant

In South Africa, psychiatrists report increasing pressure to support disability grant applications for patients with psychiatric conditions, with depression, anxiety and post-traumatic stress disorders, the most listed diagnoses for which disability grant applications are made (Mokoka et al., 2012; South African Society of Psychiatrists (SASOP), 2017). Mokoka et al (2012, p. 1) report that "personality disorders are not usually regarded as a cause of permanent disability on their own". This is despite the fact that the DSM has done away with the axial classification system, in part to give credence to and encourage engagement with personality pathology as a significant mental health problem on its own.

The South African Society of Psychiatrists (South African Society of Psychiatrists (SASOP), 2017) has established guidelines to assist with disability assessments, with the aim that the impact of the disorder on a patient's occupational and social functioning should be assessed. Two of its stated objectives in forwarding these guidelines is to:

- "Relieve pressure on the treating psychiatrist/patient relationship", and
- "Prevent patients from being labelled prematurely as disabled" (SASOP, 2017, p. 4).

As psychiatric disorder does not necessarily lead to permanent disability, severity of functional impairment should be assessed to determine whether impairment is permanent, rather than assessing the permanence of the psychiatric condition. The document distinguishes between disability and impairment in the following way:

"Disability is the alteration of capability to meet personal, social or occupational demands due to impairment and is assessed by non-medical means. Impairment is the alteration of normal functional capacity due to a disease, and is assessed by medical means after a diagnosis has been established, and appropriate and optimal treatment applied" (SASOP, 2017, p. 7).

Thus, we see that that the psychiatric assessment of impairment on a continuum may not coincide with the DSD language of present or absent disability inherent in the ideas of temporary and permanent grants. There is no engagement with levels of severity of impaired functioning in DSD assessments of psychiatric disability. Rather DSD requires an assessment of whether the *medical condition* has stabilized, worsened, or improved. For patients with personality pathology, functioning across work and other domains of living may be affected differently. How these two approaches marry to produce an assessment outcome is unclear and these incongruent concepts may be confusing to both the patient-recipient and the clinician. Further, in psychiatric assessment, disability is observed as an outcome of impairment (once impairment has been established through medical means); and non-medical assessments to determine disability should be assisted through services adjunctive to psychiatry (namely, psychometrists, psychologists or occupational therapists). When employed patients attempt to access private insurance funds for medical boarding based on psychiatric reasons, assessment reports by a psychiatrist, as well as the adjunctive health disciplines, are mandatory. Within the public health setting in which this study takes place, psychiatrists undertake a dual role of treating the mental health condition of the patient applicant and then assessing the applicant on behalf of the SASSA for completion of the disability grant application forms. Thus, the treating psychiatrist acts as proxy for all disciplines in the completion of disability grant application forms. In the absence of adjunctive services' contribution to this process there exist queries regarding the rehabilitation of personality disordered individuals. It is unclear why psychiatrists in this setting have taken on this dual role, as it may not be the norm in other provinces in South Africa (Robertson, 2023) and the question did not fall within the scope of investigation for this study. Nevertheless, it is likely that this overall responsibility-taking and dual role likely increases confusion and hesitancy that is arguably already endemic to disability grant applications for this group of patients because of difficult interpersonal engagements.

2.9.6 South African Clinician Perspectives

Doctors' subjective perspectives about disability grant applications may impact the outcome, and forms part of the experience for the patient. A qualitative study using free attitude interviews was conducted to explore factors that influenced doctors in the assessment of applicants for disability grant receipt (Tumbo, 2008). Content analysis identified themes in the areas that positively and negatively affected doctors' assessments. It was found that subjective experiences such the 'mood' of the doctor influenced the assessment, as well as personal judgements that the disability grant promoted unhelpful social habits in the community. There was evidence that doctors were biased in favour of patients with mental illness because patients suffered stigma due to the condition (Tumbo, 2008). The practice of disability grant assessments was also viewed as undesirable work for clinicians, particularly as they felt inadequately trained to perform this function. Tumbo (2008, p. 65c) suggests that this is so as disability is a legal and social problem that requires action in these areas, rather than the "medicalisation of social problems".

Some of these difficulties have been elucidated by Kelly (2017) in exploring the contested terrain of doctor-patient interactions in the assessment for disability grants in physical health presentations. Observations of these interactions in communities of high poverty in the Western Cape province point to how concepts of employability, unemployment and disability are engaged by different role players (Kelly, 2017). Patient confusion about which types of physical illnesses qualify one for a disability grant is shown to be present. In interviews with doctors, subjective biases also affected decision-making in the application process; that "the individual characteristics and behaviour of claimants strongly influenced how doctors perceived and treated them" (Kelly, 2017, p. 113). It can be argued that this response to patient characteristics has greater salience where the interaction occurs with patients who have personality pathology, possibly contributing to greater contestation around access to disability grant support and the gate-keeping thereof. Both Tumbo (2008) and Kelly (2017) point to the contestation and dissatisfaction arising from the gate-keeping role that has devolved from the SASSA official to treating clinicians (having arisen from calls for stricter implementation of social support in the post-apartheid era). However, economic and political changes that have happened globally and locally due to the impact of the SARS-CoV-2 pandemic since 2020 has encouraged a greater inclusivity in the disbursement of governments' social support strategies, and clinicians' role as gatekeepers might be contested as both inappropriate and increasingly burdensome.

The review of the literature implicates impaired personality functioning in impaired psychosocial functioning, making a case for disability grant access during the course of illness. Psychiatric disability, however, is a conflicted terrain for clinicians and patients. Systemic and procedural difficulties as well as personal attitudes might act as barriers for clinicians as gate-keepers to access, while access might also have negative sequelae for patients.

CHAPTER 3 METHOD: MULTI-METHOD

3.1 Setting

The broader setting of the study is the Western Cape Government, Department of Health (WCG DoH) adult psychiatric service. The study was conducted at Ward 1, Valkenberg Hospital, a tertiary psychiatric hospital in the Western Cape province of South Africa. Ward 1 is a 10-bedded, mixed-gender use inpatient unit, offering a 4-week psychotherapy programme to voluntary patients. Patients stay on the ward for 4 days of the week and engage in group therapy to acquire emotional, cognitive, behavioural and communication skills which are generalised on weekends at home. Referrals are made from district and primary health care facilities that drain from an urban and rural catchment area. The unit also accepts referrals from the pre-discharge wards at the hospital and from private practitioners. In a 2004 study (n = 60), the most prevalent disorders in this population were major depressive disorders (68.3 %), followed by any anxiety disorder (41.7 %). Personality disorder or traits were diagnosed comorbidly in as many as 85 % (n = 51) of the total sample (Joska, 2004).

3.2 Research Design

A multi-method approach was used to investigate the interface between personality pathology and disability grant support use. The use of multiple sources of data aimed to give an inclusive account of experiences of central participants (patients and clinicians) in the process of making disability grant applications (Creswell & Creswell, 2018). For a relatively new phenomenon of study in the South African context, a multi-method design allowed the integration of quantitative and qualitative data, for triangulation of data from each method and for complementarity – offering alternative insights into the phenomenon of disability grant use, and patient and clinician perspectives of access and use (Driessnack, Sousa, & Mendes, 2007). There were three stages of data collection and analysis: file reviews, semi-structured qualitative interviews, and a clinician survey.

3.3 Participants

For the first stage of this study, patients who had been discharged from Ward 1 were the target population. The age criterion for admission to Ward 1 is 18 to 60 years. Files of these patients admitted to the Ward 1 programme from January 2018 to December 2019 were included in the study regardless of language, socio-economic background, or whether they completed the 4-week programme. For the second stage, the patient files that showed evidence of disability grant receipt for a psychiatric reason, and of personality pathology (disorder or traits) were identified and sampled for qualitative data collection. Psychiatrists and psychiatry registrars employed in the WCG DoH were participants in an online survey for the third stage of data collection.

3.4 Procedure

3.4.1 File Reviews

A retrospective file review of patients admitted to Ward 1 over the period 2018 and 2019, was conducted. The expected number of files for review was two hundred. All files were expected to include a psychiatric history-taking sheet that would contain information about a personality disorder diagnosis or about disordered personality traits. Diagnoses were recorded in patient clinical records after an intake clerk (duration of approximately 2 – 3 hours) and presented to the Ward 1 clinical round, at which the patient was interviewed by the consultant psychiatrist with input from the multidisciplinary team (MDT). If changes in diagnoses were made during the patients' stay, these were indicated in the clinical discharge plan. Patients' employment and disability grant status were routinely recorded in the hospital admission sheet, and available in the file. The purpose of the file review was (1) to report on the Ward 1 patient population and identify patients with both personality pathology (either disorder or traits) and disability grant support; (2) to collect information regarding demographics, course and evaluation of disability support; (3) to identify common themes for possible exploration in semi-structured patient interviews and in a clinician survey; and (4) to identify and recruit participants into the second stage of data collection through purposive sampling.

3.4.1.1 Procedure

The researcher coordinated and implemented the file review. A Microsoft Excel (MicrosoftCorporation, 2018) code book for data extraction from patient files was developed that included demographic data, psychiatric diagnoses, and number of hospital admissions (see Appendix 1: Information from File Review attached). Input and consensus were sought from members of the research team for the final code book. The researcher kept a database and liaised with administrative support staff at Valkenberg hospital regarding logistical arrangements for receipt, safe-keeping and return of confidential patient files. A research assistant (Masters graduate in Clinical Psychology) was appointed, who received training in the code book, to review patient files. The research assistant signed a confidentiality agreement and was paid an hourly rate for their work through a research fund in the researcher's name, administered by the University of Cape Town.

i. The research assistant reviewed patient files in a private office in the Psychology department at Valkenberg hospital. Patient information of interest was extracted directly into the Microsoft Excel (MicrosoftCorporation, 2018) database on a password-protected laptop. A list linking the patient's unique code to a patient identifier was kept separately in a lockable cabinet of the researcher, if data needed to be verified.

ii. A pilot was conducted, with the researcher and research assistant each coding the same ten (10) folders. When there were discrepancies in coding, the rationale for coding was discussed and consensus reached on how to proceed with coding. During this pilot the researcher also reviewed files for themes of interest that might be included in the clinician survey protocol.

iii. The researcher met with the research assistant at the end of each day to discuss confusing file entries and to discuss and agree on coding queries that might have arisen over the course of the day's data collection.

3.4.1.2 Analysis

i. Data was checked by the researcher and cross-checked by another member of the research team. Data was exported to and analysed using IBM SPSS Statistics for Windows, version 26 (IBM, 2019).

ii. Statistical analysis of the demographic data and variables of interest was done. Calculation of basic frequency distributions and descriptive statistics (table 1) for continuous and categorical variables to characterise the patient sample was done. The associations between demographic variables, personality disorder, sex, substance use and the receipt of a disability grant were determined using Chi-squared and Fischer's exact test where appropriate. Two-tailed tests with a significance level of 0.05 were used throughout. The objective was to describe access to the disability grant.

3.4.2 Semi-structured qualitative interviews

Based on clinical experience and a review of existing knowledge in the area, a semi-structured patient interview schedule was developed to explore and obtain descriptions of patient experience and to confirm demographic information retrieved from the file review. It included prompts to probe identified areas of interest for the research being undertaken. All members of the research team reviewed and gave input to the interview protocol. The expected number of patient interviews were 15-20, or until thematic saturation occurred.

The semi-structured interviews were used to gather information on (1) course of disability grant utilisation, including first access, context for periods of disability grant lapse and renewal; (2) patient understanding of the impact of their personality functioning on disability grant use; (3) possible barriers to access of the disability grant; and (4) the impact of disability support on patient economic and psychosocial health and well-being.

3.4.2.1 Procedure

All patients who were included in the file review were sampled for having both a personality disorder diagnosis or pathological personality traits, and for being in receipt of a state-issued disability grant for a psychiatric disorder. Participants excluded from the interviews were those who received a disability grant for a medical condition, with cognitive impairment and intellectual disability as evidenced in the file review, or whom upon contact were experiencing a current episode of acute illness, or who refused consent.

The researcher telephonically contacted eligible participants to introduce and discuss the rationale for the research, confirm their eligibility and explain what study participation entailed, for recruitment into the face-to-face individual interviews. They were informed that the researcher, a clinical psychologist at Ward 1 with experience in treating patients with personality pathology, would be conducting the 60-90-minute interview in English. The intended use of the research results and access to the research data was described. Principles of ethics and confidentiality, voluntary participation, and that no negative consequences would accrue with non-participation, were discussed telephonically. The researcher answered any questions asked. Prospective participants were informed that individual interviews would happen at the Valkenberg hospital outpatient department, whilst maintaining all Covid-19 pandemic lockdown regulations at the time, namely mandatory screening on arrival, mask-wearing, social distancing, and hand-sanitizing. Prospective participants were informed they would be reimbursed for their travelling expense. They were informed of the intended use of audio recording and that signed consent for this would be sought at the interview (see Appendices 2 and 3: Patient Informed Consent Form and Patient Semi-structured Interview attached).

3.4.2.2 Analysis

Participant interviews lasted between 40 to 90 minutes. Demographic data extracted from the file review was confirmed in the interview. Verbatim transcription of participant interview recordings was outsourced to an independent provider approved by the Centre for Public Mental Health, UCT, who signed a confidentiality agreement.

A Framework Analysis method was used to make sense of participant data with the use of existing theory. Commonalities and differences in the qualitative set of data were identified. This method is commonly used for analysis of semi-structured interview transcripts and thus where the data is expected to cover similar key issues (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Theme selection took a deductive approach, given that there were specific questions under investigation and that a knowledge base already existed. However, there was room to discover unexpected information or 'emergent themes' about participant experiences, and codes were assigned to this new or unexpected data. This is in keeping with the contention that a framework analysis approach is not aligned to a particular epistemological approach and that both a deductive and inductive approach, or a combination of both, can be used (Gale et al., 2013; Goldsmith, 2021).

Following Framework Analysis, the following steps were taken to analyse data:

i. Early in data collection, the researcher deviated from the interview protocol by including a description of personality disorder. This was necessary as it was participant-led and arose from participant reluctance to claim knowledge of personality disorder as a diagnosis. There was a subsequent request that the researcher explain this, and the researcher made room for this in a non-threatening manner, to facilitate acceptability for the participant. The researcher's stance to maintain focus but also introduce flexibility was given credibility by their experience with personality disorder and with the interview protocol and the aims for research; and may not have been achievable by a research assistant without this experience. Reflexivity around this, and in consultation with research team members, resulted in this change being deemed appropriate. Once the change was made the researcher was consistent in assessing participant understanding of a personality disorder diagnosis in subsequent interviews, thereby increasing the dependability of the data and for transferability of ideas in this area (Forero et al., 2018).
ii. Once the interviews were transcribed, the researcher familiarised herself with interview material by reading through the transcripts line by line, and relistening to parts of the interviews that were unintelligible. A sample of the transcribed interviews was read by the research team, whilst the researcher prepared for subsequent interviews This was done to identify and include emerging and relevant themes for exploration in future interviews, and to ensure trustworthiness of the data.
iii. NVivo12 software was used to store and organise data from the interviews (QSR, 2018). The researcher and another member of the research team coded four (4) transcripts independently to reach agreement on codes for continued coding of subsequent transcripts.
iv. Coders met to review coding of the transcripts. During these meetings:
    a. Different words used to describe the same idea were standardised.
    b. Reflexivity was used to discuss contested coding names and modified after agreement was reached.

    c. Where difference in coding concepts occurred, coders reviewed the transcript to understand the material in the context of the interview discussion. Inter-coder consensus was reached through discussion, increasing reliability and confirmability of findings.
    d. The calculation of an inter-coder reliability coefficient was not done because of the small sample size. Reliability was achieved through reaching consensus. This coding framework was applied to analysis of further transcripts. The analytical framework remained open until the last transcript was coded to include any new, emergent findings.

v. Participant interviews were capped at ten (10), after determining by sampled reading of interview transcripts, discussion and analysis between research team members, that data saturation had been reached.

vi. The researcher used the NVivo software to select data and charted this into themes and sub-themes in a Microsoft Word document. This was possible to do as interpretation of the data occurred as an organic part of the process, with possible themes identified during the data collection phase, during reflexive coding meetings and in review of drafts by the research team. Where it was useful to do so, diversity within themes as well as frequency of themes was captured within sub-themes.

3.4.3 Clinician Survey

Themes that emerged from file reviews, patient interviews and literature in the area was used to inform the development of the clinician survey about opinions and beliefs that act as barriers and facilitators to supporting disability grant applications for patients with personality pathology. Clinicians sampled into the survey were psychiatrists and psychiatry registrars working in adult psychiatric services and were employed in the WCG DoH at the time of data collection in 2021 and 2022. A ten-minute (10) web-based survey using Google Forms was developed by the researcher. This was reviewed and members of the research team gave input into item construction and suggested items. Clinician respondents endorsed opinions on a 5-point Likert scale. Information was elicited under the following areas: experience of working with patients with personality pathology, clinical and mental health system factors that impacted disability grant assessment for disability grant applications, clinician and patient interpersonal interaction around disability grant applications, and clinicians' own personality, beliefs and values. Clinicians were asked to rate levels of agreement to statements using "Mostly Agree", "Somewhat Disagree", "Neutral", "Somewhat Agree" and "Mostly Agree". Information on clinician-identified needs that will assist clinician confidence in making disability grant applications for patients with personality pathology was also gathered with free text response options.

3.4.3.1 Procedure

The Strategy and Health Support office in the Directorate: Health Intelligence of the WCG DoH liaised with state-owned health facilities including day hospitals, district clinics, the central hospital and specialised psychiatric hospitals within the catchment area, to facilitate information-giving about, and seek participation in the project. Identified liaisons at these facilities included chief executive officers, medical managers, and human resource management, who either gave access by providing clinician email addresses to distribute the survey, or who distributed the survey to staff themselves. Respondents received information about the project and consent for participation electronically, and completed the 10 - 15-minute survey, which was returned anonymously and confidentially (see Appendices 4 and 5: Clinician Consent Form and Clinician Survey). Demographic data including age and sex, and information regarding work experience, including work with personality disorders was sought.

3.4.3.2 Analysis

For the clinician survey, basic descriptive statistics were calculated for demographics, work experience and experience in working with personality disorder. Descriptive statistics were also used to indicate endorsements of items regarding opinions and beliefs about working with patients with personality disorder and their access to the disability grant. Free responses were reported on qualitatively.

3.5 Data management

Qualitative and quantitative data was collected and analysed with SPSS, Nvivo and Microsoft Excel software. These files were uploaded to the researcher’s password-protected OneDrive account on the UCT network. All data was anonymised. Access was given to supervisors when requested. Confidentiality of patient participants was assured by assigning all participants a unique numerical code instead of the patients’ name or folder number. Both qualitative and quantitative data are kept in safe-keeping, separate from identifying data, on a password-protected laptop and a University of Cape Town desktop computer. Participants were informed of who will have access to the data, namely the supervisors, transcriber, data capturers and analysts.

3.6 Ethical and legal considerations

This study is adherent to the ethical principles of the Declaration of Helsinki for conducting research with human subjects ("World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," 2013), and is applicable to both patient and clinician participants. The Health Sciences Faculty Human Research Ethics Committee at the University of Cape Town (UCT) approved the study (HREC REF: 609/2020). The research project was located within the Western Cape Province Department of Health and registered as WC_202101_022. Approval from the Department of Health to conduct the study with clinicians employed by the state and with patients accessing state health services, was gained. The Ethics Committee at Valkenberg Hospital gave permission to access patient files, and to contact and conduct patient interviews on Valkenberg hospital premises.

3.6.1 Informed Consent, Voluntary Participation and Refusal to Participate

The researcher contacted all potential patient participants sampled from the file review. The study was described, and potential participants were given information about what participation would entail, the time demands, and that they would receive monetary compensation for their travel expenses to attend the individual interview. At the individual interviews the researcher again offered a description of the study, discussed voluntary participation and that participants would still receive compensation should they choose non-participation, at any point. Participants were informed of any risks or benefits to participation or non-participation, and reassurance given that no negative consequences would be accrued should they refuse to participate in the study or withdraw at any point. Participants were informed of the intended management of data for the study, and the use of data by those beyond the research team should other researchers request the data in the future. All participants were given the contact details of the principal investigator, supervisors and UCT Research Ethics Committee, should they wish to raise ethical concerns, or have follow-up questions about the research. Clinicians participating in the web-based survey were given information about the nature of the study and its confidential and anonymous nature. An item on the survey required clinician respondents to indicate their understanding of this, in order to proceed with completing the survey.

3.6.2 Dual Relationships

Reflexivity was engaged around the role of the interviewer researcher who had previously been involved in the treatment of interview participants as a group facilitator or individual case manager, whilst they attended the Ward 1 programme. In discussion with research supervisors, it was felt that the researcher would be best placed to conduct the interviews as it would more likely encourage openness. Anyone sampled into this stage of data collection and currently in treatment with the researcher would be approached by another member of the team should they not also concurrently be in treatment with them. None of the participants were in psychotherapy treatment with the researcher at the time of the interview. Participants were encouraged to voice any concerns they may have had to being interviewed, due to a prior relationship. If they considered that their participation would be constrained by this, they would have been given the option of being interviewed by another member of the research team. No participants voiced this concern. Prior relationship with the researcher might also have confounded the data if the participant was not explicit in the discussion, due to an assumption of knowledge by the researcher. However, it was considered that a prior relationship would encourage ease, and that the researcher's clinical experience would facilitate richer discussion than employing a trainee to conduct patient interviews.

3.6.3 Privacy and Confidentiality

The researcher conducted one-on-one interviews with participants in a consulting office at the Outpatient department at Valkenberg hospital. Confidentiality of data is described under Data Management (Section 3.5)

3.6.4 Mandatory Reporting

At the start of the interview, all participants were informed about the duty of a health care provider to report acts of abuse against a child, and to take steps to intervene if suicidality or homicidality was reported. The researcher informed each participant of the possibility of contacting their case manager, treating team or social services if such a need arose.

3.6.5 Risks and Benefits

It was considered that participants might experience distress during the data-gathering process, whilst recalling difficulties of functioning. In this event, the researcher would offer the participant containment, which could include taking a break, rescheduling the interview, or the possibility of withdrawing participation. Participants might also have reported current suicidal or homicidal ideation during the interview. Further assessment of intention to act would have been done, containment offered, and referral made for further support if this was not already in place. All these risks were discussed with each participant before commencing data collection.

3.6.6 Compensation

Each participant who arrived for the interview received compensation of one hundred and fifty rand for transport and costs incurred to attend the interview. This was done before the interview commenced, to address any preoccupation about financial outlay.

CHAPTER 4 RESULTS

4.1 Quantitative Findings: File Review

4.1.1 Characteristics of the sample

The file review of patients admitted to Ward 1 in 2018 and 2019 produced valid data for n = 237 patients. Quantitative findings below are given for socio-demographic and for clinical demographics of the sample.

4.1.1.1 Socio-demographic information

Information about age, gender, marital status, number of children, level of education attained, and employment at the time of admission was gathered and represented in Table 1. The mean age of patients on admission was 36.4 (SD = 11.6), with the lowest age of 18 and the highest 62. The age category of 26 to 40 represented most patients' age at time of admission, followed by the age category above 40 years. 18 - to 25 - year-olds was the category that presented for admission least. Female sex accounted for the majority of admissions. It is unlikely that all patients identified in a binary way. While other categories were available to code data on gender, information about sex was extracted from the clerking admission form, rather than from a patient gender-identifying narrative likely available later in the file, and thus might not represent all patient identifications. Patients who were single and/or widowed at the time of admission comprised 43.9 % and those who were married or in a partnership at the time of admission 43.0 % of the sample. Patients who were divorced accounted for 11.8 % of the sample. Nearly half of patients did not have children, and of those who did most had 2 children. Patients admitted to Ward 1 were categorised nearly equally into the three areas of education achievement; having completed 7 or fewer years of primary school education, or having completed high school, or completed a tertiary level of education. A smaller percentage of the sample had completed matric and were engaged with some form of ongoing training at the time of admission. This smaller group reflects the lower admission rates of patients in the 18 – 25 - year-old category. Most patients were unemployed at the time of admission to Ward 1, some reported formal employment, whilst the least were involved in informal employment. Patients were mostly living with members of family of origin. Thereafter, most lived with a spouse or romantic/life partner, then alone. Those in a community living arrangement, such as with a friend, in a group home or in a shelter formed the smallest group. A quarter of patients admitted to Ward 1 had access to disability benefits through current receipt, through having made an application and were awaiting the outcome, were in the process of applying, or were engaged in discussions with their doctor or employer about applying for disability benefits. The state-issued disability grant had been accessed by 53 patients, accounting as the source for most disability benefit pay-outs, with 6 patients receiving pay-outs from the private sector (previous work or personal insurance).

Table 1: Socio-demographic information for Ward 1 patients 2018 and 2019

	Total	**N**	**%**
Age	**237**		
18 – 25		54	22.8
26 – 40		100	42.2
40 +		83	35.0
Sex	**237**		
Female		174	73
Male		63	27
Marital Status	**234***		
Single or widowed		104	43.9
Married or partnership		102	43.0
Divorced		28	11.8
Number of children	**234****		
0		114	48.1
1		41	17.3
2		45	19.0
3		27	11.4
4		6	2.5
9		1	4
Level of Education	**231*****		
Primary school or less		65	27.4
High school		66	27.8
Tertiary education		73	30.8
Matric & ongoing training		27	11.4
Employment	**236******		
Unemployed		174	73.4
Informally employed		19	8.0
Formally employed		43	18.1
Living arrangements	**235*******		
Alone		35	14.8
Spouse or partner		62	26.2
Family		112	47.3
Friend, group or shelter		26	11.0
Disability grant access	**237**		
No access		178	75.1
All access		59	24.9
Disability grant source	**59**		
State-issued		53	89.8
Private		6	10.2

*Missing data for Marital status: n = 3, 1.3 %
**Missing data for Number of children: n = 3, 1.3 %
*** Missing data for Level of education: n = 6, 2.5 %
****Missing data for Employment: n =1, 0.4 %
*****Missing data for Living arrangements: n = 2, 0.8 %

4.1.1.2 Clinical characteristics of the sample

Information about psychiatric diagnoses, personality pathology, substance use, number of diagnoses and previous therapeutic admissions was extracted and represented in Table 2. Frequency of psychiatric diagnosis is represented as count and percentage of times it occurred, regardless of whether it was the primary or comorbid diagnosis. A personality disorder diagnosis was made in half of the sample (n = 122, 51.5 %). The personality diagnosis that was most given was Borderline personality disorder (n = 68, 28.7 % of all 2018 - 2019 admissions), followed by Personality disorder not otherwise specified / Mixed personality (n = 39, 16.5 %). Mostly women received the personality disorder diagnosis. Thirty-seven per cent (n= 88, 37.1 %) of the sample did not have a historical or current problem of disordered substance use. In those who did, polysubstance was the category of most disordered use, followed by alcohol and cannabis. Of the 237 patients' files reviewed, nearly half had been assigned two psychiatric diagnoses (n = 115, 48.5%). Frequency counts for number of previous therapeutic admissions to Ward 1 showed that most patients were new to the service (n = 203, 85.7 %). This is in keeping with ensuring the opportunity to access for all who need the service.

Table 2: Patient clinical characteristics

	Total	**N**	**%**
Psychiatric diagnoses	**237**		**100**
Any personality disorder or traits		189	79.7
Any substance use disorder		149	62.9
Depressive disorder		88	37.1
Any anxiety disorder		62	26.2
Generalised anxiety disorder		38	16
Bipolar disorder		36	15.2
Post-traumatic stress disorder		35	14.8
Schizophrenia spectrum disorder		18	7.6
Social anxiety disorder		18	7.6
Panic disorder		15	6.3
Neurodevelopmental disorder		10	4.2
Impulse control disorder		9	3.8
Eating disorder		8	3.4
Neurocognitive disorder		5	2.1
Personality disorder diagnosis	**122***		**51.5**
Schizotypal		2	0.8
Schizoid		2	0.8
Borderline		68	28.7
Antisocial		2	0.8
Avoidant		5	2.1
Obsessive-compulsive		1	0.4
Dependent		3	1.3
Personality NOS/Mixed		39	16.5
Substance use	**149****		**62.9**
Alcohol		35	14.8
Cannabis		20	8.4
Sedatives		3	1.3
Stimulants		1	0.4
Poly-drug		88	37
Over-the-counter drugs		2	0.8
Number of psychiatric diagnoses	**237**		**100**
1		53	22.4
2		115	48.5
3		60	25.3
4		7	3.0
5		2	0.8
Number of previous Ward 1 admissions	**236*****		**99.6**
0		203	85.7
1		28	11.8
2		4	1.7
3		1	0.4

*No personality disorder diagnosis in n = 115 of sample, 48.5 %

** No substance use history in n = 88 of sample, 37.1 %

*** Missing data for Number of previous ward admissions: n = 1, 0.4 %

4.1.2 Correlates of disability grant support utilisation

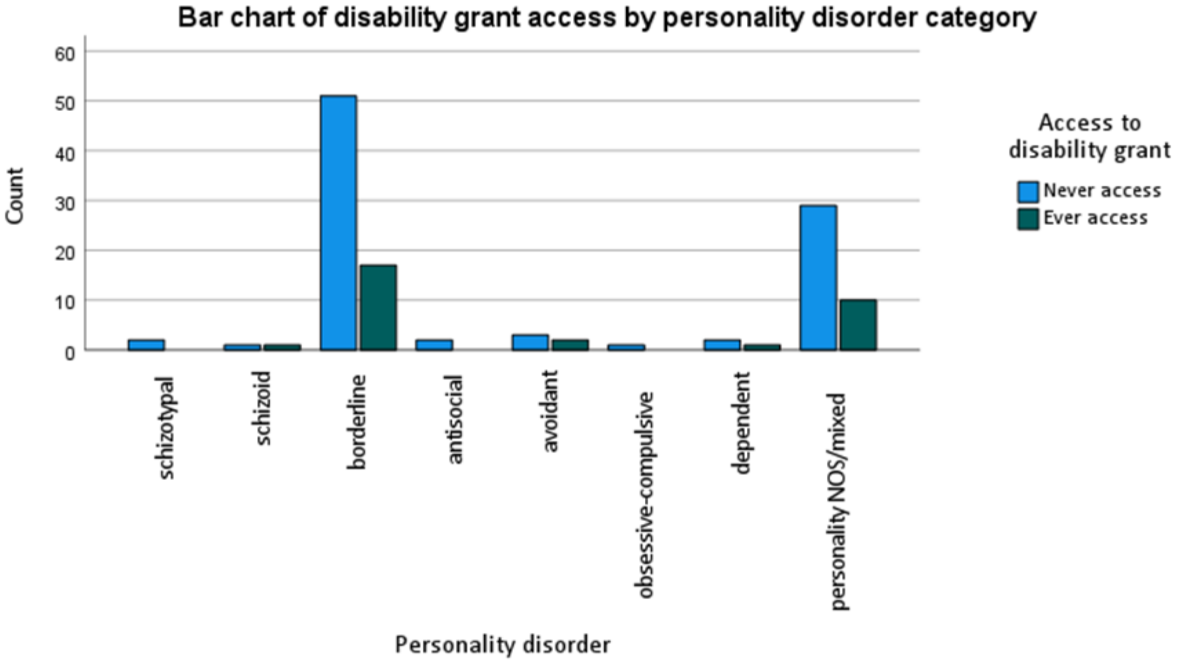
4.1.2.1. Association between sex, and disability grant access

Fourty-six women (n = 46, 78.0 %) and 13 men (22.0 %) with access to the disability support. However, the difference between sex was not statistically significant (χ^2 = .833 (df=1), p= 0.361).

4.1.2.2 Association between different personality disorder diagnoses and disability grant access

Of those patients with a personality disorder (n = 122, 51.5 %), only a quarter reported accessing the disability grant (n = 31, 25.4 %), while most did not (n = 91, 74.6 %). This included current or past access or being in the process of making and awaiting application outcomes or planning with their employer or doctor about gaining access. This means that of all patients with access to disability benefits in 2018 and 2019 (n=59), over half of the disability grants were accessed by patients with a personality disorder (n = 31, 52.5 %).

Chart 1: Bar chart representing patients per personality disorder category and their access to the disability grant



The relationship between type of personality disorder diagnosis and disability grant access was explored in the subsample of patients with a PD diagnosis (n=122). Using Fisher's exact test, there was no statistically significant association between type of personality disorder diagnosis and disability grant access (Fisher's Exact test, p = .896).

4.1.2.3. Substance use association with disability grant support and personality disorder

The relationship between any substance use history and access to disability support was explored. A significant positive association between any substance use history and access to disability support was found ($\chi^2 = 4.86$, df=1, p=0.027). However, when stratifying on the variable of personality disorder the association between substance use and disability grant support was no longer significant in both the personality disorder group (n=122; $\chi^2 = 3.56$, df=1, p=0.059) and for the group without personality disorder (n=115, $\chi^2 = 1.82$, df=1, p=0.177). The association in the personality disorder group between substance use history and disability grant access approached significance, indicating some heterogeneity between subgroup with and without personality disorder.

4.2 Qualitative Findings: Patient Interviews

Ten (10) patient participants were recruited for the semi-structured interview phase of data collection. During recruitment two lists of patients were generated; one of patients who had a personality disorder diagnosis and another of those with pathological personality traits but who did not meet all criteria for a specific PD. This was done so that the researcher would remain aware of this as possible proxy for the inclusion of diagnostically more or less impaired individuals in data collection. In doing so it was noted that more individuals with a personality disorder diagnosis were uncontactable than those with pathological personality traits. Consequently, more individuals with pathological personality traits and not a specific personality disorder were interviewed than those with a personality disorder diagnosis. This might describe a tendency in the diagnosed group to experience ambivalence about their contact with others, and render themselves unavailable to interpersonal contact, particularly at times of increased stress (Ferguson, 2016). Relationships with health care providers might be managed in a similar way, although it is not certain that prospective participants would have recognised the contact attempt from the hospital telephone number. Should the diagnosis be indicative of greater impaired interpersonal functioning, it would be necessary to speculate on those individuals' poorer motivation and agency to stay in relation to and access state support generally, including the disability grant. Analysis of interviews that resulted in themes are categorised as findings in areas of focus. Other themes are categorised under emergent findings in that they were not a priori an area of focus for the semi-structured interview.

The findings as themes are represented in the table below and described thereafter:

Table 3: Themes emergent from patient interviews

Findings in areas of focus			
Theme 1:	**Knowledge and beliefs**		
	Subthemes:	Pathway to knowledge about personality disorder	
		Personality disorder and eligibility for the disability grant	
Theme 2:	**Course and access to the disability grant**		
	Subthemes:	Impaired functioning	
		Attempts at re-engaging employment	
		Negotiating access to the disability grant	
		Personality style and negotiating access to the disability grant	
		Reasons given for disability grant re-application	
Theme 3:	**Barriers to accessing the disability grant**		
	Subthemes:	Engagement with health professionals	Questioning validity of need in the absence of visible disability
			Avoidance or stonewalling
			Judgements and dissonance with self-concept
		Experience of SASSA administration exercising illegitimate control	
		Disability grant lapse	Bureaucratic difficulties/barriers
			Impact of the covid-19 pandemic and inaccessible human resources
			Emotional impact of disability grant lapse
		Stigma as accompanying narrative in accessing the disability grant	Receipt of disability grant for mental illness
			Economic demand and the stigma of laziness
			Internalised stigma
Theme 4:	**Psychosocial impact of disability grant**		
	Subthemes:	Disability grant pay-out too little	
		Economic survival and role maintenance	
		Role maintenance, self-concept and mental health	
Theme 5:	**Negotiating barriers and recovery from disability grant lapse**		
	Subthemes:	Goodwill arrangements	
		Financial interdependence	
		Relationship with mental health professionals	Doctors' dual role
			Noticing positively experienced characteristics of assessing doctor
			Sensitisation to impairment and responsiveness
		Withdrawal from interpersonal interactions	
		Cognitive strategies to deal with stigma	
Theme 6:	**Participant service needs**		
	Subthemes:	Mental health interventions at community level	
		Accessible psychological interventions	
		Multidisciplinary psychosocial interventions	
		Vocational needs	
		Individualised financial need assessment	
		Raising of income threshold	
Unexpected emergent findings			
Theme 1:	**Engagement with personality disorder diagnosis**		
Theme 2:	**Getting knowledge about processes**		
Theme 3:	**Suspicion of marginalisation**		
Theme 4:	**Research participation contributes to motivation and self-esteem**		

4.2.1 Findings in Area of Focus

4.2.1.1. Knowledge and beliefs

4.2.1.1.1. Pathway to knowledge about personality disorder

A domain of interest was the knowledge held by participants about their psychiatric diagnosis, inclusive of a personality disorder diagnosis. All 10 participants were able to share their axis 1 diagnoses. Where participants excluded their personality disorder diagnosis or pathological personality traits, they were prompted, and they acknowledged prior awareness. This was the case in all except one instance; **Participant C,** a fourty-two-year-old male who cited significant difficulty with anxiety and depression, and who denied a personality disorder diagnosis. Few participants claimed to understand the personality disorder diagnosis, with outright requests to have it explained, some gave neurobiological explanations for its cause, and others describing specific traits that earmark the presentation.

Recalling first being diagnosed with personality disorder or discussion of pathological traits, participants reported minimal engagement at the time. Following clinician introduction, robust engagement only came when individuals started seeking information, through social media in the form of online searches and YouTube videos (**Participant F**), and through reflection on their own experience. Education was a process that participants had needed to engage with on their own terms over time, whilst for some there had been no further exploration of the diagnosis after it had been given. For **Participant J**, a thirty-six-year-old woman who described herself as a "housewife" for the past five years looking after her stepchildren, it appeared that the addition of a personality disorder diagnosis was not as demanding an adjustment, as it had followed an axis 1 diagnosis.

"When Ward 1 told me look it's borderline personality disorder too it didn't affect me that badly. Perhaps I was in a better space. I felt more equipped and I didn't even look into it. …but when I heard Bipolar Type 1 I was reading books. I was researching. I joined groups. I went into it hard. But with borderline I didn't pay too much attention to the label and it didn't affect me really. Now I am learning a bit about it."

Participant J

Prior experience with a psychiatric diagnosis may have played a role in sensitising participants to the fact of mental health challenges that would be ongoing. It is also likely that prior diagnosis may have led to selective attention to information, in order to cope with additional psychiatric labelling that might have felt overwhelming. **Participant J** thought that when she became knowledgeable about the personality disorder diagnosis, it was helpful for understanding her difficulties:

“.. I can see that I have certain traits but the information is good for me. So I can identify certain things that I do and it links up with what borderline personality disorder is… So I use it as information that can benefit me improving myself and handling situations better.”

Participant J

4.2.1.1.2 Personality disorder and eligibility for the disability grant

Participants appeared confident in their assertion that patients should receive a disability grant for a personality disorder. Participants named impaired functioning in the workplace, in interpersonal relationships and in managing household responsibilities as areas of eligibility to receive the disability grant. There appeared to be a recognition and concern for the impact of their impaired functioning in the workplace. This then appeared to support ideas of eligibility. **Participant H** was a forty-eight-year-old mother and wife who had been struggling to overcome bureaucratic difficulties with her grant application and had been without if for nearly six months at the time of the interview. She thought that impaired functioning meant she was viewed as “not normal” for having these difficulties, and therefore appeared to identify with disablement.

“Because first of all you live in a world where a lot of people don’t understand that - why you can’t just live a normal life and juggle three kids and a husband and work and everything else that goes with functioning normal. Which I think handicaps us in a certain way that we are not able to do those things. So I feel that it (a personality disorder) is a disability and that just like any other illness it should be recognised as an illness and not just a phantom theory that comes to mind.”

Participant H

Participant H also appeared to be suggesting the invisible nature of psychiatric disability as an inherent attribute of a personality disorder diagnosis. Society had little knowledge of it and its attendant impairments, whilst reserving the right to impact this group’s access to the support they needed, which was experienced as an impingement.

Participant B, a fifty-nine-year-old female, with a grade six education level, had held various informal positions in family businesses, and described the impact of her impaired personality functioning on others in the workplace as a reason she should receive a disability grant:

“Because why, the next person is a bit scared of you in the workplace. They scared to ask you for something or just to help.”

Descriptions of personality being 'split' suggested that participants noticed their own inconsistent engagement, and that others also noticed this. Participants described the constancy of this inconsistent functioning, namely, that the problem did not go away. This understanding seemed to contribute to one participant's belief that the disability grant for individuals with a personality disorder should be a permanent instatement:

"(I)f you talk about split personalities sometimes it does affect everything. Your work, it does affect your work. … people with personality disorders they are not always capable of being what they should be at their work. So I think they should also be able to qualify for getting a disability grant. And not just a temporary one but a permanent one."

Participant G (forty-eight years old, wife and mother)

Participant F ascribed his disability grant receipt to medical difficulties and identified with a diagnosis of borderline personality disorder, but also thought that impaired functioning due to the disorder should ensure eligibility for the disability grant. Personality disorder was viewed as permanent condition, much like that of an axis 1 disorder.

"Because it's like a schizophrenia. It's something you can't undo. And that is the other thing / realisation that came through; like oh shit this is for life. This isn't going to change. … It's a condition. It's a medical condition. It is not something you can give me a pill and tomorrow it's gone. It's not like the flu or some sort of illness that you can cure. It's cast in stone".

4.2.1.2 Course and access to the disability grant

Self-evaluation, and other- evaluation of functional impairments and the distress attendant to this, appeared to mark the path to a resolution of conflicts in giving up employment and making a disability grant application.

4.2.1.2.1 Impaired Functioning

4.2.1.2.1.1 Identification with impairment in functioning and disability

Participants all reported historical and current impairment in daily functioning, describing their functioning as inconsistent or unstable. This impairment was experienced in previous work environments, in initiating attempts at re-employment, in the completion of tasks of everyday living, and was also experienced in the management of their emotions and being in interpersonal interactions. Five participants believed that functioning in various areas had continued to decline over time.

Participants described the interaction between their inability to perform their job descriptions, interpersonal engagements, and experience of distress around this in a candid manner. These factors contributed to being fired or participants deciding for themselves to leave their employment. **Participant A**, a forty-nine-year-old female who was finishing her matric studies at the time of the interview, had been working as teacher's assistant when she was asked to leave her employment:

"He (my employer) didn't want to say, you're fired. He said that, 'I think you're a bit unstable and I think you can't handle pressure and what do you think?' But I do agree that I cannot handle pressures. Like I said earlier, deadlines and, come time, that's a bit of a issue for me. "

Continuing in employment whilst struggling with functional impairments in occupation was experienced as a conflict that could not be reconciled. **Participant G**, who identified with disablement, started teaching at the age of 17. She first applied for the disability grant at the age of 42, having moved from a mainstream school to teach at a school for children with disability, and experienced a cognitive dissonance that had to be resolved:

"I can't work with a child with a disability because I've got one. … To me it just doesn't feel right. I am supposed to be able to help. How am I supposed to help when I can't help myself?".

Participant H also struggled to reconcile the notion of disability in the work environment and suggested that others in that environment might assign these difficulties to who she was as a whole person:

"I will find it hard to work in an environment that will actually accept me with my disabilities without seeing me as difficult."

4.2.1.2.1.2 Attributions made to personality in impaired work functioning

Participants could describe how their usual personality style was implicated in problems with interpersonal engagement in the workplace. For example, rigidity as a personality trait for **Participant B** with obsessive-compulsive personality disorder put her at odds with her employer (a family member) and, coupled with impairments in impulsivity and affect regulation, resulted in physically violent altercation:

"Yes, because at her place also that I work, everything that she got, everything must be in order then we get argument. I'm very short-tempered. I can take something long but then I burst then I get violent. Because I grabbed her already over the desk".

Participant B,

whilst **Participant A** described difficulties with interpersonal sensitivity:

"So with the teacher that I worked with, he's one of those people; get that, write this, do that and I get nervous. And then obviously he gets irritated, and I don't like it and then the personality clashes comes in",

and that this could impulsively lead to her giving up on her employment:

"During arguments yes, … I do seem to exaggerate. … It never was such a big thing. In fact, that happened with myself with this last boss. He never - didn't mean it like that - and I took it too personally. … that's the time that I don't feel like going back."

Participant A

Participant A identified that a specific personality trait meant that she compromised herself in work situations, and that this contributed to the evaluation of an inability to cope in the work environment:

"I'm very submissive and then at the end of the day I feel taken advantage of. That's a problem"

Participant A

4.2.1.2.2 Attempts at re-engaging employment

Despite the above impairments in work functioning and leaving their employment, participants described continued attempts to engage in 1) planning to re-enter employment, and 2) repeated attempts at employment. However, when employment was gained, it was short-lived, and this presented as a pattern. For example, **Participant I**, a fifty-seven- year-old female, maintained an active role in community-based organisations when she could, but emphasised her struggles with maintaining full-time employment:

"I choose to not work permanently because I always feel when I work permanently I fail. I fail dismally when I work permanently. I fail because I get late to work. I fail because I cannot sit for hours behind a desk, I cannot. I don't know how to explain that to people because people might think that you are lazy. And I am not lazy. I work the whole time but I cannot hold a nine to five job".

Participant I

Participant D, a fifty-year-old female who had qualified and worked as a nurse, described resigning from her post in a government hospital after many absences on sick (mental health-related) leave rather than being fired, as a strategy to ensure future employment opportunities:

"So I thought rather before my debt accumulated and before I lose everything we decided to resign so I can still get my pension and pay off the debt. And then I felt before I get into a situation where they say I am incompetent rather resign before then so I can still go out with a good reputation. And when I am better then I can reapply again but it never happened".

Participant D

However, the inability to re-enter formal employment meant that she, as for many participants, had to consider employment that would accommodate mental health struggles, and even to acquire new skills that would facilitate this:

"It still, it stresses to be… amongst people or going to the interview also. Working with people. So I am looking at employment now like that I can do at home but without interacting with people, like transcribing…",

"I am brushing up on my typing skills and I saw an advert transcribing that they teach you the basic skills. So I thought that would be more ... because I am scared to -. It's difficult. It is very difficult to - I have lost my nerve, I don't know. I don't know it's just it's difficult."

Participant D

For some, identification with disablement appeared necessary to consider accessing the disability grant whilst others circumvented identification with disablement and spoke of accessing the disability grant merely as an option during periods of exacerbated impairment or economic need, with plans to re-engage with vocation in the future. It was not clear that these attempts would result in economic participation. Neither was there evidence that the disability grant resulted in a return to full-time employment. For example, **Participant J**, who had occupied eight different job roles in the past, and wanted to consider employment in the future, had stopped the disability grant as she felt her mental health had improved and that she would be able to start looking for employment. She anticipated that in the future she would study Psychology but had no commitment to a completion date or use of these studies except that it fulfilled a long-held interest.

4.2.1.2.3 Negotiating access to the disability grant

Participants noted that along with mental health professionals, lay persons such as acquaintances or family members were sources of information about the disability grant. Both mental health professionals and participants themselves were able to initiate discussion around the possibility of a disability grant application, in their engagement with each other. Initial applications appeared to be experienced in a straight-forward manner, except for one - **Participant F**, a fifty-three-year-old university graduate - who believed that the doctor did not want to engage with him around this.

First-time applications were a lengthy process, though there appeared to be an acceptance of this, even whilst experiencing uncertainty around how decisions for eligibility were made. This included uncertainty that one could be eligible for a disability grant for a diagnosis that was not a physical health condition. One participant was confused about how they were found eligible on their second attempt even though the first application two months earlier, had been made in a similar manner and rejected:

"I think that whoever is behind the thing is, are they actually taking note of what the paperwork says? Because Dr [Name] wrote the exact same thing down, what he wrote from the first application to the second application. He wrote the exact same things down. Why didn't I qualify the first time? The first time around?"

Participant G

4.2.1.2.4 Personality style and negotiating access to the disability grant

Participants who described their style of interpersonal engagement in the disability grant assessment interview with the health professional appeared to engage usual patterns of interaction. For example, **Participant D**, with a diagnosis of dependent personality disorder, described efforts to appear calmer than she felt and so may have come across as "pleasing" to the clinician, by her own account. At one point **Participant F** had voluntarily allowed the disability grant to lapse. He had been working in his field on a contract basis up until the covid-19 pandemic lockdown. He had read a doctor's note that described him as "arrogant", though continued to be critical of services when engaging in the application process. Participants had limited insight into how own style of engagement might act as a barrier in the subjective impact on the health professionals' engagement, or even that the experience was co-constructed. For example, Participant F denied anything about his personality style could have negatively affected the outcome with the assessment doctor:

"No. I feel quite the opposite. I feel it's the doctors".

Participant F

4.2.1.2.5 Reasons given for disability grant re-application

Participants all described successful re-applications for the grant, when made. Reasons given for re-application related to 1) unemployment and economic stress and 2) absence of improvement in functioning.

“Well to be honest with you the situation that I am in. I have three kids. I have a husband that don’t work. I have a mom staying with us who is pensioner. I am very dependent on that money... And the fact that my personality disorder is not just something that disappears so I think that I am possibly - what is the word I am looking for- a good candidate for the disability.”

Participant H

The experienced ‘permanence’ of impairments and strained economic circumstances therefore promoted reliance on the disability grant.

4.2.1.3. Barriers to accessing the disability grant

4.2.1.3.1. Engagement with health professionals

In their engagements with health professionals, participants seemed to distinguish between the quality of interaction with mental health professionals such as psychiatrists and mental health sisters at community health clinics, and the interaction with student doctors or doctors who did not specialise in mental health. Problematic engagements with non-specialist health professionals included the following attitudes:

4.2.1.3.1.1 Questioning validity of need in the absence of visible disability

Many participants thought that the absence of physical illness appeared to create doubt in health professionals about genuine disablement and need for support. Questions about the extent to which participants had pretended to be ill in order to access state support - either in the form of a bed (hospital or shelter stay) or money (disability grant) - formed part of health workers’ engagement with participants. **Participant F** reflected on how this contributed to the experience of ‘othering’ and the effect on the self:

“Or they tell me you are not homeless. You don’t look homeless. What does a homeless man look like? So all of that is also people just creating that space that isolates you… and then the isolation perpetuates into inner isolation. So it continues”.

Misrepresentation on the part of the patient is suggested, and that they could not be trusted to determine their own needs. This might be internalised for some, seen in doubting the validity of their needs when measuring it against mainstream conceptions of disability.

Participant A expressed her own expectation that she would be measured against the yardstick of physical disability:

“.. initially when you go in there and you’re not with crutches or in a wheelchair or has 12 different illnesses it looks like,’ what are you doing here, you’re young, go work.’”

4.2.1.3.1.2 Avoidance or stonewalling

Two participants described clinician avoidance or stonewalling of the request to apply for the disability grant. **Participant B** described difficulty with the re-assessment for the disability grant at the central hospital she usually attended, when she was devolved without her consultation after she complained about the professional behaviour of the doctor. After protracted engagements and making a formal complaint, she was assisted. After **Participant F** had been hospitalised for three to four months, he challenged the doctor about assistance with social support applications again, and received an about-turn in assistance:

“Well I told her that I was going to land up on the street and that I understood that it is the doctor that pulls out the paperwork. So she asked me is that something you want us to help you with? And I said yes, of course.”

4.2.1.3.1.3 Judgements and dissonance with patient self-concept

Two participants reported that negative clinician judgements were communicated directly. These judgements were at odds with how participants themselves experienced their struggles with functioning. **Participant F** expressed greater need of support than doctors thought he needed. Doctor response was viewed as a combination of subjective judgement of functioning and a reaction to Participant F’s personality style:

“So I think also because the doctors find me arrogant they bring their own personal prejudice to it. Like why should I? Why should this guy be on SASSA? I also think they see me as very high functioning, that I don’t really need SASSA. I could go out and sort myself out. And in last year he said exactly that; you know last time you were here you got, you sorted yourself out so why should we help you?”

A participant also spoke of the inverse; that of being assessed to be more greatly impaired than they experienced themselves. The incongruence between how they experienced themselves at a particular time in their illness history, and clinician judgement of it, led to deferment of disability grant support till a later stage in her life.

“One psychiatrist a good few years ago when I said to him I am going to study. ... And he said that was my (delusion) of grandeur. And I want to tell you that for many times when I think of that doctor then I think I wanted to prove the doctor wrong. And I had a thing with the doctors there.”

Participant I

4.2.1.3.2 Experience of SASSA administration exercising illegitimate control

Four participants described the attitudinal approach by SASSA officials as intimidating and unhelpful. At times this was also experienced as personalised and inappropriate, when diagnosis on a form was treated as a curiosity:

"To be honest with you I have been asked quite a few times what is a mood disorder. What does it mean to be borderline personality".

Participant H

The DSD allowance of income supplementation through work compensation up to twice the amount of the disability grant was experienced as ambivalent support for disability grant recipients, as they were faced with SASSA officials' scrutiny that was difficult to tolerate. **Participant G** noted:

"But now if you are working and they see a R500 in your bank account they want to know what that money was for; where you got it from? Whom you got it from? Because they questioned me. They questioned me because my sister put a R100 into because I could have gone to fetch the money from her but she put the money into my bank account. I had to answer for that R100 that was there".

Employer tolerance for this obstacle was also low:

"Because it is so easy to EFT now. Now they (the employers) have to go to the bank to withdraw money to pay you, which is like the lady said; it is a hassle. Life is too fast they can't still worry with going to banks …"

Participant G

Participant G had had the experience of earning good money as an au pair a few days a week but lamented that as she could no longer be paid in cash, she would rather discontinue work than face the scrutiny of SASSA officials into electronic payments to her bank account. This suggested an attitudinal approach that was experienced as intrusive and punitive. This was in keeping with the area of most concern for participants: that administration officials behaved as if they had authority over them, including the personal power to approve the application, or not. This contributed to applicants' experiences of voicelessness and disempowerment. One participant likened the SASSA officials' attitude to a strict school-teacher character from the 'Heidi' children's book:

"They don't say to me. I don't know what they write on there because it's private that others lady on top there at Groote Schuur that take the papers in, that's a 'Rottenmeier'".

Participant B

Queuing, experienced as ceaseless and unnecessary, also appeared to be way in which participants believed unjust control was being exercised over them. For **Participant A**, both the attitudinal approach and long queueing contributed to increased anxiety

"Yes, however, at the SASSA offices when you do go back, there, there's this thing that I personally don't like. That people, generally, has the attitude of I'm getting you this money. So if you don't …I'll decide, that's intimidating. That's not nice. You will just queue outside here very long and keep quiet or else your grant won't be approved".

"They cause a lot of anxiety. And I think also sitting there, waiting. Am I going to get this assistance or not?"

Participant A

4.2.1.3.3 Disabilty grant lapse

Due to the temporary nature of the grant, lapse in disability grant receipt occurs at 6 months to 1 year, and may be reinstated on application, pending re-evaluation. Recipients wait till the month after the grant lapses to re-apply, resulting in a 2-month period where there is no income from this source, and possibly also not from any other source. Periods of disability grant lapse appeared to be difficult terrain for participants to negotiate and became points at which they experienced increased economic distress, an exacerbation in symptoms of mental illness, increased interpersonal distress and risked loss of this social support mechanism for protracted periods.

4.2.1.3.3.1 Bureaucratic difficulties/barriers

Bureaucratic difficulties around management of time and processes were concerns for participants. Efficiency was considered a problem as multiple processes could be administered at the same time, and were not, highlighted by **Participant F,** who complained about the insistence on queue-standing for individual administrative processes, when forms from several agencies were required:

"So I did all the paper work and then they give me the -. And I am like, seriously why did you give the - at the same time? … and Capitec (bank) is literally on the next corner. So I say, can I go and come back? No, you got to come back next week. So you have to stand in the line again the next week just to hand in a form. And then you got to come back the next week."

Participant report on bureaucratic barriers with re-application inevitably included the impact of the covid-19 pandemic, which entrenched barriers related to processes but also introduced barriers of inaccessibility of human resources and access to up-to-date information.

4.2.1.3.3.2 Impact of the covid-19 pandemic and inaccessible human resources

The covid-19 pandemic and various levels of lockdown in South Africa meant that participants endured restricted and staggered access to the disability grant. As the government's aim was to limit physical contact between people to curb the spread of disease, businesses and state departments suffered closures, with a consequence that during the highest lockdown level, all social support grants were continued despite need for re-assessment. When SASSA offices re-opened, the backlog in applications, and the limited numbers of people granted physical access to buildings to ensure lockdown regulations, resulted in further delays in access:

"This year, the beginning of this year due to the lockdown last year, there was a backlog. The SASSA offices was very, very busy and full and because of everybody's grant lapsing at the same time. So, this time around, I have to wait four months. And I'm still recovering from that four months."

Participant A

Three participants spontaneously offered examples of how DSD was responsible for poor access. The pandemic appeared to affect the SASSA human capacity available, stationed at the DSD. Further, participants believed that access was skewed depending on follow-up site, and that participants that followed up at the central or psychiatric hospital were luckier than those who had follow-up at community health centres (CHCs).

"… DSD is in a mess. They are hectic. … Capacity. Human resources. I think it is that and then even the medical has been taking long for people to get a medical. I know like I live close to [Name] so everybody goes there and they have been waiting long to get an appointment. I was fortunate because I am a J2 patient and I see the psychiatrist."

Participant I

If participants managed to complete a medical assessment, long waiting times for appointments at SASSA meant that medical assessments may have expired, and applicants would need to start the process again.

"Then when they tell you that your medical has expired and then your documents don't last until your next medical comes and then you have to do all of those things again. And I have now done it thrice for this year."

Participant H

Uncertainty prevailed about why pay-out dates had changed post-pandemic, creating difficulty with important financial arrangements, and contributing to feelings of anxiety. **Participant G**, who used disability grant money to pay off her son's academic fees on a monthly basis, had to arrange a different payment date each month:

"We have no idea why it changed. We just know that we don't get paid on the first anymore. The pensioners get paid on.. it is supposed to be the first Tuesday of the month but it's not always the first Tuesday of the month. And then we get paid next. And if it is on a weekend then we only get paid the Monday. (L)ike last month I only got paid on the 6th … actually it doesn't cover month to month."

When managing the agency's internal processes, disregard for accountability to those making use of the state service was noted:

"Well having to get up at 4 in the morning because they were only taking the first 70[?]. Remember it was lockdown four. And then the one week I didn't get seen at all because they were having a staff meeting. You see all these trollies with nice food can you believe that? And you think is this what pays for. Nobody got seen. They opened the doors like half-past-eleven in the morning. Now remember they close at 3. How are they going to see these people by 3 o'clock?"

Participant F

4.2.1.3.3.3 Emotional impact of disability grant lapse

Whilst the process of initial application was described in a straight-forward manner, descriptions of distress related to disability grant re-applications were consistent across participants. These included 1) experiences of uncertainty and feelings of anxiety about the outcome, and 2) the loss of financial independence and contribution. The emotional impact of the disability grant lapse was recounted by nearly all the participants as having negative effects on mood, and contributing to dissonance in self-concept:

"And, personally, I don't like to beg and ask. I think I'm the giver. So if I don't have, I go without it which depresses me eventually because it's not nice to be hungry and feel like I don't want to ask you because I'm a burden."

"It definitely affects my relationships because I get depressed because I can't see to myself. And it affects my moods."

Participant A

"I also tend to be a bit more depressed that time… there is so much pressure on you at times. Because the arrangements are made but now you can't pay for that time and what will happen? It's incredible stressful".

Participant D

Depressed mood during this period appeared to make it difficult to interact with others, contributing to interpersonal conflict. **Participant H** described her engagement with her husband during this time:

"I would get annoyed and frustrated with him and we would fight. I would get rude and say things and sometimes I regret it and sometimes I don't. But it would cause animosity and hurt and unpleasant tensions which I also sometimes can't handle."

Anxiety increased in its acuity at the time of re-application, as it involved a re-evaluation of commitments made in the past, and uncertainty about honouring commitments in the future. This appeared to make planning difficult:

"It is always at the back of my mind that they said initially it's for six months to a year and I have been now more than two years on it. So I am so scared that the next time that I apply I might not qualify and I already have arrangements in place. Like I must pay over the next couple of years to bring things into order. And if I don't get it and I don't have employment what am I going to do?"

Participant D

4.2.1.3.4 Stigma as accompanying narrative in accessing the disability grant

Stigma formed a significant part of participants' experience in the course of living with mental illness and impaired functioning. Participants in this study described stigma at three levels, namely; for having a psychiatric diagnosis, for receipt of a disability grant for mental illness, and for the label of disability attached to the grant.

4.2.1.3.4.1. Receipt of disability grant for mental illness

The double burden of 1) having a mental illness and 2) receiving a disability grant for it, was described by **Participant A** who thought it was used to dismiss her and diminish her status:

‘It was my sister-in-law. I shouted at the children and then she said, ‘los daai mal ding [leave that crazy thing]’. So, I said, I told my mother she keeps calling me crazy and then she said ‘ja, jy kry dan geld vir mal wees, jy kry dan mal geld [yes, you do then get money for being crazy, you do get crazy money]’”.

Stigma was not described as a barrier to accessing or re-accessing the disability grant. It did, however, inhibit disclosure around mental health diagnosis and grant receipt, for fear of judgement. In this way it could act as an indirect barrier to access, as disclosure would contribute to common knowledge about the availability of the disability grant for a seemingly invisible psychiatric disability.

Where disclosure was made direct judgements by others, and participants’ own view of themselves was experienced as stigmatising.

“I do now (disclose) with certain people. I would but I think I still have a stigma around it.... I still feel like not everybody know and so often people say to you ‘wow’, and then I say no, I don’t. And then they say ‘but you do so much.’”

Participant I

This suggested that less would have been expected from Participant I, had her disability status been known, thus her competencies would have been dictated by social conceptions of disability, rather than by her own competencies. Being a passionate community activist, **Participant I** was also concerned that the label of disability would diminish her status in situations where she experienced ability and even expertise.

“... I almost feel like people might not feel I am worthy or credible to serve on these platforms.”

4.2.1.3.4.2 Economic demand and the stigma of laziness

Economic pressures and lack of knowledge of mental ill-health within family systems helped to construct a narrative suggesting that mental illness was an illegitimate reason for failing to access employment. **Participant J** experienced this judgement with extended family:

“When it comes to my in-laws… there is a big problem on his side of the family that I am mentally ill and that I haven’t worked for five years or so. So they want me to work.”

Participant C reported:

"I think like generally people look down on you because they don't understand what you are going through. So for them you are lazy or something. It impacted my relationship like with my siblings because they are fine and they don't understand why I am the way I am."

4.2.1.3.4.3 Internalised stigma

Internal conflict around acceptance impairment and disablement attached to the disability grant was painful for many. The felt experience of being 'disabled' was seemingly affected by confusion about diagnosis and its contribution to experiences of impairment:

"Like I said to you I don't really understand it fully. I struggle to differentiate between depression and the borderline so it sometimes makes me feel like I am looked at as a handicap."

Participant H

Participant I described the conflict when first discussing it with the mental health professional:

"I didn't want to have that discussion because I never feel like I should be able to apply for a disability grant. I mean that came up so many years ago already and so many times and I kept on saying, no, I don't want. It almost felt to me like having a disability grant acknowledges that there is something wrong."

Participant J noticed:

"So, there is such a bad energy around having a mental disability. You are almost treated less equally and mocked at. And treated like you are less than when it comes to mental health. And then there is still leaning on a grant to help you while you struggle with mental health. That even for me I felt bad. All my life I was independent. I was working and now there is something wrong with me and this would prove it on black and white. I am taking help for something that is wrong with me. … And that I am taking help in a queue that is for crazy people, if I can just put it that way".

Participant J, who had been able to cease receipt of the disability grant - and the only participant at the time of the interview not accessing it – not only wanted to distance herself from 'others' labelled "crazy" but also those who might illegitimately access the grant:

"And I know that there is lots of people that take advantage of these grants. They use it as comfort when they can actually go out and generate an income. I don't want to be one of those."

4.2.1.4 Psychosocial impact of disability grant

4.2.1.4.1 Disability grant pay-out too little

The majority of participants spontaneously commented that the disability grant pay-out was too little to cover basic expenses for a month. The disability grant was used to pay for rent and utilities, namely, water and electricity accounts, with little left to ensure food security, for example:

"I can't eat. My rent alone where I stay is R1200. I must buy electricity which comes to about R500 per month; R400/500. Where is food? Where is money for food? There is no money. I play shop-shop. I play house-house because I have to buy small; a small packet of sugar because that's what I can. I don't even drink coffee and tea anymore and live mainly on water because I can't afford it."

Participant G

4.2.1.4.2 Economic survival and role maintenance

Most participants indicated that the disability grant was helpful and "better than nothing" in allowing them, for example, to contribute to shared household expenses, buying food and personal toiletry items, and paying for school-going children's needs, that contributed to a feeling of independence.

"So you have a sense that you are not completely hopeless. You can buy yourself toiletries … fruit in the house. I am able to catch a taxi and take a R10 out of my purse as opposed to one of my family members. I can even - if it is just a Bar One chocolate to have that. Just a little bit of independence. It is super helpful. You have a sense of confidence that pushes you into the right direction."

Participant J

4.2.1.4.3 Role maintenance, self-concept and mental health

Value was placed on the experiences of contributing and independence. This appeared to increase feelings of pride and self-worth, which had a positive impact on the experience of mental health:

"… when I do have my mental - my disability grant - it allows me to do things that makes me feel good about myself; whether it is buying myself lunch or being able to buy socks or not asking my mother money for cigarettes. It just gives me a little bit of self-worth and a little bit of independence which I feel is beneficial to me as a person."

Participant H

However, choice to not re-apply for the disability grant was also related to feelings of recovery, agency and independence. This also appeared to have had a positive impact on mental health. **Participant J** reported:

"I feel like it's an achievement that I don't feel the need for it".

4.2.1.5 Negotiating barriers and recovery from disability grant lapse

Participants used a range of strategies to cope with barriers to accessing the grant, whether at the point of first access or more significantly for this group, when the grant lapsed. Strategies were directed at ensuring economic survival and support of their mental health and was centred around management of relationships. This occurred by making goodwill arrangements with acquaintances, getting financial assistance from friends or family, or presenting their need to mental health professionals to secure the disability grant or to secure mental health support during this time.

4.2.1.5.1 Goodwill arrangements

Recovery from grant lapse was a theme that occurred naturally around the temporary nature of the grant, not just with the impact of the Covid-19 pandemic. This required recipients to make good-will arrangements with places of accommodation, with friends, or for groceries from the shop by 'bookie' (receiving on credit or borrowing against the disability grant). The grant, when reinstated, was largely used to service these loans. Most recipients prioritised shelter, whilst other areas of life such as food security and mobility were severely curtailed. When talking about arranging late payment of accommodation fees at the shelter he lived at, **Participant F** said:

"Well we will see if the shelter will be nice and accept that? But they probably will because they know you are on SASSA so they will probably… it just means you will have nothing, walk everywhere."

However, Participant F also disclosed feelings of panic, when thinking about how thin this social support safety net is, especially in his context of an absence of family support.

4.2.1.5.2 Financial interdependence

Financial interdependence (sharing of financial income and expenditure) between individuals in a household or between blood relatives living in different households, appeared to significantly contribute to the capacity to survive economically. Adult children and siblings contributed to disability grant recipients experiencing a lapse in payments, by paying their utilities or rent, or providing a meal, but when receiving the disability grant, participants also contributed to parents who received the old age pension, and to adult children who were struggling financially.

"My daughter's husband left her now when the COVID started with five kids and then he don't want to support her. And I support her from my pension and from my mommy's pension."

Participant B

Not only was assistance bi-directional, but different government grants were pooled for assistance across generations.

4.2.1.5.3 Relationship with mental health professionals

Participants experienced relationships with mental health professionals as supportive. They identified qualities particular to mental health professionals that offset those of the general medical professional. These included an experience of a relationship where one could be 'known' and treated with humanity.

4.2.1.5.3.1 Doctors' dual role

Participants described the dual role of doctors as helpful when engaging with disability grant re-applications. Disability grant application assessments were mostly completed by doctors whom they were routinely following up with, for their mental health care. Regular mental health visits increased confidence that participants could be 'known' by their doctors. This appeared to increase confidence in the fairness of the assessment:

"Well I don't really have a problem with it because my doctor knows me. He sees me every month. He knows the fact that - I think he would be a good person to judge whether or not I am reliable. Not 'reliable', I 'qualify' for the disability. If he felt in any way that I have improved and I am able to go back to work he would decline my application. But he hasn't."

Participant H

Participant H received follow up at a psychiatric hospital and for her, previous follow up at the CHC where she only received medication without the opportunity to establish a relationship with a mental health professional had been dissatisfactory:

"... because there is never a nurse or doctor on duty for me on mental health. And when there is a registrar you don't really get the opportunity to get to know them because every time you come back there is a new registrar. You don't find that you can build a relationship with that person and trust them in the way that you would if you had one doctor who knew you for, would it be a year or two or three. There is a big difference."

4.2.1.5.3.2 Noticing positively experienced characteristics of assessing doctor

Participants described qualities of humanity of the assessing doctor, that eased the process of disability grant assessment, regardless of whether the doctor was already well-known to them. The ability to identify with and share similar struggles was important for **Participant A,** who described:

"My personality style, it goes up and down. So I think I was just lucky that I got a doctor that could relate because it was an elderly guy that also suffers from or suffered from major depressive disorder. And he could relate to it and that was the very first doctor I saw. … He could relate to me and he started chatting."

A strict demeanour was anathema to containment in the process of application:

"He was very pleasant. … he did not come across as so stern. You know some people they come across as very strict, very stern but he was more like a… older like the .. how can I describe? He was - he had more reassurance around him",

and,

"So there was more humanity or more, I don't know, he made me feel like a person and not just a piece of paper that he has to sign. Does that make sense"?

Participant D

Participant I particularly felt that re-visiting the possibility of a disability grant application with a mental health professional was able to remediate previous discussions with a doctor that had been experienced negatively:

"… then that doctor was kind to enough to have that conversation with me. So yeah. And so for many years I did not want it. I resisted it because of what he said to me years before that and he's been there for many years. … And then in 2020 it felt better with the conversation with that (different) doctor",

and elaborated on the helpful quality of that interaction; in that

"(h)e didn't make me feel like I am inadequate. He presented it to me like an aid not like you are unable so you need this. The way he presented to me sounded different. Sounded to like, okay it is going to help me cope, it is going to help me; not I am stupid so I need this."

Participant I

4.2.1.5.3.3 Sensitisation to impairment and responsiveness

Mental health professionals were experienced as helpful in regard to being responsive to participants who wanted to discuss problems and to think through difficulties and offer alternative perspectives. Helpful gate-way discussions that progressively sensitised participants to impairments in functioning, were an important part of participants' contact with these clinicians. For example, **Participant G** said:

"So, I didn't want to accept (needing to apply for the disability grant) but then also as doctor spoke to me and explained to me what is going on with me I started accepting slowly that there is something wrong."

Responsiveness was noted by **Participant D:**

"And I was saying that time I am so worried about my finances that we are struggling. So the doctor said that they can help me."

4.2.1.5.4 Withdrawal from interpersonal interactions

Withdrawal from close interpersonal interactions was a strategy employed by many in order to cope with the stress related to disability grant lapse. Whilst social isolation and withdrawal from social or family support is maladaptive and acts against mental health, it may be that participants might have found it to necessary to manage multiple stressors that could include stigmatising judgements in close interpersonal spaces, by withdrawing. Participants might concomitantly have sought increasing connection with mental health professionals to meet the need for support during this vulnerable time. Withdrawal as a way of coping was used to manage to feelings of helplessness and worthlessness about the inability to make a financial contribution to the household.

" I don't have relationships besides with my mom. … I pull away from everybody because every time, it's like every time I see somebody then I must make a loan for this. So it's very depressing."

Participant G

"So it's just my children and my husband and I tend to spend a lot more time in my room in my bed."

Participant D

Interpersonal relationships were strained as others had to engage with participants' financial need. Withdrawal also dealt with the 'affordability' of interacting with others. Visiting acquaintances would require refreshments, which was not affordable to the disability grant recipient to dispense. **Participant G** commented on this:

"It is rather best to just struggle on your own and pull away from everybody. It is easier because people come and they want a cup of tea or they want this and I can't afford it. Sorry to say so but I don't invite people over because I can't."

4.2.1.5.5. Cognitive strategies to deal with stigma

Participants described cognitive strategies to cope with the challenges of being labelled with mental illness and disability grant recipient status. Others' judgement of participants as "lazy" for receiving a disability grant for psychiatric conditions, was dismissed as them not having knowledge of the difficult experience of impairment, with Participant B denying that she is affected by this:

"No, not at all. They're ignorant".

Participant B

Most participants disputed that it was easier to receive a disability grant than to earn a higher income through employment, to make ends meet. **Participant C** had last earned wages through informal work for his brother three years before, and described internally negotiating a less than ideal situation to reach a realistic compromise with himself, given his impairments in the workplace:

"… because personally I don't think anybody would want to prefer R1800 per month instead of having a job and earning maybe R10 000. So if I had a choice I would go for the normal life. So for me personally it has been a God-send and it has been helping me a lot".

For those who experienced disability grant receipt as maintaining illness status, independence from the disability grant was highly valued as a means to achieving 'normal' status in society, and they continued to - at least cognitively - engage with future employment:

"I don't see this disability grant as a way of oh you know I can relax now I've got the subsidy. Everyday I am still out there trying to make it because that is the way I am. I don't want to be dependent on the disability grant because for me it reinforces being ill".

Participant F

Participant J reasoned that her intermittent use of the disability grant was to support her journey to eventual independence from it.

"I patted myself on the back for getting the help that I needed and I made others aware that there is help. And that I am entitled to the help and that there shouldn't be any shame around it. And if it

is something I need right now it doesn't mean that I am going to need it forever, which is why I didn't reapply. I feel like I can actually work now and generate my own income."

4.2.1.6 Participant service needs

4.2.1.6.1 Mental health interventions at community level

In keeping with participants' concerns regarding personality and work impairment, they were asked what services they felt they had needed which could have contributed to improved functioning. Most participants felt that very specific mental health-related services would have assisted them, particularly at clinic level, with **Participant D** suggesting that explicit skills advice was needed:

"But every month I go to the day hospital they just ask how are you doing? Is this okay? Is that okay? Are you sleeping well? Are you eating well ? They are not giving me concrete advise on how to deal with situations."

Failures in service expectation were mostly referenced at the level of community health services and it was at this level that it was thought more mental health services were needed, with **Participant J** comparing services to those delivered at a psychiatric hospital:

"There should be more mental health support in clinics in general. Like there is one nurse to all of the mental health patients for that entire establishment servicing different areas around there. The same like at Woodstock. It was just nurse [Name] for all of the mental health patients and then it was certain hours of the day. And it was just one doctor and no available psychologist. That would improve recovery and stuff for people like me if there was more support. More information. More guidance. More Valkenberg I would say. If there was more of Valkenberg, I'd say."

Participant J

Participant J explained they only received appropriate mental health care treatment after presenting to a district hospital. They had been to the community clinic several times but that responsivity to their mental health distress was slow:

"So I know it is up to me to get the help for myself which I did but it took a long time and I was in and out of the clinics' doors every month. Saying I am not coping. I am crying all the time. I am gaining weight. I am telling this to the mental health nurse. "

Participant J

Participant G echoed this belief that they should have had inpatient treatment sooner:

"… besides financial. I struggled to get into the psychiatric. I wasn't admitted immediately. If they had to - I only got admitted after my fourth attempt."

4.2.1.6.2 Accessible psychological interventions

Nearly half (four) participants described difficulty accessing outpatient psychological interventions, which they deemed necessary for improvement in functioning. These interventions included both individual psychotherapy and group interventions. One participant believed that psychotherapy might be valued higher even than the financial assistance given through the disability grant:

"I think more psychotherapy. I think many times we need psychotherapy before money. I don't think people realise the value of psychotherapy. For me as a mental health patient and not being able to afford that at times is a bigger thing to me than having a grant."

Participant I

Participant D believed that the skills taught at a therapeutic unit would have helped her post-discharge as well, and rationalised why this had not been made available to her:

"When I started off at Hanover Park I asked if I could be in a with the psychologist? The one that runs more, give you, like they had at Ward 1 where they give you like tips on how to handle stressors or how to cope."

"I was still the workload there is too many people on that needs assistance and the person that is running the groups, the group is full. So if there's not enough skilled people to run groups and me being there. There are more people in need for the group that's why my name hasn't come up as a candidate for a group."

4.2.1.6.3 Multidisciplinary psychosocial interventions

Failures in multi-pronged psychosocial interventions were vociferously highlighted by Participant F, who thought that health care professionals should be able to identify patients' vulnerable social circumstances that could be ameliorated through provisions made by the DSD, and that they should be proactive in offering this.

"So isn't there a way that the doctor can say there are these… There are these safe houses that, I have seen a lot of kids in here have terrible house problems. Why are you sending them back home? They are going to come back. You put them right back in the trauma that made them come here. So

and again it should be the doctor and the social worker working together into aftercare. How do we support where this person goes after he is discharged."

4.2.1.6.4. Vocational needs

Only three participants spontaneously offered that earlier employment support or occupational activity might have contributed to improvements in functioning. These participants took a passive approach, noting that employment should be given (**Participant E,** a fifty-nine-year-old female with grade ten level of education who last worked full-time at age twenty-eight), or had noticed an information sign about work assistance at their mental health follow-up site, but that they did not inquire about it themselves, but still wished for occupation:

"Anything where I can just move. I cannot sit too long. I won't be able to do office work because I will get agitated to sit long… Maybe to move around with folders or go fetch the folders or put the folders there, like that".

Participant B

These participants contributed that occupational interventions that were stimulating, and that they could achieve contributed to a quality of self-experience that was meaningful and was experienced positively. One participant identified meaningful activity as an inpatient that regrettably ceased once an outpatient:

"Because if you do beading you can do different patterns and different styles. So I think that would be beneficial. And if you do it a lot and perhaps you would learn to focus and maybe that can inspire you maybe if you focus on that creative side of you".

Participant C

4.2.1.6.5 Individualised financial need assessment

In keeping with the expressed need for earlier interventions and more psychotherapeutic interventions, participants also asked for more nuanced assessment of financial need. This arose from the experience of the disability grant being too little and uncertainty about how this amount was decided on. **Participant F**, who had lived in the United Kingdom (UK), compared the South African social grant system to those in the UK and the United States of America, and suggested that financial allotments through the grant, should be based on urban/suburban location, that these should be granted through both national and provincial departments as the cost of living in some provinces was higher than in others. He also thought that physical disability should weigh more that psychiatric disability, in determining amounts paid out to recipients.

Participant C echoed the idea that the amount paid out by the disability grant should be determined by how the cost of living was affected by individual circumstances, and for them this included having a partner and dependents:

"I think minimum – I suppose if you think about it the cost of living is so high; to rent a place you pay R7000. I mean is there a minimum? I mean if you can't have a family [unintelligible 00:36:14] then I suppose R4000".

Participant C

4.2.1.6.6 Raising of income threshold

Many participants highlighted the DSD-stipulated limit imposed on income generation whilst receiving the disability grant, as a difficulty.

"And they should look at raising the bar because if you are saying you can't earn more than three-and-a-half a month. I mean three-and-a-half a month is not a lot to live on".

Participant F

This acted as a barrier to individuals motivated to continue to engage with employment in a graduated way. These were participants who experienced uncertainty about their ability to sustain their employment and who foresaw themselves as incapable of managing the distress that would arise from the removal of the disability grant safety net, should they 'fail' at employment.

There also appeared to be misinformation about the restriction on working, for example:

"Yes, because I need the grant but I also want to work. I want to be able to, even not to get the flashy jobs but where I can actually earn extra because we are told if we are on the grant then we can't work. It now takes that away. But if I work for something else again I wouldn't be earning that amount money that I am used to but just to get something extra in".

Participant G

4.**2.2** Unexpected Emergent Findings:

The following responses arose during interviews and have been included as noteworthy, as it was felt to hold importance for those being interviewed. As such, it could be considered a significant agenda for participants, though was not extensively explored due to the focus on the area of investigation. These responses have been understood as arising directly from the act of being interviewed, which participants engaged with as an opportunity to 1) access knowledge, 2) address marginalisation and 3) actively contribute. These are understood in themes and sub-themes, below:

4.2.2.1 Engagement with personality disorder diagnosis

An unexpected finding was the apparent reluctance of participants to admit to having a personality disorder diagnosis even though when pressed it became apparent that they had previous information on it. All except one participant acknowledged a diagnosis of personality disorder, or pathological personality traits, assigned to them. However, in comparison with "axis 1" diagnoses which all participants made attempts to describe their understanding of – and even authoritatively speaking on the diagnostic criteria for these - there was reticence in admitting to having been given the diagnosis or descriptor and then knowing what the diagnosis meant. In almost all cases, there was a request that the researcher explain the diagnosis of a personality disorder.

The researcher attempted to engage empathically and reflexively, aware in the moment that this was an important decision for how to continue data collection. The decision was based on:

i) an immediate response of empathy for participant vulnerability in asking for this understanding,
ii) the realisation that participants might be unwilling or not know how to continue with the interview, if they did not feel sufficiently helped to participate in a competent manner and,
iii) consideration that scientific rigour would be compromised if participants did not understand one of the key concepts under investigation.

The decision was made to speak generally to patterns of being that were descriptive of problems in personality functioning. This shift in design after entering the field is deemed appropriate in qualitative studies, allowing for the emergence of new aspects of the study (Cresswell, 2018). Where it was deemed appropriate - given what the participant had already disclosed about their struggles - personality traits illustrated in participant-specific experiences were reflected back to them, in order to facilitate access to understanding. For example, with **Participant A**:

Interviewer: "… it's essentially about how you tend to see the world, experience your emotions and then how you behave, and the consistent tendency that you have to do it in a particular way. So, like your tendency to be submissive as you say, it doesn't really work for you. It can get you into a lot of difficulty and you don't feel like you're doing things sort of in your best interest. So, we look

at the extent to which certain personality traits or characteristics get in the way of your functioning…”.

Participants, thereafter, appeared to express more candour in identifying with the diagnosis, highlighting particularly difficult behaviours related to their personality style. This can be illustrated through **Participant B’s** statement:

“I can maybe see it in myself when I get so aggressive. Maybe that’s one of the signs. It’s ugly because my grandchildren suffer. My mother suffer, everybody around me suffers when I'm in a bad state. I show it in my face. I don’t let it out, if I let it out, oh my goodness…”.

However, it did not appear to unduly influence **Participant C’s** insight into personality functioning, who was the only participant to disagree that his personality functioning contributed to his experience of anxiety:

“I don’t think so. I think I don’t have like a very big personality or anything. I think I am a normal person and I shouldn’t have anxiety because of my personality. I should be okay with that. I should be okay with my personality. I should not have anxiety.”

4.2.2.2 Getting knowledge about processes

Some participants had decided to bring questions about the administration of SASSA grants. For example, Participant G was unsure about whether her pursuit of mental health recovery placed receipt of the disability grant in jeopardy. She was concerned with whether she would continue to qualify for the grant if she was discharged from tertiary psychiatric care and psychotherapy:

“Because if I get better and things like that and you say ‘Ms [Name] we are going to discharge you from mental health but we will re- evaluate you say in another six months’ time and then we will…’. But what if I am not mental healthy… to do it mentally? Because I am not mental healthy - now my disability grant stops because I only get re- evaluated within six months’ time. So for that, until my re-evaluation are they going to stop my disability?”.

Her confusion about the difference between a temporary and a permanent disability grant was also evident:

“There is something that I also wanting to know. We are on a disability grant hey. When I … it says permanent. So does that mean I will be on the disability grant until I must switch on to (old age) pension?”

Participant G

It appeared that the invitation for the interview had increased motivation to get information about the security of the grant. However, that this uncertainty prevailed, taken with the anxiety inherent in re-applications for the disability grant previously discussed, suggests that the bureaucratic nature of the process works against mental health.

4.2.2.3 Suspicion of marginalisation

Two participants considered that the research interview was a conduit to the cessation of state disability grants. Although it would have been a reasonable concern that this might be a consequence of the research, anger and devaluing of the social support system was actively done in the room, even though both participants felt that receiving the disability grant was useful to them in some ways. Both these participants had hostility as a significant personality trait.

"Do you people don't want to give it or do you feel the person must go work. Now what then? We were told that already"

Participant E

However, the fact that the interview might contribute to a review of the disability grant and its possible end, was eventually treated with resignation by both participants.

"Do you understand what I am saying. I am so past a lot of things that nothing can bother me. So I don't understand what is the reason. I did hear you say the other time that it is about the grant. Now what is it about the grant because you what, I could've been at home already. I thought I am here to do something for people. … If they gave it to me and if there is any reason they want to take it away for whatever reason they think, I can do nothing. Because what is there now that I did wrong from 2014 until now?".

Participant E

It can be surmised that this response spoke to a power differential as it could have been experienced between the patient-recipient of the disability grant, and through a) the state's ability to act on the individual with ill consideration of the individual's needs; and b) the researcher, assigned as an organ of the state to facilitate this acting upon the individual, a relationship that has previously been noted (Kelly, 2016).

4.2.2.4 Research participation contributes to motivation and self-esteem

Older participants used the interview to attempt to gain information on how to ensure their future financial security through asking about the transition to the state old age pension. Participants also inquired about availability of registrars to assist with follow-up they had failed to attend to. Although it would be reasonable to assume that attempts to address these questions could have been made by channels already in place, it appeared that the invitation to interview as a non-normative engagement may have disrupted a complacency that many described, and encouraged agency and motivation to direct these questions. This motivation was also evident in participant expressions that interview participation would contribute to broader betterment of patient mental health care and “help others”. Motivation for a particular good outcome, was given expression by **Participant J:**

“I hope I am able to help get the right answers to continue helping people with the disability grant and getting them more support. It is really a good thing.”

The researcher was surprised by this spontaneous assertion and was careful to notice and inhibit an urge to elevate participant contributions beyond affirmation and thanks for their participation in the study. Researcher caution around colluding against an unrealistic health or outcomes status may have arisen from awareness that participants still struggled significantly in various areas of functioning, and that this was so despite interventions which the researcher herself had participated in. However, identifying and acknowledging patient contribution to others or to bettering difficult situations is a significant skill that encourages and maintains self-esteem in individuals with impaired functioning. This is known to promote further skilful behaviour such as emotion regulation and is actively encouraged in some psychotherapeutic interventions (Linehan, 1993). Reflexivity in the moment encouraged a balanced response and supported participants to actively engage in the process of research.

It might be useful to consider examining these unexpected responses as an artefact of this particular group in their feelings of dependency on the disability grant and thus the state. The researcher likely contributed to these responses if viewed as a gatekeeper to the disability grant or as a gatekeeper to future psychotherapeutic treatment at Ward 1. This would arise in the interaction with participant personality functioning but also in the social and economic climate worsened by the Covid-19 pandemic.

4.3 Clinician survey findings

The central hospital, psychiatric hospitals, district hospitals and community health centres approached to participate in the clinician survey amounted to sixteen (n = 16). In 2021, seven (n = 7) institutions responded, agreeing to the request for participation. One district hospital then reported that they did not have patients with personality pathology presenting to the facility and that they were expecting to attend to covid-19 patient admissions and withdrew from the study. One eligible staff member at a facility was on long leave and withdrew, and another institution did not have specialists or registrars attending to their psychiatric patients, thus leaving 4 facilities. One manager preferred to receive the survey link and disseminate to their staff, but a year later did not recall the communication and so it is not certain that it was distributed. Researcher attempts to liaise with these institutions often did not result in returned communication. Extension of ethics in 2022 meant that the same institutions were approached again, and response to the request was low. As a result, only four facilities who were eligible in having registrars and psychiatrists appointed to them, participated. The clinician survey was distributed to approximately 55 psychiatry consultants and psychiatry registrars within these facilities, and only 12 responses were received, accruing to a response rate of approximately 21.8 %.

4.3.1 Sociodemographic characteristics

Sociodemographic characteristics of respondents to the clinician survey are presented in Table 4, below. Most respondents to the survey identified as female, and the majority of respondents were above the age of 30.

Table 4: Sociodemographic characteristics of participants in the clinician survey

	Total	**N**	**%**
Gender	**12**		
Female		8	67.0
Male		4	33.0
Age	**12**		
25 – 34		4	33.3
35 – 44		7	58.3
55 +		1	8.3

4.3.2 Clinician experience data

Work experience that was of interest to this study was sought, and is represented in Table 5, below. Most respondents had achieved specialisation in psychiatry and worked in a psychiatric hospital. The majority of respondents had 4 years or more of experience working in a state psychiatric setting. Only 1 repondent reported less than 4 years of experience working with adult personality pathology. Most clnicians (n = 9) reported that they had completed 1-4 disability grant applications in the preceding two years for patients with personality pathology.

Table 5: Clinical work experience of participants in the clinician survey

	Total	**N**	**%**
Qualification	**12**		
Psychiatry specialisation		7	58
Medical degree only		5	42
Work setting	**12**		
State psychiatric setting		9	75
District hospital		3	25
Years of work experience in state psychiatric setting	**12**		
1 - 3		1	8
4 - 7		5	42
8 – 15		3	25
16 – 25		2	17
26 – 35		1	8
Years of work experience with adult personality pathology	**12**		
1 – 3		1	8.3
4 -7		4	33.3
8 – 15		5	42
16 – 25		1	8.3
26 – 35		1	8.3
Disability grants completed in past two years for patients with personality pathology	**12**		
1 – 4		9	75
5 – 8		2	16
9 – 12		1	8.3
13 – 16		0	0
17 – 20		0	0
21+		0	0

4.3.3 Experiences, attitudes and beliefs about personality pathology and the disability grant

Clinicians were canvassed about subjective experience, attitudes and beliefs in their work with patients with personality pathology and how this interacted with making disability grant applications for this population.

4.3.3.1 Report of clinical experience with personality disordered individuals

Most respondents agreed that working with personality pathology was a routine part of their work in the DoH. The majority of respondents did not think that making disability grant applications for patients with personality pathology was a routine part of their work. Most clinicians reported that they experienced more confusion about how to make the disability grant application assessment for patients with a primary personality disorder, than for patients with a CMD such as anxiety or a mood disorder. Most respondents agreed that they experienced more confusion about how to make disability grant application assessments for patients with a primary personality disorder than for those with a serious psychiatric disorder, such as a psychotic disorder. When it came to distinguishing between application for state-funded or private disability support, respondents mostly disagreed that they worried more about applying for state-issued disability grants for patients, than when making medical boarding applications for those with private insurance.

Table 6: Clinician report of experience working with personality disordered patients

Statement	**Mostly disagree**	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Mostly agree**
Working with patients with personality pathology is a routine part of my work	0 %(n=0)	8.3 % (n=1)	0 % (n=0)	16.7 % (n=2)	75% (n=9)
Making applications for patients with personality pathology to receive state-issued disability grants is a routine part of work	25% (n=3)	33.3% (n=4)	16.7% (n=2)	25% (n=3)	0% (n=0)
I experience more confusion about how to make the disability grant application assessment for patients with a primary personality disorder, than for patients with a common mental disorder such as anxiety or mood disorder	16.7% (n=2)	16.7% (n=2)	8.3% (n=1)	41.7% (n=50	16.7% (n=2)
I experience more confusion about how to make a disability grant application assessment for patients with a primary personality disorder, than for patients with a serious psychiatric disorder (e.g. psychotic disorders)	16.7% (n=2)	8.3% (n=1)	0% (n=0)	41.7% (n=5)	33.3% (n=4)
I worry more about applying for state-issued disability grants for patients with personality pathology, than for medical boarding of patients with personality pathology who are paid by private insurers	33.3% (n=4)	16.7% (n=2)	16.7% (n=2)	25% (n=3)	8.3% (n=1)

4.3.3.2 Clinical and mental health system factors

Respondents were asked about clinical and mental health system factors that were experienced as a barriers to optimal assessment of personality disordered individuals in application for a disability grant.

Most clinicians agreed that they often feel uncertain that they are accurately assessing the level of functioning in a patient with personality pathology. Most agreed that they could sufficiently decide on the patient's level of functional impairment through informant collateral such as family, previous employer and treating clinicians and that it was necessary to include allied health professionals' (such as social worker, occupational therapist, and clinical psychologist) reports when making disability grant applications for persons with personality pathology. Equal proportions both somewhat agreed and somewhat disagreed that there was sufficient collaboration with allied health professionals to help with the assessment of the patient's level of functional impairment.

Clinicians mostly agreed that they felt conflicted in their dual role as a treating clinician or case manager, and then making an assessment and application in aid of the disability grant for their patient with personality pathology. Most clinicians agreed that another doctor should make the disability grant assessment and application on behalf of the patient that the clinician was treating. Most respondents agreed that patients with personality pathology should first have received optimal treatment (medication, psychotherapy, rehabilitation and recovery services) before being considered for a disability grant. There was mostly disagreement that patients with personality pathology had already received optimal treatment from therapeutic and rehabilitation services by the time they presented for a disability grant application.

Most clinicians disagreed that there were sufficient therapeutic and rehabilitation services to optimally intervene with patients with personality pathology before being considered for a disability grant. Regarding whether clinicians were happy to make disability grant applications for patients with personality pathology even while they were still undergoing therapeutic and rehabilitation treatment, most agreed that they were. Most somewhat disagreed with the statement that they worried that when they saw a patient for a disability grant application, that the patients' personality disorder diagnosis prevented them from considering further therapeutic and rehabilitative services for the patient. Most respondents disagreed that the SASSA disability grant application forms sufficiently captured the way in which the patient with personality pathology is impaired.

Table 7: Clinical and mental health system factors experienced by clinicians making disability grant assessments

Statement	**Mostly disagree**	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Mostly agree**
I often feel uncertain that I am accurately assessing the level of functioning in a patient with personality pathology	0% (n=0)	33.3% (n=4)	0% (n=0)	58.3% (n=7)	8.3% (n=1)
When completing a disability grant application, the fact that the patient has personality pathology makes me uncertain whether I am assessing their current level of stress, rather than their level of functioning	16.7% (n=2)	0% (n=4)	8.3% (n=1)	41.7% (n=5)	33.3% (n=4)
I am able to sufficiently assess through informant collateral from treating clinicians, family and previous employer before deciding on the patient's level of functional impairment	0% (n=0)	16.7% (n=2)	25% (n=3)	33.3% (n=4)	25% (n=3)
It is necessary to include allied health professionals' (occupational therapist, social worker, clinical psychologist) reports when applying for disability grants for patients with personality pat...	0% (n=0)	8.3% (n=1)	25% (n=3)	25% (n=3)	41.7% (n=5)
There is sufficient collaboration with allied health professionals to help assess the patient's level of functional impairment	0% (n=0)	41.7% (n=5)	16.7% (n=2)	41.7% (n=5)	0% (n=0)
I often feel conflicted that I have a dual role as the treating doctor or case manager, and then have to make the assessment and application for a disability grant on behalf of my patient	0% (n=0)	16.7% (n=2)	16.7%(n=2)	16.7% (n=2)	50% (n=6)
As the treating doctor of the patient with personality pathology, I think that another medical professional should be making the assessment and application for the patient's disability grant	25% (n=3)	0% (n=0)	16.7% (n=2)	16.7% (n=2)	41.7% (n=5)
Patients with personality pathology should first have received optimal treatment (medication, psychotherapy, rehabilitation and recovery services), before applying for a disability grant	0% (n=2)	16.7% (n=2)	16.7% (n=2)	16.7% (n=2)	50% (n=6)
By the time that the patient with personality pathology has approached me for a disability grant, they have already received optimal intervention from therapeutic and rehabilitation services	33.3% (n=4)	41.7% (n=5)	8.3% (n=1)	16.7% (n=2)	0% (n=0)
There are enough therapeutic and rehabilitation services to optimally intervene with patients with personality pathology, before considering applying for a disability grant	66.7% (n=8)	0% (n=0)	8.3% (n=1)	8.3% (n=1)	16.7% (n=2)
I am happy to apply for a disability grant on behalf of the patient even while they are undergoing therapeutic and rehabilitation services for their primary personality disorder diagnosis	16.7% (n=2)	16.7% (n=2)	16.7% (n=2)	33.3% (n=4)	16.7% (n=2)
I worry that when I see a patient with personality pathology for a disability grant application, their diagnosis prevents me from thinking about any further therapeutic or recovery interventions for them	16.7% (n=2)	50% (n=6)	8.3% (n=1)	25% (n=3)	0% (n=2)
The SASSA disability grant application sufficiently captures the ways in which the patient with personality pathology is impaired	58.3% (n=7)	25% (n=3)	16.7% (n=2)	0% (n=0)	0% (n=0)

4.3.3.2.1 Qualitative analysis of free responses on clinical and mental health system factors affecting disability grant applications

There were 5 free responses, with only 1 outright opinion that patients with personality pathology should not receive the disability grant. This appeared to be based on an evaluation of deservingness, giving credibility to the experiences of judgement that had been reported by patient participants, about their interaction with mental health professionals.

"I disagree that people with primarily personality pathology deserve disability grants"

A statement regarding clinical and mental health system factors appeared to contradict itself, but in context seemed to support patient experience that there was a dearth of therapeutic services, both in state and in the private sector:

"there are very few therapeutic services in both private & state sectors. Also in both sectors there is sufficient group therapy options, particularly outpatient group therapy"

Social ills which seemed to be defined and reduced to unemployment and the absence of supported employment sites, complicated the decision to apply for a disability grant:

"the social problems in our country place an added dimension to this complex decision. as any disability makes it very hard to find work when unemployment is so high and there are few supported employment options.."

When trying to act 'rationally' in making the disability grant application, this same clinician experienced a frustrating process where they were met with forced compliance with the 'irrational', through the return of the disability grant forms.

" in addition, the DG form is confusing and the way SASSA capture it is very frustrating. they often refuse to accept forms that are completed in a rational manner because of an arbitrary rule that is not obvious from the form itself".

This appears to echo the arbitrary and careless way in which patient participants also experienced SASSA's management of their concerns about waiting periods and disjointed, repetitive processes.

4.3.3.3 Clinician-patient interaction around disability grant applications

Most clinicians disagreed that it was easy to talk to patients with personality pathology about the disability grant application. However, most respondents agreed that being the treating doctor as well as an assessing clinician for the patient with personality pathology made it difficult to discuss a disability grant application with the patient. Most respondents agreed that their ability to be helpful in the discussion about a disability grant application was often influenced by the quality of the interpersonal interaction with the patient with personality pathology. In discussion about the disability grant application, most clinicians worried that the patient was pretending to be more functionally impaired with them, than in their interactions with allied health professionals.

Table 8: Clinician-patient interaction around disability grant applications

Statement	**Mostly disagree**	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Mostly agree**
It is easy to talk with patients with personality pathology about applying for a state disability grant	25% (n=3)	33.3% (n=4)	16.7% (n=2)	16.7% (n=2)	8.3% (n=1)
My dual role as the patient's treating doctor and the assessor for the disability grant application makes it difficult to talk to the patient with personality pathology about applying for a disability grant	8.3% (n=1)	16.7% (n=2)	16.7% (n=2)	33.3% (n=4)	25% (n=3)
The quality of the interpersonal interaction with the patient with personality pathology often influences whether I can be helpful when talking to them about applying for a state disability grant	0% (n=0)	0% (n=0)	8.35 (n=1)	83.3% (n=10)	8.3% (n=1)
When talking about a disability grant application, I worry that the patient with personality pathology pretends to be more impaired in functioning with me than they are with other allied health professionals	0% (n=0)	16.7% (n=2)	25% (n=3)	33.3% (n=4)	25% (n=3)

4.3.3.3.1 Qualitative analysis of free responses on clinician-patient interaction around disability grant applications

Only two responses were received. One recommended the establishment of rapport as assisting in the judgement of qualification for the grant.

"Good rapport may help to make a correct judgment as a clinician".

Another clinician was candid about their feelings:

"I really dislike it!"

4.3.3.4 Clinician own personality, beliefs and values

Clinicians were asked about personal ideas that could be speculated to be present in their work with patients with personality pathology. Most respondents disagreed that they were concerned that they had too much empathy for certain patients with personality pathology and that it made them encourage a disability grant application. Respondents equally mostly agreed, somewhat disagreed, or somewhat agreed that they were unhappy about making disability grant applications for patients with personality pathology. Respondents equally somewhat agreed and somewhat disagreed that they thought that once patients with personality pathology received a disability grant, that it had negative consequences for coping and recovery. When patients with personality pathology were issued with a state disability grant, a third of clinicians mostly disagreed that they felt happy that state funds were being used optimally, and a third were neutral about this.

Table 9: Clinician own personality, beliefs and values

Statement	**Mostly disagree**	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Mostly agree**
I worry that I have too much empathy for certain patients with personality pathology, and that it makes me encourage a disability grant application	33.3% (n=4)	33.3% (n=4)	25% (n=3)	8.3 5(n=1)	0% (n=0)
I worry that I have too little empathy for certain patients with personality pathology, which makes me discourage a disability grant application	16.7 % (n=2)	25% (n=3)	25% (n=3)	33.3% (n=4)	0% (n=0)
I feel unhappy about making disability grant applications for patients with personality pathology	25% (n=3)	255 (n=3)	8.3% (n=1)	16.7% (n=2)	25% (n=3)
I believe that once the patient with personality pathology receives the disability grant, it has negative consequences for coping and recovery	16.7% (n=2)	25% (n=3)	16.7% (n=2)	25% (n=3)	16.7% (n=2)
When patients with personality pathology receive state disability grants, I feel happy that state funds are being used optimally	33.3% (n=4)	0% (n=0)	33.3% (n=4)	16.7% (n=2)	16.7% (n=2)

4.3.3.5 Open-ended questions

Participants were asked open-ended/free responses questions in areas such as:

4.3.3.5.1 Whether the economic and mental health impact of the covid-19 pandemic had affected their views and/or approach to assisting patients with personality pathology, with disability grant applications?

Most respondents (58 %) did not think that the economic and mental health impact of the covid-19 pandemic had affected their views and/or approach to assisting patients with personality pathology, with disability grant applications. Twenty-five per cent did think that it had and 17 % thought that maybe it had.

4.3.3.5.2 Those who answered yes or maybe were asked to elaborate on how their views/approach had changed

Two respondents merely reiterated the fact of economic hardship whilst 1 respondent thought that financial/economic hardship and the increase in comorbid psychiatric difficulties made them more likely to apply for disability grants for the patient with personality pathology:

"More financial difficulties and co-morbid illnesses have arisen since the start of the pandemic, compounding existing issues that would cause me to apply for a DG for a patient especially with primary personality pathology".

One (1) participant wanted to respond more actively precisely because they believed administration by SASSA had become restricted:

"Tried to be more hands on in applying as the SASSA services seemed to be less available".

4.3.3.5.3 What resources and/or training would assist clinicians to experience greater confidence in making disability grant applications for patients with impaired functioning that have personality pathology?

Respondents thought that increased confidence in their assessment could be assisted through receiving training on the assessment of functional impairment, collaboration with occupational therapy, and in revision of the SASSA application forms, for example:

"Training on what are meant descriptions of the functional scores for how impaired an individual is. Training on what would mistakenly disqualify a patient from a DG".

and

"SASSA being more functional and the forms being more easy to complete for mental health conditions. Mostly we require supported work opportunities for people with some impairment to be able to re-enter the workforce. If this was in place it would be easier to apply for temporary DG to allow someone to recover and know there is some hope of work in the future. But applying without this usually means lifelong DG which often does not support their recovery".

4.3.3.5.4 Are there any other barriers you think exist for patients with personality pathology, who try to access state disability grant support?

Eight (n = 8) clinicians identified barriers they thought existed for patients with personality pathology who wanted to apply for the disability grant. These included stigma from clinicians and patients themselves, difficult interpersonal reactions, and the SASSA application forms. One respondent did not believe that individuals with personality pathology should receive a disability grant

“People with primarily or only with personality pathology should not be considered for state disability pensions. Otherwise almost everyone in the country would be entitled to a state disability”

Awareness of occupation as a health-promoting activity left one clinician confused about how this married with a disability grant application. The added perception that disability grants were poorly controlled seemed to contribute to the judgement of the process as a complex one. This seems to reinforce the role of a more experienced doctor as a gatekeeper for the SASSA grant:

“I know that not working has enormous negative impact on physical and mental health outcomes and so want to encourage people to work at all costs. This complicates applying for DG even if I think the person is currently impaired. In addition, the poor control over DG's means that a short-term grant is more difficult as it may be continued indefinitely by less qualified clinicians who simply reapply again in future”.

The aptitude of the SASSA form for the assessment of psychiatric disability was experienced an non-inclusive:

“Form not designed for mental illness. Difficult to explain or justify disability”.

CHAPTER 5 DISCUSSION

5.1 Integration of findings

This study employed a multi-method design to explore experiences of access to and use of the disability grant for people with personality pathology, any barriers experienced to that access, and clinician experience and opinions as gatekeepers to that access, in Cape Town, South Africa. This section begins with a summary of the integrated findings from the three main study methods that were used. Limitations and the impact of the study are considered, thereafter.

5.1.1 Personality disorder access to the disability grant in an inpatient sample

A significant finding from this study is of the high rate of personality disorder diagnosed in this inpatient sample (n = 122, 51.5 %) compared to the estimated community prevalence rate in the SASH study (6.8 %) (Suliman et al., 2008). Half of the patients with access to the disability grant in this study also had a personality disorder (n = 31, 52.5 %). This is suggestive of the fact that access can be achieved, possibly equally to those patients who have a CMD without personality disorder. Further support that access is achievable comes from the Franken (2016) study with double the sample size of this study, where it was found that 37 % of patients in an acute psychiatric setting had access to the disability grant. Increased sample size for the population of interest may tend towards similar rates.

5.1.2 Impact of the disability grant

The disability grant is viewed ambivalently and achieves mixed results as a tool for social support and as a measure of disability. For recipients it is mostly experienced as helpful and necessary for economic survival, but also as insufficient and contributing to experiences of dependency and stigmatisation. The disability grant is used in unintended ways, such as supporting those other than the designated recipients, and in the service of loans that have been given based on the fact of disability grant receipt. For all patients with personality pathology in this study, the disability grant served to meet basic needs for food and shelter. The grant also was a means of connection with family and friends and functioned not just as a social bond but as a guarantee of reciprocal support when financial resources ran out. This is consistent with other South African findings in the use of the disability grant (Brooke-Sumner, Lund, & Petersen, 2014; Kelly, 2019). Findings from this study suggest that grant income had other, unintended impact in that it could support higher order developmental aspirations in the form of individual recipients’ role as a contributing member of a family system. It appeared at times to support the development of mature personality in that the income allowed the recipient to be goal-directed and independent to a felt degree. This appeared to have effects on feelings of increased self-worth.

This latter outcome has support in other state cash support programmes in South Africa and Brazil (Badue & Ribeiro, 2018; Hunter, Patel, & Sugiyama, 2021).

The cessation of disability grant receipt that comes about through an intentional lapse during re-application, has significant negative impact. Participants reported the experience of diminished independence and economic and family participation, and the erosion of self-worth and social bonds. In that the period of lapse of the disability grant can last for 4 to 8 weeks and sometimes longer, the negative effects on mood (anxious and low mood) and self-esteem mean that a significant impact of the disability grant is on mental health. Further, instability in identity and affect regulation that is pervasive in the personality disordered population is reinforced when supportive resources are destabilised such as when there are unintended extended delays in access that come about with long appointment waiting times, not queueing early enough to be assisted, or engaging in repetitive or duplicate processes. The reinforcement of this symbiotic relationship through mandatory re-applications eschews alternative ways of relating outside of that relationship. This is an important consideration for understanding patients' relationship with access to other supportive means for mental health recovery, and six-monthly or yearly reinforcement of this could cumulatively lead to negative mental health outcomes downstream. Distribution of government social support grants that are timed to meet bureaucratic logic have already been shown to compromise the gains that it had originally meant to achieve, with the child support grant (Luthuli, Haskins, Mapumulo, & Horwood, 2022). Of note, participants did not dispute that the grant lapse and re-evaluation should be reviewed. This group seemed resigned to the inevitability of this happening and did not argue that their 'invisible' illness should be treated differently to a physical disability that prompted a permanent disability grant.

5.1.3 Return to work

A sustained, long-term return to work did not seem possible for participants in this study. This was true despite repeated attempts to engage in formal or informal work. This finding supports previous evidence from South African households that those with disabilities (all-cause) are more likely to have fewer years of education and remain outside the work force than those without (Hanass-Hancock & McKenzie, 2017). Given together with findings from this study that social services grants are often pooled amongst the patient's family network, and findings from personality disorder research that spouses of this group have lower earned income than matched controls (Hastrup et al., 2019), it is a concern that this group is subject to bonded networks that reinforce economic insecurity. Participant inability to return to work seems to be multi-factorial and may include systemic factors such as the failure to integrate psychiatric disability within supported and meaningful work placement. This is evinced in the report that willingness to be accommodated at work is lacking and can arguably be seen as the failure to translate disability activism beyond policy to implementation. The World Health

Organization promotes work as a protective factor for mental health and, concomitantly, work can pose a risk to mental health where individuals may experience rigid norms, lack of control over their work, discrimination, exclusion or conflicting personal and work demands ((WHO), 2022). The WHO offer guidelines on mental health at work that are concerned with the protection from discrimination of those with mental health conditions, to promote rights to access and for support when returning to work. This includes improvements to the workplace at the organisational level and workplace implementation of evidence-programmes that promote mental health and prevent mental health conditions ((WHO), 2022). Workplace accommodation interventions are used to promote sustained participation in work activity "by providing favourable and adapted working conditions, matching the needs and requirements of workers living with disabilities" (WHO, 2022, p. 24). However, workplace and societal culture that has prevented reasonable accommodations from becoming mainstream, may continue to marginalise those with disability. Further to this study, a reluctance to assign disablement to a personality disorder diagnosis could contribute to delegitimising this as a mental health issue and thus with no option of workplace support where it might have been available, increasing marginalisation. Identification and stigma as a beneficiary of reasonable accommodation may also prevent individuals with psychosocial disability from accessing these interventions. For individuals with mental health difficulties or psychosocial disability, access cannot be achieved without also mitigating stigma about these.

The intersection of broader socioeconomic policy and the personal is a factor in return to work. The low supplemental income threshold set by the DSD was cited as a barrier to sustained engagement with formal or informal employment. Where this might have been overlooked in order to engage in employment that would offer above-threshold income, participants were concerned that SASSA officials would respond by enforcing the rule in a punitive manner. Stepping foul of SASSA income mandates created scenarios of punitive treatment by officials who already had problematic relationships of power with grant recipients. Ideas around these power dynamics with government officials were not explored. Rather, participants' uncertain assessment of whether recovery would be sustained during employment, contributed to circular thinking that they should not violate income threshold prescriptions and so they did not test this by engaging the capacity to work, thereby contributing to a delimiting address of their economic and psychosocial need. Consequently, it is suggested that the inability to return to work would likely mean the erosion of a skillset over time that would make return to work at a later point even more unlikely, increasing disablement.

5.1.4 Barriers to access

Qualitative data from mental health users with a serious mental illness of schizophrenia in South Africa suggest that knowledge of mental health diagnosis is low (Brooke-Sumner, Lund, Petersen (2014). While participants in this study on personality pathology requested knowledge about their personality disorder diagnosis, the delayed acknowledgement of having some knowledge suggests that this low reporting might have acted as a placeholder for some other phenomenon. Given the context of a one-on-one interview, this is surmised to be an unarticulated need for an increased level of validation for the diagnosis. This may be suggestive of internalised stigma and is supported by findings that those with psychosocial disability and mental and physical ill-health, are notably reluctant to also ascribe disablement to mental ill-health as well as physical illness (Ringland et al., 2019).

Stigma was a significant experience of disability grant recipients and was described as internalised, as directed to them by their communities and familial members and by health professionals and SASSA officials. This is in keeping with findings from a Lancet commission review (Thornicroft et al., 2022) that describes self-stigma, stigma by association, public and interpersonal stigma and structural stigma as routinely experienced by people with lived experiences of mental health conditions (PWLE). Despite South Africa being a signatory to the United Nations Convention on the Rights of Persons with Disabilities, and the African Union Protocol on the Rights of Persons with Disabilities, report findings suggest that the country faces significant on-going challenges in dealing with gender-based violence, xenophobia and albinism. Inconsistent application of the disability grant for people with albinism has been found and this calls for caution around the influence of stigma that contributes to an emphasis on medical disability whilst over-looking psychosocial impairments ((OHCHR), 2019). Stigma in the current study was ascribed to judgements for having a psychiatric illness and receiving a disability grant for it. Where participants experienced a barrier of clinician judgement around access to the disability grant, this delayed access and contributed to experiences of distress. Some participants were aware of hesitancy of doctors to make these applications, and this is supported by views expressed in the clinician survey. Barriers in assistance with the grant appeared to happen more with general medical doctors (as opposed to psychiatrists), according to patient participants. However, this same hesitancy was admitted to by mental health professionals who responded to the clinician survey. Although most clinicians agreed that working with personality disordered patients was a routine part of their work, they did not believe that making disability grant applications for this population was a routine part of the work. This stands in opposition to the fact that most patients admitted to Ward 1 with disability grant access had a personality disorder diagnosis, rather than CMD without personality disorder. It can thus be hypothesized by integrating these findings from the file review and the clinician survey that clinician ideas of what routinely arises as part of their work may be a biased assessment based on subjective dislike for the task, or perhaps a lack of engagement with the personality disorder diagnosis. Findings suggest that mental health professional barriers to engaging with disability grant applications for personality disordered patients may stem both from personal attitudes about disability in this group of patients, as well as assessment issues with the SASSA application form.

Clinicians involved in the disability grant assessment and application process experienced uncertainty about the accuracy of their assessment practice for distinguishing between enduring impairments in functioning, and difficulties that may be associated with acute stress and episodic deteriorated functioning, in the patient with personality pathology. Whether clinicians believe that this distinction is possible in CMD is unknown and might benefit from consideration. Regardless, it appears that the fact of personality pathology appears to complicate this assessment and subjectively causes concern for the clinician about their ability to perform their role function. Most clinicians expressed confusion about how to make assessments for the patient with personality pathology compared to those with other CMD or a serious psychiatric disorder and were also mostly uncertain whether they were conducting the assessment accurately. Some clinicians were uncertain about whether patients with personality pathology were pretending to be more impaired than they were, possibly contributing to experiences of being professionally compromised. This could contribute to feelings of vulnerability and beliefs of incompetence in the process, given that the majority believed that the SASSA application forms were insufficient to capture the impairments of a patient with personality pathology. Patient participants, however, generally spoke favourably of their experience with mental health professionals across different settings, compared to general medical professionals. These participants felt confident about the process of application when assessments were made by mental health professionals who had the dual role of being the treating doctor and assessor for the disability grant. For the clinician this role was more conflicted, and they preferred to not act in this dual capacity, with most believing that another clinician should act in this role.

Clinicians indicated that patients with personality pathology should have received optimal treatment before being considered for the disability grant, and that in most cases they had not. This might contribute to hesitancy in talking about disability grants with patients. Both patients and clinicians thought that access to therapeutic services, particularly psychotherapeutic services, was limited. Whilst psychological therapies rendered by psychologists appeared to be the focus for patients, they also noted that resources for developing emotional, occupational, and relational skills are lacking. According to their subjective report, clinicians did not hesitate making disability grant applications because of the demand for more rehabilitative services, and neither did it prevent them from considering the therapeutic options for patients. Despite difficulties with assessment or with interpersonal engagement of patients with personality pathology, clinicians did not subjectively appear to believe that they ‘give up’ on the patient with personality pathology when they present for a disability grant assessment and reported that they do still consider therapeutic services for these individuals to support their mental health.

Clinicians and patients shared the view that the quality of the interpersonal relationship was important for a helpful discussion about the disability grant. For patients it was apparent that the clinician's person-centred approach that emphasised a quality of humanity worked to successfully contain and support their mental health, and in its absence contributed to experiences of discomfort and distress, confrontation and isolation. Promotion of a person-centred approach may also be at the heart of disrupting stigmatising of patients who receive disability grants in the absence of visible physical disability.

Clinician report supports the idea of MDT collaboration when making assessments for the disability grant application and endorsed patient report that it does not happen as a routine practice. The barriers that prevent this MDT collaboration were not explored in this study. Benefits of the collaboration appear to be evident for both the clinician and the patient, in that clinicians are likely to feel assisted and supported when risk of decision-making in a complex process is shared amongst health professionals. It can be speculated that patients themselves would likely view the assessment outcome as having increased objectivity, though this would have to be assessed against the finding that patients' experience of being 'known' by the doctor who both treats and assesses for the disability grant is preferrable in its supportive and containing function. Rather than dual roles of doctors being anathema to focussed and sound clinical work, it was experienced as a moderating factor for a stressful experiences of patients, whose narrative is an important part of their interaction with health care professionals and for their recovery/rehabilitation process.

The clinicians' report that they were not more concerned with public spend of money on disability support pay-outs compared to private spend, was noted. However, the large proportion of neutral responses should raise suspicion that responses were biased for reasons that weren't immediately explored. The fact that a third of clinicians admittedly were concerned with proper spending of government funds suggests a concern with risk that is outside the ambit of work for their discipline. However, psychiatrists concern themselves with managing mental health-related and medical risk as a routine part of their work. Carrying 'risk' for societal economy may be an extension of that risk-concern, considering their visibly responsible role in society. However, it has been demonstrated that practitioner emphasis on health risk avoidance (vulnerability, harm to self and others) can be a barrier in doing recovery-oriented work with patients (Tickle, Brown, & Haywar, 2012) . What might be an over-extended concern with risk may also stand in place of real feelings of confusion about how to go about the task of addressing tensions between differing and perhaps conflicting roles and their execution.

A positive association between substance use and disability grant use has been demonstrated in the population admitted to Ward 1 over two years. Taken together with other findings from a South African sample of patients in a rehabilitation programme that found that never having received a disability grant was associated with increased likelihood of completing the rehabilitation programme (Dreyer et al., 2020), it appears that the relationship between substance use and disability grant use requires further investigation.

5.2 Limitations of study

There are several limitations to this study. A retrospective record view may not be representative of the broader population of people who live with PD and do not have access to the DG. This is particularly so given that the study was based on a clinical population. Further, sampling of the target population of patients with personality pathology may have been skewed towards those with pathological personality traits, as those with a personality disorder diagnosis were observed to be less contactable. The latter group may be considered at higher risk of being lost to mental health follow up, and for mental ill-health, than those with personality traits who were contactable. As it pertains to this study on access to the disability grant, it can be speculated that those with a personality disorder diagnosis might have more pronounced difficulties with access even than those with disordered traits, and that the findings of this study are also valid to the former.

A significant limitation to the study was the low response rate to the clinician survey. Because the clinician survey aimed to include areas for exploration identifiable from the patient interviews, it was not distributed concurrently to it. Patient interviews commenced in July 2021 and had to be suspended twice due to ethical restrictions on human contact for research purposes during the covid-19 pandemic. The distribution of the clinician survey occurred in December 2021, at a time that the South African healthcare system anticipated the fourth wave of the covid-19 pandemic. The impact of the pandemic in the preceding 20 months meant that health professionals were experiencing a deterioration in mental health that could have affected motivation and interest. In a population with high levels of anxiety, depression, and stress (Dawood, Tomita, & Ramlall, 2022) the request to make a further contribution in a study about a 'difficult' patient group may have engendered experiences of frustration and resentment, and contributed to the barrier to access that was experienced. Because of a low response rate and uncertain impact of the covid-19 pandemic on mental health professionals' mental health at the time, results of the clinician survey should be treated cautiously. It is also a shortcoming in the survey that clinicians were not asked if their view of the poor aptitude of the SASSA assessment form affected the likelihood of their initiating talk about a disability grant assessment with patients with personality pathology.

Creswell et al (2018) make the point that “backyard research”, namely, research undertaken in one’s own organisation or work setting, holds the possibility of a power differential between the researcher and the participants. Research on one’s own work setting may compromise the ability of the researcher to ask critical questions (Creswell & Creswell, 2018). The researcher argues that it is in fact the criticism of her own organisation/work setting that led to this research, namely that there had been concern that noticing own and others’ confusion about personality disordered patients’ ‘deservingness’ of the disability grant, should be interrogated. This interrogation required reflexivity that could allow for easing of a power differential in the researcher’s contact with patient participants, but also in the researcher’s contact with colleague participants where item content in the survey might have held judgement. Challenges to researcher attitude through personal judgements in patient interviews based on likeability, presented itself, with the experience of a strong response to some participants’ attempts to be pleasing. Reflexivity in the interview and after, was necessary to facilitate the freedom of opinion and views in the participant, and to prepare the researcher for what could be similar challenges in subsequent interviews. During the analysis of qualitative results from patient interviews, the researcher experienced increased feelings of emotionality, likely arising from the material of need and the dual role of ‘studying’ patients with personality pathology as well as providing care – mirroring some of the conflict experienced by psychiatry colleagues in their dual role. To the extent that this is a complication of engaging in backyard research it is deemed more appropriate to have a clinician with knowledge of personality pathology conduct these interviews, rather than not.

Limiting this study was the Western medical model approach, utilising a language of ‘symptoms’ and ‘impairment’, that had also been internalised by this small psychiatric population sampled. It may be that community samples of individuals with personality pathology would have different explanatory models for their experience of distress and the factors that ameliorate it, other than those offered through health professional and social services, as reported by the patient participants in this study.

5.3 Impact of Study

The study is relevant for all stakeholders including patients, health professionals and organs of the state aiming to achieve mental wellbeing in South African society. It provides some knowledge on the impact of social protection interventions for a population of people with a specific disability, about which little has been known. This study has demonstrated that appropriate and timeous access to the disability grant for the occupationally impaired patient with personality pathology may be hindered through the state requirement for review and lapse of the grant. A similar difficulty of government mandates around a grant has been demonstrated amongst expectant mothers who work informally in Durban, South Africa, who are only allowed to apply for the state child support grant once they have had a live birth. This policy guideline is seen to create greater economic vulnerability for these women at the time just before and after giving birth, when they are more likely to be unemployed and financially in need, affecting both child and maternal health (Luthuli et al., 2022). This study on patients with personality pathology suggest that the way in which the grant is provisioned at time of review may result in inequitable access to state cash support that would otherwise support economic and mental health and well-being (Bhugra, Tribe, & Poulter, 2022).

This study forefronts stigma as an ongoing challenge in mental health. Stigma related to 1) having a psychiatric disorder and 2) receiving state support for a psychiatric disorder has been documented and points to the need for mainstreaming of state social support programmes for psychiatric disorders so that communities have knowledge to cite it. This study also demonstrated that patients themselves did not name their personality traits or disorders. Thus, we see that disorders of personality have not yet been accepted as a valid psychiatric disorder for patients labelled with it and has not yet fallen within the common parlance for citing and judgement by communities in the South African context. Of concern is the observation that health professionals, rather than laypersons, were identified as directing discrimination towards this group of patients for having state cash support and a personality disorder diagnosis, with evidence of internalisation of this by patient participants in this study.

Mental health professionals' opinions have been given voice in the difficulties they encounter with patients with personality pathology and the application process for disability grants, to which they act as conduits. To this end, recommendations for practice have been derived and presented, below.

5.4 Recommendations

5.4.1 Re-evaluation of grant lapse during DSD review

Findings from this study suggest that initial access to the disability grant is achievable and that despite difficulties, mental health professionals can negotiate this with their patients, but that what happens in the course thereafter when the disability grant lapses, is fraught. Poorer mental health and deterioration in functioning might arise directly from the fulfilment of the DSD review and the lapse in grant pay-out during this process. Intervening to prevent relapse in the form of marked deterioration of occupation, leisure and interpersonal functioning that results in moderate to severely impaired functioning should be the concern of holistic health (clinical) and social management. Where increased impairment occurs, it is necessary that these individuals are held within safety-nets that promote return to their well-being even within the context of a longstanding mental disorder (Campion et al., 2022). This poses a direct challenge to DSD to address unintended harmful consequences when fulfilling a bureaucratic mandate.

It is recommended that:

1) DSD mandates that disability grant reviews be scheduled 2-3 months prior to the grant end date. It is suggested that this would:
    i. Prevent negative mental health and social well-being outcomes that are associated with an absence of cash support.
    ii. Encourage early discussions about functioning between the clinician and patient that could manage patient expectations and uncertainties about the future.
    iii. Support the clinician in longer-term planning with patients about approaches to rehabilitation and occupational engagement.

2) where 1) has failed to occur timeously, that there is continuation of the disability grant if the necessary application has been made and whilst awaiting the outcome of such application.

3) The above requires that DSD consider untying the "temporary" disability grant descriptor from a lapse in the grant, and better align this with opportunities to engage in incentivised programmes for health and recovery, in a partnership with the private sector.

5.4.2 Larger-scale epidemiological studies

In the South African context, personality pathology suffers from a lack of quantifiability – both in terms of epidemiological data but also in terms of the cost to treat. This likely contributes to suboptimal treatment, recovery and support, including access to disability grants. Whilst government cash pay-out support may be a protective economic, social and mental and physical health variable (McGuire et al., 2022), given the South African context it would be necessary to conduct larger epidemiological study that:

1) is adequately powered to detect personality pathology and their access to the range of social protection programmes and its allowances, and
2) to determine associations between government cash support and psychosocial and health outcomes that are objectively measurable.
3) Attempts to understand the possible bi-directional relationship of disability grant use and improvements in psychosocial functioning, given the hypothesis that there may be a proportion of individuals for whom the negative sequelae of disability support would need to be weighed against the benefits. This could include individuals with specific personality characteristics (for example, avoidant personality disorder), which could be elucidated in such large-scale studies.

5.4.3 Multi-sectoral coordination in aid of mental health

Psychotherapy rendered by psychologists are a scarce resource in South Africa. A patient-psychologist ratio of 2.5 psychologists per 100 000 population (Padmanabhanunni, Jackson, Noordien, Pretorius, & Bouchard, 2022) renders one-on-one service delivery requests by this patient cohort unrealistic. Patients may not be aware that psychological therapies also fall within the scope of services delivered by clinical occupational therapists, social workers, specialist mental health nurses and psychiatrists. The formulation of the personality disordered group's sensitivity to ecological impingements requires a holistic health response that promotes resilience through education, occupation, leisure, social and familial relational practices, which these disciplines can offer. This requires intersectoral coordination and support. Findings of an association between substance use and disability grant access in the current study require further elucidation. Further findings of an association tending towards significance suggests that personality disorder may be an effect modifier for disability grant access, where a substance use disorder is present. Large cohort health sciences research has a role to play in understanding how the economic and social strategy of government cash subsidy mitigates social ills that impact health care in certain groups. This might point to the incentivising of rehabilitation programmes that are linked to disability support pay-out. An example of this kind of incentivisation would be the conditional cash transfer system in Brazil, the implementation of which is dependent on recipient compliance with health behaviour such as school attendance, pre-natal visits and vaccination scheduling (Magalhães, Bodstein, Coelho, Nogueira, & Bocca, 2011). Substance rehabilitation programmes that incentivise rehabilitation or abstinence and other health behaviours with disability cash support might want to consider the mediating impact of personality when considering participants to this programme. Further, whilst the transactional nature of this agreement requires active responsibility-taking from government agencies and the targeted population, it does also raise the spectre of necessary compliance that may be a civic rights issue. The proscribed nature of this agreement may lend itself to abuse through skewed assessments of compliance to this agreement. This is likely a risk in a personality disordered population that struggles with compliance, particularly where they are in relation to agencies that demonstrate a punitive culture, such as described by participants about SASSA officials. Whilst in South Africa the emphasis on multi-agency coordination and intervention for holistic wellness is nascent (Simon, Adams, Goh, Suhaimi, & Hassem, 2021), the 2022 rebranding of the Western Cape provincial DoH into the Department of Health and Wellness augurs a reorientation from pathology to contextual and holistic health provision. However, it is as yet unclear how policy and strategic cooperation between agencies within government will be articulated.

It is recommended that:

1) Patient education for this population about, and normalisation of, multi-pronged and multi-agency intervention should occur to encourage agency and access.

2) Incentivising patient participation in recovery such as employment programmes, and possibly substance rehabilitation and abstinence, could be areas of multi-sectoral focus that would require coordination.

3) Given the growing base of social grant recipients in South Africa, government and the private business sector need to collaborate to give articulation to DSD's "temporary" disability grant, through facilitating opportunities for levels of recovery and participation in the economic sector, rather than as a necessary lapse during which losses occur and little is gained.

5.4.4 Government role in redress of stigma in psychiatric disability

Societal messaging about the government approach to cash pay-out support is lacking. This is needed to encourage agency in individuals with psychiatric disability to access the disability grant. This would also aim to legitimise access as a right and normative for this reason, amongst broader South African society, as evidence suggests that both knowledge and direct and indirect contact with PWLE can work to reduce stigma. In South Africa there is support for this in awareness campaigns about the child support grant that increased rights-based access and uptake of this social support measure (Hunter et al., 2021; Luthuli et al., 2022).

It is recommended that:

1) multiple government departments of health and wellness, social development, labour, and ancillary societal agencies contribute to awareness campaigns about social support for individuals with psychiatric disability. This promotes knowledge and acceptance culture of the support available for the range of 'invisible' needs.

2) Stigma redress will benefit from the realignment of the "temporary" grant to include recovery-aligned incentivisation, giving access to the economy and acceptance culture.

5.4.5 Clinical training and decision-making with MDT collaboration

Social support gatekeeping and decision-making by psychiatrists is not feasible and does not fall within the professional scope of treating psychiatric doctors. Ideal practice in management of the personality disordered individual is inclusive of adjunctive health care disciplines with psychiatry. This has been identified as a need amongst the group of clinicians in this study and may alleviate the burden of gatekeeping through sharing and collaborating on their tasks with adjunctive disciplines. Patients and clinicians identified that clinicians need to attend to both patient personality style that confounds clinical assessment of need, and to see beyond this to identify the impairment attendant with pathological patterns. This would require reflexivity that steps outside of the medical model approach to disease, to draw on psychotherapeutic concepts in facilitating this interaction.

It is recommended that:

1) Mental health practitioners would benefit from training guidelines for making assessments that relate to levels of impaired functioning, beyond what they are being asked to consider by the DSD forms. This would:

    i. Align the assessment process with clinical guidelines for understanding the patient with personality pathology.
    ii. Support a re-alignment of DSD's use of the "temporary" disability grant to incentivise amelioration of impairment, and recovery and economic participation.

2) Mental health practitioners would benefit from ongoing training opportunities that addresses difficulties in their work with personality disordered patients, including:

    i. Developing insight into unconscious bias, and the impact of stigma
    ii. Awareness of transference and countertransference that might arise in the interaction around disability grants for this population, and the use of reflexivity in the encounters.
    iii. Skills training and supervision to manage difficult interactions with this patient population, as a routine part of the work.

3) An argument can be made that clinicians should be supported in their usual treatment of personality disordered patients by allocating disability grant assessments of their patients away, to another colleague. However, resource capability and the factors that contribute to patient confidence that a legitimate and fair outcome would arise from such a referral would need to be considered. The latter would be important for patient satisfaction and adherence to services. Further, it would need to be understood whether contact under the condition of making these assessments could assist to ameliorate stigmatising attitudes of any health professionals. This is an area that requires further study.

4) Whilst the clinicians who reported a concern with gatekeeping of state financial resources might be in the minority, it is important to adequately address role limits through their professional training. This would preventatively act to address burnout and straying into the area of social support with judgements, opinions and behaviours, that might compromise them professionally.

5.4.6 Qualities of mental health support

As personality diagnosis was often left out of participant account of diagnoses, it would be necessary to consider that they lacked knowledge of having this diagnosis or significant pathological personality traits assigned to them. When questioned, however, participants did indicate awareness of this. The hesitation to include these descriptors from the outset may be attributable to lack of understanding or stigma about these diagnostic descriptors. Though participants were likely to have their personality diagnoses, or significant personality traits implicated in impaired functioning discussed with them during their admission to Ward 1, it is also likely that the latter group may not have explored this further for the above reasons. It is uncertain that robust patient engagement with personality pathology as driving impairment is necessary for patients' engagement with recovery-oriented strategies. Whilst empathic communication of diagnoses and pathological personality traits could contribute to experiences of being understood, it is the provision of consistent mental health support focussing on 1) experiences of identification with others 2) feelings of being treated humanely 3) assistance with problem-solving, and with 4) perspective-taking, that seem to be valued in this group. However, even though a person-centred approach is valued and reduces stress for the patient, it is not certain that this would translate into recovery-oriented strategies supporting economic participation.

It is recommended that:

1) Noting the observation that those with a personality disorder diagnosis were less likely to be contactable than those with pathological traits and no specific PD, it is suggested that patients with a personality disorder diagnosis be considered for more active follow up strategies during periods of disaster and societal distress, such as was experienced during the covid-19 pandemic and in the period that this study was conducted.
2) Personality disorder, like any other psychiatric disorder, carries the risk of impairment and disability, and an argument can be made for disability grant utilisation due to attendant impairment. This would increase the cost from health expenditure to include government social support expenditure in the form of the disbursement of disability grant support to this population.

More needs to be understood through investigating the life-long trajectory of disability grant use, personality pathology and rehabilitation for this group of patients, to plan for the demands on state cost in healthcare and social support for this group.

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APPENDIXES

Appendix 1: Information from File Review

Date of review: Code: Reviewer:

DEMOGRAPHIC INFORMATION					
DATE OF BIRTH					
NATIONALITY					
GENDER (IDENTIFYING)	Male	Female	Other		
RELATIONSHIP STATUS	Single	Partnership	Married	Divorced	
DEPENDENTS	No of dependents		Ages of dependents		
CO-HABITATION	Alone	Spouse/ Partner	Family of Origin	Friend	Social Service
EDUCATION LEVEL	Primary	Secondary	Tertiary	School of skills	Learnership
EMPLOYMENT STATUS	Unemployed	Informal Employment	(Returned to) Formal Employment		
DISABILITY GRANT STATUS					
DISABILITY GRANT RECEIPT (D.G.)	Never	None (unemployed but undecided re application)	Current (State)	In re-application (lapsed) (State)	Private Insurance
REASON FOR D.G. GIVEN	Not given	Medical		Psychiatric	
AGE OF FIRST APPLICATION					
PSYCHIATRIC & MEDICAL INFORMATION					

PRIMARY PSYCHIATRIC DIAGNOSIS					
COMORBID DIAGNOSIS	1.	2.	3.	4.	
PERSONALITY DISORDER DIAGNOSIS					
PERSONALITY DISORDER TRAITS					
SUBSTANCE USE	Alcohol	Cannabinoids	Sedatives incl. over-the-counter medication	Hypnotics incl. over-the-counter medication	Other Illegal Substances
SUBSTANCE REHABILITATION	Never	Inpatient	Outpatient		
MEDICAL CONDITIONS	1.	2.	3.	4.	5.
PSYCHIATRIC ADMISSIONS IN PAST 10 YEARS	0	1-2	3-4	+4	

Appendix 2: Patient Informed Consent Form

University of Cape Town

Department of Psychiatry & Mental Health

Thank you for agreeing to learn more about this study. The study is being led by Hayley Julius, at the University of Cape Town and clinical psychologist at Ward 1, Valkenberg Hospital.

Title of the Study: Disability grant utilisation, and barriers to access for patients with personality pathology: A mixed-methods study.

About the Study: We are interested in your experience of receiving a government disability grant for your psychiatric illness. Your personality characteristics or traits, which contribute to your tendency to think, feel or behave in a certain way may have influenced how you experienced your mental health condition, and the ability to get access to a disability grant. We would like to know how you experienced this. We are also interested to hear if you felt helped by receiving the disability grant. We have very little information about this for South Africans. We would like to be able to understand your experience of receiving a government disability grant so that it can help with the process for similar patients in the future.

Why you have been asked to participate: You received treatment at Ward 1, Valkenberg hospital where some patients' ability to look after themselves, interact with others and with their work is affected by their personality, and as a result want to consider a disability grant. We have identified you as someone whose personality functioning we are interested in and who has been able to access a government disability grant.

How we will do the study: We are inviting several previous Ward 1 patients to participate in a private and confidential interview. If you have agreed to participate, the researcher (Hayley Julius), will meet with you alone in a consulting room at Valkenberg hospital outpatient department. You will be asked to confirm some of the information from your Valkenberg hospital file, and you will be interviewed on your experience of accessing the government disability grant. You will be reimbursed R150 for your travel expenses and refreshment.

What you are being asked to do: The interview will last between 60 and 90 minutes. You will be offered a break in between. You can ask questions at any time or refuse to answer certain questions that you feel uncomfortable to answer. We are asking you to talk about how you experienced getting a disability grant, the problems you encountered around this, and whether being on a disability grant affected you in positive or negative ways. We would like to audio-record the interview in order analyse the information when listening to it again so that we don't miss anything you said.

Who will have access to your information: We will not use your name but will assign you a random number so that your information is anonymous and so that you can't be identified. The researcher will keep all information locked away in an office. Your answers will only be discussed with the researcher's supervisors and members of the research team in order to understand and agree on the information that is necessary for the study, but you will not be identifiable by name.

Researchers and supervisors at the University of Cape Town, the Human Research Ethics Committee, or researchers at other universities may want to examine the information collected, but this will not include your identifying information. If the results get published in a journal, you will not be identifiable.

Risks to You: During the interview, you may become upset at being reminded of something. We will support you should this happen. The interviewer may have to inform staff at the outpatient department or of your treating team, if there is a risk of you hurting yourself or someone else, in order to keep everyone safe. There will be no negative consequences to you if you choose to not continue for the time-being, to reschedule the interview, or to withdraw from the study.

Benefits to You: During the interview, you may realise something about yourself that may be to your benefit.

You Have a Choice: You can choose not to participate in the study and there will be no negative consequences to you or your receipt of the disability grant.

Who to speak to if you have any questions: Please contact the researcher, Hayley Julius on 021 440 3109 (Ward 1, Valkenberg Hospital), or on 021 826 5855 (Building HA4, Valkenberg Hospital), if there is anything you would like to discuss further.

You may also contact the Human Research Ethics Committee at UCT on 021 406 6338 if you are concerned about your rights and welfare as a research participant.

University of Cape Town

Department of Psychiatry & Mental Health

CONSENT TO PARTICIPATE IN RESEARCH

Thank you for agreeing to learn more about this study. The study is being led by Hayley Julius, at the University of Cape Town and Clinical Psychologist at Ward 1, Valkenberg hospital.

DECLARATION BY PARTICIPANT

By signing below, I ________________________________ agree to take part in the research study entitled: ***Disability grant utilisation, and barriers to access for patients with personality pathology: A mixed-methods study.***

I declare that:

1. I have read or someone has read this information and consent to me in a language that is understandable to me
2. I understand the study is confidential
3. I understand the risks and benefits of participating in this study
4. I have had a chance to ask questions and my questions have been answered fully
5. I agree that the interview will be audio-recorded
6. My participation is voluntary at any time of the study and I can choose to not answer certain questions, or withdraw from the study and will not suffer negative consequences for doing so

Signature of participant: _________________________

Signed at (place) ________________________________ on (date) ___________________________

DECLARATION BY INVESTIGATOR

Name of person taking consent: ______________________________

Signature of person taking consent: ___________________________ Date: _________________

Appendix 3: Patient Semi-Structured Interview Protocol

“Disability grant utilisation, and barriers to access for patients with personality pathology: A mixed-methods study”

A. Instruction to Interviewer:

Welcome and thank the participant for agreeing to the interview. Explain the purpose of the study (see informed consent form). Remind them of what they can expect and invite questions. Request the use of audio recording and have them sign the consent form.

During the interview:

DO notice if the participant seems to change in attitude (e.g. friendly to unfriendly, responses get fewer and further between, or they become restless or upset). You may inquire what is happening for them and offer a break, support and also the opportunity to continue.

DO pay attention to the participant’s responses in order to notice where you need to probe further related to the areas of study; or where new and possibly relevant information is emerging.

DO strike a balance between making notes during the interview (in case the recording fails), and making eye contact and being responsive to the participant.

B. Structured Questions: Confirmation of demographic details

Date of Birth: Identified Gender:

Disability grant status: Current Lapsed In application

Level of Education: Primary Secondary Tertiary School of Skill Learnership

Employment status: Unemployed Informal Employment Returned to formal employment

C. Open-ended Questions:

1. Knowledge/Beliefs

1.1 “Can you tell me what your mental health diagnoses are?’

Probe: all diagnoses. Explore where hesitancy is noted regarding a particular diagnosis, especially personality disorder diagnosis

1.2 “Can you tell me how your diagnoses affect the way that you function in your daily life, your relationships, and in your attempts to worlk?”

Probes: Explore attributions made to personality functioning

1.3. Can you tell me why you are receiving a government disability grant?”

Probe: also ascertain whether patient believes that general tendency to be a certain way in their life wrt thinking, feeling and behaving has a negative effect on their functioning

1.4. “Do you know what a personality disorder is?”

1.5. “Do you think patients with personality disorders should be able to receive a disability grant? Why/not?”

2. Course

2.1 “Tell me about the times you applied for a government disability grant”

Probes: start with first time/ages/when/where/who motivated for it?

2.2 “What was happening all those times/why were you applying?”

Probes: factors related to deteriorating functioning, e.g. exacerbation of economic, interpersonal, psychosocial stressors, effects of clinical syndrome

3. Experience and Difficulties

3.1 “What was the experience like (of applying for a disability grant)?”

Probes: barriers and facilitators in the process e.g. systemic, social, clinician, administrative, participant. Also note experience of positive assistance.

3.2 “What kinds of things would happen with you and (identified problems)”

Probes: how patient characteristics interacted with problem area

4. Own Personality

4.1 “Do you think your personality characteristics played/play a role in not being able to function in a job?” “How?”

Probe: also note other factors that the participant feels are more important, e.g. economic climate

4.2 “Do you think your personality functioning/interaction affected the process of applying for a disability grant?”

4.3 “If yes, in a helpful or unhelpful way?”

Probe: tendencies to behave, think in a certain way, emotions or interpersonal style

5. Impact

5.1 “Did receiving a disability grant help you in your life at all? How?”

Probes: experience of self, relational, socio-economic, clinical syndrome, overall quality of life

5.2 “Have you ever been off the disability grant?” “For how long?”

5.3 “How was life when you were off the disability grant?”

Probes: experience of self, relational, socio-economic, clinical syndrome, overall quality of life

5.4 “Are there any negative things about receiving a disability grant?”

Probes: experience of self, relational, socio-economic, clinical syndrome, overall quality of life

5.5 “What would have helped you in your struggles with functioning, and trying to get access to the disability grant?”

Probe: also, whether participant believes they should have received more (optimal) treatment/rehabilitation instead of a disability grant

END: Instruction to Interviewer

Thank the participant. Do they have any further questions about the study? Hand them an envelope with reimbursement, and have them sign receipt.

ATTACH THE SIGNED CONSENT FORM & RECEIPT OF COMPENSATION TO THE INTERVIEW PROTOCOL

Appendix 4: Clinician Informed Consent Form

University of Cape Town

Department of Psychiatry & Mental Health

Thank you for agreeing to learn more about this study. The study is being led by Hayley Julius, at the University of Cape Town and clinical psychologist at Ward 1, Valkenberg Hospital.

Title of the Study: Disability grant utilisation, and barriers to access for patients with personality pathology: A mixed-methods study.

About the Study: This study forms part of a broader investigation that includes the experience of patients with personality pathology accessing state-issued disability grants. We are interested in your experience as a clinician in the Western Cape Department of Health facilitating disability grant access for these patients through the completion of disability grant forms. We are particularly interested in the difficulties you experience when approached to complete disability grant applications for patients with personality pathology. It is hoped that this study will offer insight into the kinds of difficulties clinicians encounter and contribute to considerations for how this could change.

What you are being asked to do: Should you choose to participate, you are requested to complete this online survey of approximately 10 minutes that includes responses on a Likert-type scale, and some free response. Please feel free to express yourself candidly in the free responses, as your participation is anonymous and confidential.

Who will have access to your information: The study has been approved by the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee, and the Western Cape Department of Health. Your anonymous answers will only be discussed with the researcher's supervisors and research team in order to analyse data. Researchers and supervisors at the University of Cape Town, Human Research Ethics Committee, or researchers at other universities may want to examine the anonymised information collected.

Who to speak to if you have any questions: Please contact the researcher, Hayley Julius on 021 440 3109 (Ward 1, Valkenberg Hospital), or on 021 826 5855 (Building HA4, Valkenberg Hospital), if there is anything you would like to discuss further. **You may also contact the Human Research Ethics Committee at UCT on 021 406 6338 if you are concerned about your rights and welfare as a research participant.**

Appendix 5: Clinician Survey

Demographic Details:

Please share some information about yourself:

Gender	Male	Female	Other	
Age				
Race	Black	Coloured	White	Indian or Asian
Highest level of Education	MBChB	MSc	Specialisation	Other
Current work setting	Community Health Centre	District Hospital	Central Hospital	Psychiatric hospital
Current patient population	Adult services	Forensic services	Child and adolescent	
Years of experience working in the state psychiatric setting				
Years of experience working with adult patients with personality pathology				

Survey Instruction: On a scale of 1 to 5, please indicate your level of agreement with the statements below about your work with patients with personality pathology, where:

1 = Mostly Disagree

2 = Somewhat Disagree

3 = Neutral

4 = Somewhat Agree

5 = Mostly Agree

Experience of working with patients with personality pathology:

1. Working with patients with personality pathology is a routine part of my work

2. I routinely make assessments and applications for patients with personality pathology to receive state-issued disability grants

3. I experience more confusion about completing disability grant applications for patients with a primary personality disorder diagnosis than for patients with common mental disorders such as the anxiety or mood disorders

4. I experience more confusion about completing disability grant applications for patients with a primary personality disorder diagnosis than for patients with serious mental disorders (e.g. psychotic disorders)

5. I experience more concern about applying for state-issued disability grants for patients with personality pathology than about applying for medical boarding of patients with personality pathology when they are being paid out through private insurers

Clinical and Mental Health System Factors:

6. The fact that the patient has personality pathology makes me uncertain whether I am assessing their level of functioning, and not their current stress

7. I often feel uncertain that I am adequately assessing the level of functioning in a patient with personality pathology

8. There is enough time to properly investigate, namely, get informant collateral from treating clinicians, family and previous employer before deciding on the level of the patient’s impairment

9. It is necessary to include other disciplines’ reports when applying for disability grants for patients with personality pathology

10. There is enough collaboration with allied health professionals (clinical psychologists, occupational therapists, and social workers) to help assess the patient’s level of functional impairment

11. I often feel conflicted that I have a dual role as the treating doctor or case manager, and then to make the assessment and application for a disability grant on behalf of my patient

12. As the treating doctor of the patient with personality pathology, I think that another medical professional should be making the assessment and application for the patient's disability grant

13. Patients with personality pathology should first have received optimal treatment (medication, psychotherapy, rehabilitation and recovery services), before applying for a disability grant

14. There are enough therapy and rehabilitation services to optimally intervene with the patient with personality pathology, before considering applying for a disability grant

15. I am happy to apply for a disability grant on behalf of the patient even while they are undergoing psychotherapeutic and rehabilitation services for their primary personality disorder diagnosis

16. The SASSA disability grant application sufficiently captures the ways in which the patient with personality pathology is impaired

Would you like to add anything more about clinical and mental health-system factors:
____
____
____
____

Clinician-Patient Interaction around Disability Grant Applications:

17. It is easy to talk with patients about the benefits and drawbacks of applying for a state disability grant

18. My dual role as the patient's treating doctor and the assessor for the disability grant application makes it difficult to talk to the patient about applying for a disability grant

19. The interpersonal interaction with the patient often adversely influences whether I can be helpful when talking to them about applying for a state disability grant

20. When they ask for a disability grant, I worry that the patient with personality pathology pretends to be more impaired in functioning with me than they do with other allied health professionals

Would you like to add anything more about clinician-patient factors:
____
____
____
____

Own Personality, Beliefs and Values

21. I worry that too much empathy for certain patients with personality pathology affects the willingness with which I make a disability grant application

22. I worry that too little empathy for certain patients with personality pathology affects the willingness with which I make a disability grant application

23. I feel unhappy about making disability grant applications for patients with personality pathology

24. I believe that once the patient starts receiving the disability grant, it frequently has negative consequences for their adaptation and recovery

25. When patients with personality pathology receive state disability grants, I usually feel unhappy that state funds are not being used optimally

Would you like to add anything more about personal beliefs and values:
____
____
____
____

What would assist you to experience greater confidence in making applications for patients with impaired functioning that have personality pathology?

____
____
____
____

Thank you for agreeing to participate in this study.