

**A STUDY OF THE LIVED WORLD OF THE PATIENT WITH BORDERLINE
PERSONALITY DISORDER IN NEW ZEALAND**

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MARLENE DOR

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SUPERVISOR: PROFESSOR M MOLEKI

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Student Number: 5524358

DECLARATION

I declare that **A STUDY OF THE LIVED WORLD OF THE PATIENT WITH BORDERLINE PERSONALITY DISORDER** is my own original work, except where acknowledgements have explicitly been made. The work has not been submitted before for any degree at any institution.



SIGNATURE

Marlene Dor

June 2015

DATE

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STUDENT NUMBER: 5524358
STUDENT: Marlene Dor
DEGREE: D Litt et Phil
DEPARTMENT: Health Studies, University of South Africa
SUPERVISOR: Professor M Moleki

ABSTRACT

Borderline Personality Disorder (BPD) is a major health problem and is associated with considerable psychosocial distress and impairment, resulting in a high degree of morbidity and a significant impact on the mental health system. Patients with BPD are difficult to treat clinically, the main issue being engaging the patient and then maintaining the relationship. Patients with BPD constitute 10-20% of psychiatric inpatients, utilise a large amount of mental health resources and have a 10% successful suicide rate. Therefore, it is essential that attention is given to improving effectiveness of treatment approaches for patients with BPD, including engagement.

The purpose of the study was to explore and describe the lived world of patients with BPD in order to develop supporting guidelines to improve non-compliance of patients with BPD. The objective of the study was to develop guidelines to improve compliance, which is expected to minimise self-harm risks and improve the quality of the patients' lives.

A qualitative, phenomenological methodology was chosen because it is particularly well suited to study human experiences of health (LoBiondo-Wood & Haber, 2011:141). It is a design that emphasizes discovery through interpreting meaning as opposed to quantification and prediction. Understanding and interpretation of data was thus the hallmark of the research design. This phenomenological study examined human

experiences through the descriptions provided by the people involved, i.e. lived experiences.

Data collection was done using recorded interviews guided by a semi-structured interview schedule. Memos collected during interviews supplemented the data.

Data analysis was hallmark by constant comparison, contextualisation and description of emerging themes.

The main findings, described in three main themes, were the importance of the relationship with the clinician, the overwhelming feelings experienced by the patients and the sense of futility in treatment. These were all linked to the lack of hope the patient felt regarding their clinician, ever being able to manage their continuously oscillating emotions and the purpose of treatment.

The findings led to the construction of guidelines to foster initial and continued engagement in treatment with patients with BPD. The guidelines covered issues of clinical practice and management input.

Key words

Borderline Personality Disorder; lived world; patient.

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LIST OF ABBREVIATIONS

| | |
|-------|--|
| AWOL | Absence without official leave |
| BPD | Borderline Personality Disorder |
| CYFS | Child Youth and Family Service |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders, 5 th edition |
| WINZ | Work and Income New Zealand |

DEFINITION OF TERMS

| | |
|----------------------|--|
| Lived world | The individual's lived experience as they themselves perceive it |
| Patient | A person receiving medical treatment |
| Personality Disorder | An enduring pattern of maladaptive behaviours |
| Compliance | The extent a patient follows a negotiated treatment plan |
| Non-compliance | Not following a treatment plan for the greater portion of time or not at all |

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Low compliance to treatment amongst patients with Borderline Personality Disorder makes engagement and management of the condition difficult. Non-compliance leads to relapse, distress, revolving door syndrome, issues of safety, chronicity, sequelae and cost, which all compromise the patient's quality of life (Jin, Sklar, Oh & Li, 2008:272). The decisions the patient makes with regard to whether to engage, and whether to continue with their treatment is important as it will have an impact on their health and quality of life (Sajatovic, Velligan & Weiden, 2010:591).

An important element influencing compliance is the clinicians fit with the patient, including how the clinicians are able to identify the patients' world view (Jaeger & Rossler, 2012:49). Hence, among the variables to be considered in the study are: patient's relation with clinician, clinical practice, and management input.

Patients' attitudes can also impact their decision on whether and how to engage in treatment. The researcher noted that if time was taken to explain, in a non-judgmental and non-dictatorial manner, patients developed a positive attitude toward engagement. The patient then tended to respond by at least negotiating treatment and engaging in some form. This is corroborated by O'Donnell, Donohoe, Sharkey and Owens (2010:836) when they state that a patient's attitude toward therapy positively influenced adherence; those with a positive attitude having an 11 – 15% higher compliance rate.

Generally, compliance is seen as desirable to obtain and maintain optimal health (Robinson, Callister, Berry & Dearing, 2008:602). It gives the clinician an opportunity to respond to early warning signs quickly and thereby often prevent a relapse (Brohan, Slade, Clement & Thornicroft, 2010:3). It allows the clinician to assess whether the treatment is effective and facilitate changes to the treatment if required. From a cost and practical perspective, non-compliance leads to a waste of medication if dispensed and

not used, and a waste of clinician's time (Buntin, Damburg, Haviland, Kapur & Lurie, 2006:516).

The objective of this study was to explore the experiences of patients with BPD. This research looked particularly at the experiences of patients with BPD with regard to the decisions patients made in terms of their ongoing care. The research was done in Whakatane, New Zealand.

This chapter will give an outline of the study, describing the background, purpose, rationale research questions and introduce the methodology of the study.

1.2 BACKGROUND TO THE RESEARCH PROBLEM

Compliance and non-compliance are complex issues that involve the patient, the family, clinicians, the health service and at times society. There are many recognised factors influencing compliance and non-compliance, such as age, type of illness and financial status (Jin *et al.*, 2008:272). However, despite these factors being addressed, there is still a high rate of non-compliance amongst psychiatric patients. Kozma and Weiden (2009:31) estimate a non-compliance rate of 25-94% for psychiatric patients in general, in studies done in the USA. Another estimate is 40-68%, as stated by Sajatovic *et al.* (2010:591). Estimated compliance rates of patients with BPD in the USA is estimated by Binks, Fenton, McCarthy, Lee, Adams and Duggan (2009:3) as being between 20 and 45%, below the average compliance rate of psychiatric patients in general.

In New Zealand there are estimates of compliance rates of 50-60% with treatment by mentally ill patients as cited by Eagar, Trauer and Mellsoop (2005:714). They note that there are lower compliance rates amongst Alcohol and Drug patients, cited as 25%, and higher compliance rates amongst children and the elderly, estimated around 70%. Reavley and Jorm (2011:4) note that rural patients in New Zealand often have a much lower rate of compliance. They also note that the Maori and Pacific Island populations often engage with traditional faith healers, *tohungas*, and are often reluctant to engage with Western medicine. Other statistics on compliance rates for psychiatric patients in New Zealand have been estimated at 20-56% by Wade, Harrigan, Harris, Edwards and McGorry (2006:429). The estimate of non-compliance amid patients with BPD in New

Zealand is cited as 41–70% by Boyce, Carter, Penrose-Wall, Wilhelm and Goldney (2003:152).

Compliance is difficult to define, and also varies quickly when different influences are involved. Due to the high rate of non-compliance (particularly amid patients with BPD) and the severe consequences of non-compliance, it is important to explain compliance further.

1.2.1 Compliance

Compliance is the manner in which the patient follows the treatment advised by the clinician. Compliance is a dynamic concept, particularly when there are safety issues and also as the patient progresses toward regaining their health and independence (Larsen & Lubkin, 2009:11), thus compliance is often seen differently by various people, especially patients and clinicians.

Research in the USA by McKinlay, Link, Freund, Marceau, O'Donnell and Lutfey (2007:290) has shown that one of the most important factors in compliance is the relationship the patient has with the provider. The clinician must engender trust and respect, foster inclusion by the patient, have a positive attitude toward the patient and the treatment, show understanding, be non-judgmental and not manipulate or control the patient. This was found to be especially true regarding patients with BPD (Bender, Dolan, Skodol & Sanislow, 2010:295).

Patient/clinician compatibility is another means to increase compliance. This is addressed by having triage and referral processes where the appropriate clinician is matched with the patient, processes put in place by the various health services. This has had a positive effect on effecting appropriate clinician allocation, because far less non-compliance was noted due to inappropriate referrals. This was also noted by Van der Watt (2010:168) who notes that referral to team members who are not matched can be the reason the patient is non-compliant.

Patient and family psycho-education (to increase knowledge and, hopefully, wise, informed choices regarding engagement in treatment) has had a positive effect on compliance as the patient and family were more likely to realise the benefits and risks of

treatment and feel in control of what is happening to them (McKinlay *et al.*, 2007:290). This was also found in a study done in Taiwan by Kao & Liu (2010:562) where a group of psychiatric patients who had had psycho-education showed a 29% higher rate of compliance compared to a control group, which had no extra targeted psycho-education. This was found to especially true regarding patients with BPD (Bender *et al.*, 2010:295).

Compliance amongst patients with BPD has been cited as 20%, and 85% of non-compliant patients relapse, as well as 10% of patients with BPD complete suicide (Binks *et al.*, 2009:3).

1.2.2 Non-compliance

Non-compliance is seen as not following the advice of the clinician and has many reasons and varying consequences (e.g. decrease in quality of life).

Non-compliance is noted in all medical disciplines. Non-compliance amongst mentally ill patients has been cited as ranging from 25-94% (Kozma & Weiden, 2009:31). Across literature there was the finding that non-compliance rates regarding physical and mental health treatment were concurrent (Byrne & Deane, 2011:286). However, a study done by Lawn, Myer, Bekker and Wood (2007:337) in South Africa, shows compliance rates for treatment of Tuberculosis associated immune disease of over 90%. Cheer (2009:15) notes in her study of countries aligned to the Organization for Economic Co-operation and Development (OECD), that there was a high level of non-compliance and consequent relapse amid mentally ill patients. This is supported by a study done in Taiwan, Kenya and Japan by Kozuki, Pouporo and Schepp (2005:72) which showed similar rates of non-compliance amongst psychiatric patients ranging from 38-80%.

Once a patient has been non-compliant the relationship between the clinician and the patient is affected and it can be extremely difficult to re-engage the patient again (Holt 2007:1938). Non-compliance makes treatment ineffective and the risk of relapse after being non-compliant on medication increases three to five times (Staring, Van der Gaag, Koopmans & Selten, 2010:451).

1.2.3 Factors that affect compliance and non-compliance

Many issues affecting compliance and non-compliance have been identified and addressed. Compton, Gordon, Weiss and Walker (2011:1487) state that patients with psychosis who are treated with antipsychotics tended to gain insight which tended to increase compliance. Chang and Lee (2010:2) state that the severity of symptoms, substance abuse, attitude toward treatment and the therapeutic alliance were important factors affecting non-compliance. These have all been addressed to improve compliance. Affordability, accessibility, ensuring the provision of competent practitioners, patient/clinician fit, and psycho-education have been addressed in an effort to increase compliance, yet non-compliance rates remain high. Affordability has been addressed by offering free psychiatric care, subsidised medication and assisted transport by the various health services funded by the health budget. This has had an impact on the compliance rate as also found by Jong-Wook (2008:85). Subsidised medication has made a huge improvement in patients taking medication (Berk, Hallam, Colom, Vieta & Hardy, 2010:6), especially if the medication is due on the day the patient receives their benefit (i.e. before they have spent all their money). However, the subsidised transport has not had as big an impact as expected because the transport fee is only refunded after the patient has initially paid the fare themselves (Berk *et al.*, 2010:7).

Accessibility has been addressed by clinicians doing frequent home visits to ensure the patient can access the treatment, again funded by the health budget. This has only had some effect on compliance in that some patients do not open the door or allow the clinician in the home. Jaeger and Rossler (2012:51), in a study done in Switzerland, stated that patients sometimes perceived the home visit as coercion. Accessibility was also addressed by clinicians fetching the patient for follow up visits at the clinic, again facilitated through funding by the health budget. By so doing, the follow up rate was increased (Druar, 2005:22).

The provision of competent clinicians is addressed by employers ensuring that clinicians are registered with the relevant registration authorities and employers ensuring the clinicians are regularly updated. This does have an effect on compliance as the patient responds positively (i.e. complies) with a clinician they feel is competent and able to help them; this is also stated by Druar (2005:28), citing that patients are sensitive to

being given the run around and get frustrated and drop out if they perceive the clinician is incompetent. She states this is happening more frequently as the patient has more access to health information and sees the clinician as a resource rather than a “god that is all knowledgeable, to be obeyed”.

Addressing side effects of treatment has positively affected compliance. Side effects are often the cause of non-compliance. The major side effects are drowsiness, weight gain and tremor. Kao and Liu (2010:557) state there is a marked increase in medication compliance when side effects are addressed by offering medication and strategies to overcome the unwanted side-effects. Berk *et al.* (2010:7) found that the explanation and treatment of side effects resulted in a 22-25% increase in compliance. Applying these strategies has provided some solutions to increasing therapeutic engagement, as also found by Mahmood and Makhdum (2010:701), but there is still room for improvement.

There are times however, when compliance can be seen as counterproductive, such as when the medication has severe side effects, when the practitioner is incompetent/makes a mistake, when the relationship between patient and clinician is not a good fit or when the patient becomes dependent on the clinician (Wang, Angermeyer, Borges, Bruffaerts & Chiu, 2007:180). In addition, neuroleptic medication has shown no improvement in some patients' condition. In a study done in New Zealand with psychiatric patients, Wijnveld and Crowe (2010:1379) cite that 5-25% of patients have not shown improvement on medication. Therefore to strive for slavish and total compliance may not always be appropriate.

The problem of non-compliance is seen differently by patients and clinicians. Patients see non-compliance as a response to or consequence of poor or unnecessary treatment (Brohan, Slade, Clement & Thornicroft, 2010:3). They see non-compliance as rational and legitimate, and get angry and frustrated when others, e.g. clinicians, do not see it that way too (Berk *et al.*, 2010:3). Saxon, Ricketts and Heywood (2010:19) contend that patients also see the problem of non-compliance extending to feeling harassed, stigmatised, vulnerable and angry. Whereas, according to Byrne and Deane (2011:282), clinicians see the problem of non-compliance as having consequences, e.g. suffering, chronicity, issues around safety and cost. These two divergent approaches to non-compliance cause the problems when patients decide not to engage in treatment.

Particular issues relating to non-compliance amongst patients with BPD have been noted by Saxon *et al.* (2010:16). They state that, at least, a third of patients entering therapy discontinue prior to completion. These unplanned endings were associated with greater distress and significant safety issues. The cause of the increased non-compliance was attributed to the perceived lack of empathy and genuineness of the clinician by the patient. The clinician perceived it as the patient not being ready for therapy or having unrealistic expectations of the clinician and the patients' inability to form attachment. Another aspect of compliance by patients with BPD is the untherapeutic dependence on the clinician and thus over compliance (i.e. wanting/need to see the clinician far more frequently than perceived necessary by the clinician) (DiGiorgio, Glass & Arnkoff, 2010:214). The frantic efforts to avoid real or imagined abandonment often leads to dependence on the clinician, resulting in untherapeutic compliance. Intense mood swings are manifested by anger and hostility and this may evoke negative feelings in the clinician that may affect the patients' decision to engage because of the clinicians' reaction, e.g. anger, frustration, hopelessness (Waldinger, 2007:163).

When people are depressed or anxious, they often seek treatment; when people are psychotic, other people often seek help for them. But when someone is angry or hypercritical, they do not necessarily believe they need help and others do not want to help them because of their behaviour; if they do, the clinician often wishes they did not (Bolstad & Hamblett, 2009:4). This scenario contributes to the fact that patients with BPD do not engage or stay in treatment as there are issues regarding compliance from both the patient and the clinician, making patients' with BPD difficult to treat (Huband, McMurran, Evans & Duggan, 2007behaviour:308).

Non-compliance amongst patients with BPD is a significant problem. Due to the nature of the illness, the patient finds it difficult to make enduring attachments, including with clinicians (Varcarolis, 2008:109). This makes it difficult for the clinician to develop a rapport with the patient that fosters compliance. The patient finds it hard to commit to treatment and remain engaged in treatment, and often will demand particular forms of treatment, e.g. instantaneous and impromptu clinician attendance (Varcarolis, 2008:108). When this is not forthcoming, non-compliance ensues.

1.2.4 Borderline Personality Disorder (BPD)

Borderline Personality Disorder is a term defined by Gunderson (1987:2) and still used today, although the terms “Emotional dysregulation” or “Emotional Intensity Disorder” are also used. BPD is a psychiatric condition characterised by intense and unstable relationship difficulties, impulsivity and self-harm behaviour (Binks *et al.*, 2009:3). The patient experiences emptiness, mood instability, episodes of intense anger, depersonalisation/derealisation and fear of abandonment. The patient shows signs of neuroticism (extreme overreaction to stimuli) and psychosis (depersonalisation/derealisation), hence the term “Borderline”, relating to a condition on the border of both neurosis and psychosis (Binks *et al.*, 2009:3).

The currently recognised treatment for patients with BPD is long term psychotherapy, group therapy, work readiness training, medication, respite care and hospitalisation (to treat medical sequelae of self-harm, e.g. stomach washout, suturing and/or to ensure safety) (Clarkin & Lenzenweger, 2006:36).

The impulsivity of the BPD patient leads to quick, intense and often unprocessed, decisions including those relating to engaging in treatment, e.g. “wanting to engage right now” and “definitely never want to engage”. Their tendency to have intense relationships affects the relationship they have with the clinician, e.g. idolisation (leading to dependency and total submission and subsequent over compliance) and utter devaluation of the clinician (characterised by abhorrence followed by instant and aggressive non-compliance) (Waldinger, 2007:163). This leads to feelings of frustration and helplessness in both patient and clinician that makes on-going engagement very tenuous. Byrne and Deane (2011:285) in their study in the USA, state that one of the major reasons for low compliance rates is the absence of a specific effort to address clinician factors that influence the development of the therapeutic alliance, including fostering positive attitudes toward patients who chose not to engage in treatment. Simmons, Hetrick and Jorm (2011:3) also found that negative attitudes of the clinician toward the patient, especially the non-compliant patient, impacted on building a rapport with the patient that fostered compliance. Clinicians need to be able to understand what patients go through to be able to support them and encourage therapeutic compliance by developing empathy and fostering a close rapport.

Binks *et al.* (2009:5) have found that long-term follow-up shows a more favourable outcome; therefore they stress the importance of initiating and maintaining engagement. Waldinger (2007:164) concurs by stating in a study done in the USA, that after 10 years of treatment, 50% of patients with BPD no longer meet the diagnostic criteria for BPD, so ongoing, long term care is essential for recovery. Compliance rates for patients with BPD over a 2 year period was less than 20% in a study done in Australia by Byrne and Deane (2011:284), and 85% of the non-compliant patients relapsed, showing the importance of compliance.

There are major demands on the clinician treating patients with BPD, thus the clinician is susceptible to burnout (Ogrodniczuk, Piper & Joyce, 2006:249). This needs to be addressed as burnout affects the ability of the clinician to foster engagement of patients, especially ongoing long term engagement.

Non-compliance amongst patients with BPD is affected by the patients' difficulty to interact as well as the clinicians' capacity to work with their behaviour and prevent burnout. Therefore, it has become essential to explore the lived experiences of patients with BPD to gain a better insight from the patients' perspective.

1.3 STATEMENT OF THE PROBLEM

Non-compliance to treatment by patients with BDP remains high despite known measures to address non-compliance such as triage to foster appropriate patient/clinician fit and financial aid provided by the government.

The prevalence of BPD is 2% of the population and 20% of the average psychiatric caseload, so it represents a large portion of patients (Brink *et al.*, 2009:3). The patient with BPD displays impulsivity and this causes them to be at significant risk to self-harm, to the extent that 10% of patients with BPD die by suicide (Waldinger, 2007:164).

The clinician often struggles to engage the patient because of the patient's inability to form attachments and their impulsivity, and also due to the clinicians' own reaction to the difficult patient. The best way to investigate the problem (Bwisa, 2008:12) is to find out from the patient what they experience when living with BPD, and how this affects their decisions regarding ongoing care.

Resulting from the description of the background and the research problem, the following research questions emerged:

- What are the experiences of the patient living with Borderline Personality Disorder?
- What are the contributory factors leading to treatment of non-compliance in patients living with BPD?
- What meaning do patients with BPD attribute to treatment of non-compliance?

1.4 PURPOSE OF THE STUDY

The purpose of the study was to describe the lived world of patients with BPD in order to develop supporting guidelines to improve non-compliance of patients with BPD.

1.5 OBJECTIVES OF THE STUDY

The objectives of the research were to:

- explore and describe the lived world of the patient with BPD
- describe the factors contributing to treatment non-compliance of patients with BPD
- interpret the meaning of their lived world with regard to treatment non-compliance
- develop guidelines for facilitating compliance in patients with BPD

1.6 SIGNIFICANCE OF THE STUDY

Waldinger (2007:164) states that patients with BPD have a high rate of self-harm and suicidal tendencies, namely 10% of patients die by suicide. The envisioned significance of the study is that an understanding of the lived world of the patient with BPD will foster compliance to treatment. This understanding, alongside the guidelines developed, could lead to clinicians adapting their practice to be more successful in engaging patients with

BPD and minimise the harm from non-compliance such as distress, relapse, chronicity and issues of safety that currently exist.

1.7 DEFINITIONS OF KEY CONCEPTS

A single concept can have a variety of meanings for different people (Hsieh & Shannon, 2005:1277), therefore for the purposes of this study, the following terms pertaining to the non-compliance of patients with BPD will be clarified.

1.7.1 Borderline Personality Disorder

Borderline Personality Disorder (BPD) is seen primarily as an abnormality of behaviour as opposed to a clinical psychiatric disorder (Leichsenring, Leibing, Kruse, New & Leweke, 2011:75). The *DSM-IV-TR* (American Psychiatric Association, 2000:706) defines it as “a pervasive pattern of instability of interpersonal relationships, self-image and affect (emotion), marked by impulsivity, beginning in early childhood but manifesting in adolescence”. Chapman (2010:348) describes BPD as patients demonstrating interpersonal and emotional instability and fluctuating mood. Paris (2009:10) describes the most characteristic symptoms of BPD as chronic suicidal thoughts with recurrent self-harm behaviour (e.g. overdose and self-mutilation) in association with unstable mood, impulsive actions and troubled relationships. Thus BPD is characterised by poor interpersonal relationships and emotional dysregulation (inability to modulate emotional response) (Varcarolis, 2008:108).

Deferential diagnoses can be mood disorder, schizotypal personality disorder, narcissistic personality disorder and Post Traumatic Stress Disorder (PTSD) (American Psychiatric Association, 2000:709).

An operational definition of BPD is an abnormality of behaviour characterised by sustained relationship, mood and emotional instability resulting in fear of abandonment, attachment difficulties, impulsivity and suicidality.

1.7.2 Narcissism

Narcissism involves the unjustified edification of oneself. Narcissism is often experienced intensely by patients with BPD.

Narcissistic characteristics include:

- Grandiose sense of one's self importance
- Preoccupation of ones' own success, power and importance
- Exhibitionism
- Responding to criticism (or even general feedback), with rage and shame
- Sense of entitlement
- Exploitativeness
- Relationships vacillating between extremes of over idealisation and devaluation
- Lack of empathy

(Kohut, 2009:3)

Narcissistic pain is experienced when grandiosity is not acknowledged by others, or when anticipated entitlements are not forthcoming.

1.7.3 Emotional lability

Emotional lability is also known as emotional dysregulation.

Emotional lability refers to the marked reactivity/fluctuation of mood, characteristic of a patient with BPD. The mood state escalates very rapidly, either to the state of extreme positive feelings or to complete negativity (Jennings, 2003:2). These fluctuations are often triggered by interpersonal stressors, i.e. reactions to others, particularly when narcissistic pain is felt. The lability of mood causes the patient with BPD to react very impulsively with aggression and rage, or with self-harm behaviour.

1.7.4 Compliance

Compliance is “the act of conforming in accordance with a request or order, acquiescing or yielding, a behaviour showing co-operation or obedience” (Sykes, 2006:163). Compliance is “the measure of yielding to pressure or force to do something” (Dorland, 2006:402). To comply means “to obey a rule or order” (Laird, 2006:169). It is also seen as “to adhere and respond to” (*Collins English Dictionary*, 2006:74).

A definition of compliance from a health viewpoint given by Jin *et al.* (2008:270) is that “patients’ behaviour co-incides with health care providers’ recommendations”. A further definition of compliance given by Breen and Thornhill (2008:459) is “the extent to which a persons’ behaviour in terms of taking medication, following diets or executing lifestyle changes coincides with medical advice”.

Partial compliance is seen as patients taking medication irregularly, having gaps in taking medication or taking more or less medication at intervals bigger or smaller than prescribed, or similar scenarios with other treatment regimes, e.g. therapy (Kozma & Weiden, 2009:31).

An operational definition for compliance for this research will be “the extent to which a patient follows a negotiated treatment plan”, i.e. taking medication, observing a recommended diet and executing life style changes. The phrase “decision regarding ongoing care” relates to the decisions of the patient to enter and continue treatment.

1.7.5 Non-compliance

Non-compliance is “a deviation or cessation of a treatment plan recommended by the doctor” (Deegan & Drake, 2006:1636) or “failure to follow a treatment regime” (Deegan & Drake, 2006:1637).

An operational definition of non-compliance can be seen as not following a treatment plan (negotiated or not) for the greater portion of the time, or not following it at all.

1.7.6 Treatment

Treatment is described by Sykes (2006:973) as “care administered to improve an illness or injury”. It can be administered by professionals, lay people or it can be self-administered. It has also been described as “an integrated suite of health care that provides solutions to ailments” (*Dorland's Illustrated Medical Dictionary*, 2006:586), “a process of interventions” (*Collins English Dictionary*, 2006:906). Treatment is also seen as “to apply medical assistance to” (*Websters Compact English Dictionary*, 2007:492).

Entsuah and Rudolph (2011:237) see treatment as “therapy used to remedy health problems”. Wang *et al.* (2007:178) see treatment as “the method of handling or dealing with someone, i.e. the management of someone”. Breen and Thornhill (2008:458) cite treatment as “administration or application of remedies to a patient for a disease or injury”.

Phillips and McCann (2010:579), Byrne and Deane (2011:284) and Chang and Lee (2010:1) see treatment as encompassing a wide range of interventions, e.g. medication, follow-up visits, exercise, diet, life style changes, therapy (group/individual), surgery, ECT, psycho-education and hospitalisation.

A working definition for treatment is any intervention aimed at alleviating/preventing symptoms. Examples of treatment for patients with BPD are suturing and intervention after overdose (stomach pump, antidote medication; even if they have been compliant, they may still overdose and cut especially in the early days of treatment), individual psychotherapy, group therapy, life skills training, alcohol/drug addiction intervention and medication. Interventions such as restraint are not regarded as treatment, but management as they do not alleviate symptoms, but make it possible for staff to intervene, administer treatment and ensure safety.

1.8 FOUNDATIONS OF THE STUDY

In this section hermeneutic phenomenology, the philosophical grounding of this study, and its assumptions, will be briefly outlined and further discussed in Chapter 2.

The purpose of using a framework, e.g. phenomenology, is to help structure the study and achieve consistency in its application. The underpinning philosophical grounding of this study is the hermeneutic approach within the qualitative research design. Hermeneutics is an approach that emphasises the importance of interpreting the data, as opposed to merely reporting empirical data, i.e. to gain an understanding through interpretation, to get to the core (essence) and meaning of the studied experience (Pascoe, 2009:1311).

An assumption held by Hermeneutic researchers is that prior understandings and experiences affect the interpretive process. Hermeneutics also holds the assumption that there are multiple and competing views as well as multiple “truths” (Corbin & Strauss, 2008:7). A further assumption is that our internal and external worlds are created and recreated through our interactions (Corbin & Strauss, 2008:6), including those related to compliance. Both the patient and the clinician have an impact on the eventual decision of the patient to comply. Actions carry meanings and have emotional aspects and may generate emotions, therefore it is important to interpret the meanings people give to their experience of living with BPD in order to understand them (Pascoe, 2009:1311) and provide the best care.

The philosophy underpinning the research is post-modernism, where the emphasis is on deconstructing old ideas and constructing ideas in new ways (Polit & Beck, 2008:15). Post modernism will be evident in the research as the ideas relating to compliance are examined from the perspective of the patient and in terms of how these ideas affect the behaviour of the patient. Traditional ideas relating to compliance were that the patient did what the clinician said. Clinicians are taught today that engagement should be a negotiated and patient driven process (Simmons *et al.*, 2011:2), but is this the patients reality?

Post modernism also postulates that reality only comes into being through our interpretation of what the world means to us individually, and that reality is constructed in our minds (Loewenthal & Snell, 2003:46). So hearing what living with BPD means to the patient is valuable in interpreting what effect it has on them and understanding their behaviour. Furthermore, post modernism also postulates that realities are only social constructs and are, therefore, subject to change (Loewenthal & Snell, 2003:47). With changes in the clinician’s approach derived from a better understanding of BPD,

perhaps a change in compliance may ensue. A further assumption from post modernism is that reality only comes into being through our interpretations of what words mean to us. Hearing what different words mean to patients can help us understand their reaction to it. For example, the word “side effects” might mean an inconvenience or an intolerable experience.

The research also encompasses features of existential phenomenology, which aims at emphasising the individuals’ perception of self and their external world to understand experience and behaviour (Lopez & Willis, 2004:728). Studying phenomenological experience (namely living with BPD) helped the researcher understand what it is like to be human (ontology) as the focus is on the persons’ experiences of their world (Osborne, 2009:80). To use existential phenomenology the researcher interviewed the patient directly and framed the research title and interview questions in existential style. Rapport with participants is essential to elicit authentic descriptions when using existential phenomenology (Owen, 2004a:264). The researcher ensured she built up trust, showed respect and engendered confidence to develop the rapport needed.

Social constructionism is a method of studying how people create systems for meaningfully understanding and reacting to their world (Holstein & Miller, 2007:2). Social constructionism is a useful way of studying human/social phenomena especially to study the practice of a group (Burr, 2003:14), e.g. how patients with BPD as a group address compliance and how this is creating multiple responses to their behaviour (e.g. funding needed to trace them, court systems to enact compulsory treatment and Patients’ Rights Charters to promote their free choice). Evidence of social constructionism will be seen in the research when the manner in which phenomenon develop in social contexts is explored, e.g. what role models did they have about following instructions, especially from clinicians, what did they experience when they did not comply, e.g. ostracization by clinician and family; and how did they respond to this.

This research attempted to uncover the realities of living with BPD and how these realities affected their behaviour. Because change is possible, using their realities it may be possible to bring change in patients and clinicians to increase compliance in patients.

Thus the research used a hermeneutic approach, heavily leaning on interpretation of data, and encompassed the related assumptions, e.g. that prior understandings and

experiences affect the interpretive process, and that there are multiple and competing views as well as multiple “truths”. It linked closely to the research question of “What are the experiences of a patient living with Borderline Personality Disorder?” in that the experiences expressed by the participants were interpreted from their perspective and all interpretations were noted. A clear research approach, namely a phenomenological, hermeneutic approach, as used in this study, is essential in that it provides a frame work from the study. This frame work will be discussed further below.

1.9 RESEARCH METHODOLOGY

Methodology is defined as “a way to systematically solve the research problem” (Kothari, 2006:8). It encompasses the logic or explanation behind the method used for the research. Two main types of research methodologies are qualitative (interpretive) and quantitative (empirical) research (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005:25). This research has used a qualitative methodology.

1.9.1 Research paradigm

A *paradigm* is a lens through which a person views the world, a basic set of beliefs that guides action (Denzin & Lincoln, 2005:22). It is a set of assumptions, concepts and values that constitute a way of viewing reality. A research paradigm is the world view a researcher has when doing their research. In this research the researchers’ paradigm included seeing the patient as having some responsibility for their own health, as well as seeing the clinician responsible to provide a service that was suited to the patient and of a competent and ethical standard.

1.9.2 Qualitative research

Qualitative research is a phenomenological inquiry, using naturalistic methods to understand phenomenon in context of a specific setting (Hoepfl, 2007:524). Qualitative research design is the framework used to implement this research.

Qualitative research is a means whereby data is collected and presented as a narrative, where the focus is on the lived experience, not on empirical data, nor cause/effect determination (Goodwin, 2008:84). Qualitative research is best used when there is

limited knowledge of the research topic, the topic is complex and subjective and the subject of the study is human nature (Fossey, Harvey, McDermott & Davidson, 2008:717).

A qualitative research approach was chosen for this research, to facilitate the search for what is happening in regard to non-compliance. This determined the questions, and supported the direction of the study. An interpretive paradigm was chosen because it is best suited in the study of human science (Corbin & Strauss, 2008:13). Exploration and description was undertaken as it enabled the research topic to be studied by examining personal experiences of living with BPD (Kao & Lui, 2010:557). Exploration and description facilitated the study of a subject that is complex, subjective and difficult to quantify. It fitted with studying the research topic of living with BPD and of non-compliance as they are dynamic and open to interpretation. The research used a qualitative design within the natural setting. It focused on the interaction between researcher and object of study (i.e. the patient with BPD) by exploring variables such as emotion, experience and belief (Polit & Beck, 2008:17). The qualitative enquiry dealt with human complexity by exploring it directly; in the research the patient was interviewed to hear from them directly about their lived experience of having BPD. The goal was to understand what the lived experience of a patient with BPD was, with particular emphasis on how this influenced their behaviour relating to engaging in treatment. The qualitative researcher's assumption that there are multiple interpretations of reality and that truth is a composite of different realities was upheld by hearing several patients' accounts of their experiences, and the researcher was aware of her own experiences especially regarding non-compliance. Using a qualitative enquiry approach, she placed heavy emphasis on understanding human experience through collecting narrative and subjective data in the natural setting, e.g. in the community where the patient with BPD lives. The reason for using naturalistic enquiry was that it may give insight into the behaviours of the patient in the real world (Denzin & Lincoln, 2005:454), e.g. non-compliance by patients with BPD. The researcher also reflected on the data from a hermeneutic standpoint, in that the data was not only collected but also interpreted, i.e. what does the data mean?

This research attempted to uncover the realities of living with BPD and how these realities affected their behaviour using qualitative research design, concentrating on description and interpretation. The research approach that was used was the

hermeneutic research approach. A common use of the term hermeneutics refers to a process of (scriptural) interpretation. Hermeneutic research is a method described by Gadamer and elaborated/developed by Dilthey (1883) and more recently Crotty (1996) (Fleming, Gaidys & Robb, 2005:113). The hermeneutic research design was developed because of their rejection of the Cartesian notion of self as an uninvolved and passive object and that there was a split between the concept of body and mind (Dawson, 2002:54).

Hermeneutics look at more than the semantics of the text (what is said/written), but emphasises interpreting the text (Crotty, 1998:90). Understanding and interpretation are bound together. Interpretation is a dynamic process; therefore there is no definitive interpretation (Laverty, 2008:10). We enter research with pre-understandings and during the research these will change through collection and interpretation of data (Fleming *et al.*, 2005:117). And as our understandings change, we change those around us. The whole (people in society) change us (the individual) and we change it, and again it changes us; this is an example of the Hermeneutic circle (the phenomenon of the interaction of the components on the whole and vice versa). The main characteristic of hermeneutic research is to get an understanding of the research topic through interpreting the data using the hermeneutic circle, not merely offering straight data (Laverty, 2008:10). This hermeneutic research focused on understanding compliance by interpreting the patients lived experience of BPD (the whole) and compliance (a small piece of their daily life).

The hermeneutic approach was chosen because of the hermeneutic assumption that we can reach the truth only by understanding (McCloughlan, O'Brien & Jackson, 2011:99). It is a design that emphasises discovery through interpreting meaning as opposed to quantification and prediction. It is a design recommended for use when researching humans, subjective phenomenon or when the researcher has limited knowledge of the subject (Fleming *et al.*, 2005:115). The research design was used to help identify how people are affected by non-compliance and how non-compliance affects people. It was the researchers' intention that using Hermeneutic research would foster an understanding of non-compliance by looking for and being open to the meanings expressed by the participants and striving to interpret those meanings.

The selection of the particular research design was to assist the researcher to obtain her objectives and gain answers by allowing her to delve further than a search for quantities and cause and effect, but to get to an understanding of responses of participants regarding non-compliance through description and interpretation. The research approach dictated that the researcher be immersed in the subject matter, therefore the researcher did the interviews herself. The researcher studied a phenomenon (non-compliance) she is in daily contact with, and works amongst the potential participants; therefore was immersed in the research topic and research field. It is important that the researcher not attempt to see the topic through the eyes of the participants, as this is not possible because of differing experiences; but to work together to reach a shared understanding (Fleming, 2005:117). Therefore the researcher was open to the information shared with her and openly shared her experiences to develop that shared understanding. The researcher identified her pre-understandings and prejudices of non-compliance (e.g. that some clinicians do not foster compliance through their interaction with patients) to help her reflect on the phenomenon of compliance in hermeneutic fashion. She also included these in the research report – see Chapter 4, paragraph 4.2.2.

1.10 RESEARCH METHOD

In this section, the manner in which the research was done is described. The focus is on the techniques used to structure the study and to gather and analyse information, i.e. from population sampling, data collection through to data analysis.

1.10.1 Sample and sampling procedure

A sample is a sub-set of the population that is under scrutiny for the study, i.e. patients with BPD.

The study sample was selected from the Whakatane Mental Health Service, comprising Inpatient and Community Services, as well as allied health services, i.e. the site sample. The site sampling was purposive in that the mental health services were chosen as that was the site that would deliver the population sample sought, i.e. patients with BPD. The site is the major center for mental health services which receives all referrals for mental health patients in the Whakatane district. Purposive sampling was used to select

the participants. The researcher used purposive sampling as it involved selecting participants who are already identified as being information-rich cases for the study. The researcher had access to patient files and most patients are known to the researcher, so identification was possible.

The sample size was fairly small as it is a qualitative study where the aim was to gain rich data from each participant. The researcher continued to interview participants till saturation, i.e. no new data were forthcoming and sufficient data were gleaned to make an authentic analysis. This linked in with the research descriptive and interpretive design, in that the aim was gathering rich data.

1.10.2 Data collection instrument

Data were collected by interviewing patients using a semi-structured interview schedule, a purpose constructed formal instrument consisting of a set of questions to be asked of the respondents as described by Polit and Beck (2008:756). Semi-structured interviews are a mixture of a certain number of specific questions, with the flexibility to add additional questions to probe new avenues of potential data during the interview. The aim was to collect information/narrative in a consistent manner to gain an understanding of the topic from the perspective of the participants' lived experience (Charmaz, 2006:23). Using a semi-structured interview schedule helped limit the researchers' influence on the interview, but did allow for flexibility and probing.

The semi-structured interview schedule used had open-ended questions, so that the focus could be placed on eliciting a detailed discussion of the topic by the participant. The instrument also has closed-ended questions to solicit specific data (Charmaz, 2006:26). The use of well centered questions allowed free flow of information from the participant, the hallmark of conducting an interview. Semi-structured data collection was used as it tends to gather rich information, yet still have some structure for duplication of the research, as opposed to structured data collection which leads to empirical data only for testing of hypotheses (Nieswaidomy, 2008:59). See Annexure 5, which contains a copy of the instrument used.

Experiences are more readily elicited using interviews, and probing for in-depth information is made possible (Nieswaidomy, 2008:240). However, the study is not easily

replicated if an interview is used, and the results will also not be widely generalisable (Denzin & Lincoln 2005:702). The inclusion of the basic questions asked in the interviews and detailing the methodology and environment of the research allowed the possibility for study to be replicated to some degree; and the inclusion of excerpts from the interviews enhanced the readers' ability to scrutinise the research for vigor. The disadvantage of interviewing a relatively small group of participants was counteracted with the acknowledgement that the results were anticipated to be relevant only for that particular set of circumstances.

A rapport with the participants was developed to facilitate rich and honest data (Fassinger, 2005:158). The questions directed the conversation to uncover experiences of the respondents regarding their experiences of living with BPD, focusing on their decisions/experiences relating to ongoing care. A disadvantage of using interviews is that it may take time to get all the data needed; it may require 2 or 3 interviews. The researcher counteracted this by explaining this to the respondent so that they could anticipate the time necessary and the researcher only interviewed participants when they both had time, so as not to create a rushed atmosphere or inconvenience the participant. The researcher asked non-intrusive general questions first to build a rapport and trust. The researcher ensured that the participant was not fatigued by the process by offering breaks during the interview.

To stay true to hermeneutic research, the researcher interviewed the same participants several times to monitor change in understanding. This is because understanding changes with different situations and with hearing the opinions of others (Fleming *et al.*, 2005:118). The interviews were held at venues and times mutually agreed on with each participant, taking cognisance of availability, comfort and confidentiality. Most interviews were held in the patients home as that was where they felt most comfortable and it reduced the normal therapy environment and therapist/patient scenario.

The presence of the researcher was likely to introduce a distortion of the natural scene (Hoepfl, 2007:8). Decisions regarding the degree of involvement the researcher would have and the length of time in the field were considered to minimise the bias, e.g. enough time to build a good rapport and facilitate the participants' stories to emerge, but not so long that the participants get annoyed, tired or bored. Data collection was continued till there was recurring data (e.g. same statements, recurring themes) and

there was evidence of persistence irrelevant data (Hoepfl, 2007:9) (e.g. discussion not bringing data useful to the study).

Interviews were audio-taped and then transcribed verbatim. Further information to enhance the accuracy and detail of the data was captured by the researcher in memos written during and straight after each interview (Corbin & Strauss, 2008:120). In this respect, these methods, i.e. interview schedules and memos, enabled data to be triangulated (collected from various sources).

This section has shown that data collection was done by conducting interviews with participants, using a semi-structured interview schedule comprising open and closed ended questions. Data was also gathered through memo taking during and after each interview.

1.10.3 Data analysis

Data analysis entails making sense of the data collected, by placing it in some order/format to be able to discern the content.

The goal of data analysis in hermeneutic research is to reach a place of understanding of the phenomenon through the development of an integrated assessment of the data relating to the experience (Laverty, 2008:19). The distinguishing factor of data analysis in hermeneutic research which the researcher endeavored to achieve was the co-construction of the data with the participant as they both engaged in the hermeneutic circle of understanding (Laverty, 2008:21). The researcher played close attention to what the participant was really saying during analysis. Constant comparison of data and checking interpretations with participants and peers was done to determine accuracy. Individual pieces of text and the text as whole were studied to get the full meaning. Shared meanings were studied to develop themes.

1.11 TRUSTWORTHINESS

Trustworthiness in qualitative research is seen to correspond to vigor, i.e. the extent to which the research stands up to scrutiny specifically in the areas of credibility, dependability and confirmability, and transferability (Streubert & Carpenter, 2011:49).

Trustworthiness was addressed in this research by upholding credibility, confirmability, transferability, dependability and authenticity, and will be discussed in Chapter 3.10.

1.12 ETHICAL CONSIDERATIONS

Ethical and legal issues are concerned with the protection of human and animals during research. There are regulations to ensure the absence or at least minimisation of harm, trauma or distress. The protection of human rights need to be addressed by considering rights to self-determination, privacy, confidentiality, autonomy, and the right to fair treatment (Grove *et al.*, 2013:163).

The potential importance of the study should not outweigh the risk involved (Stenek & Bulger, 2007:830). Participants should clearly be told of the potential benefits and risks of the study to be able to give informed consent (Streubert & Carpenter, 2011:60). They should not be coerced into participation, but asked for voluntary participation. Confidentiality must be protected. The results of the study must be available to all participants.

There are always ethical considerations when doing research, especially when the study involves humans as subjects. Ethical considerations are pertinent when dealing with vulnerable participants, such as mentally ill patients. These ethical considerations must be addressed to protect the rights of the participants and the institution, and to ensure the scientific integrity of the research.

Hermeneutic research requires that the researcher interpret the data from the participants' perspective, not her own. To show respect to the participant and maintain authenticity, the interpretations must be offered to the participant for verification.

Research ethics will be discussed further from the perspective of the rights of the participant and the institution.

1.12.1 Rights of the participant

The participant engaging in research has certain ethical and legal rights during and after research. The rights of the participants include:

- obtaining informed consent
- non-malfeasance
- beneficence
- anonymity
- confidentiality
- justice
- autonomy

(Nieswiadomy, 2008:31)

These rights were addressed by the researcher and detailed below.

Informed consent was fostered by the researcher giving all the details (including risks) in a neutral and non-coercive manner to potential participants. It was ensured during the selection process, that the participants were given all the necessary information to be able to give an informed decision. All the information, including that their participation was entirely voluntary, was given in writing, with time permitted to consider at their leisure. Once they had made their choice to participate, they were asked to sign a consent form. They were constantly reminded throughout the research process that they had a choice to participate or not, and could exit the study, with no prejudice.

Non-malfeasance, the principle “to do no harm” (Butts & Rich, 2012:41) was upheld by treating the participants with respect and dignity, and remaining professional in conduct. The researcher ensured through building a good relationship and being dependable and trustworthy, that the participants felt safe, thus addressing the potential issue of fear and distress.

The topic had the potential to engender unpleasant feelings in the participant, e.g. frustration, anger, guilt. These feelings were respected and acknowledged and the participants’ safety was protected. To address beneficence (protection from harm) (LoBiondo-Wood & Haber, 2011:267) during the research, the researcher was vigilant in assessing if there was any distress. If the researcher noted that the participant was becoming distressed during the interview, the researcher offered a break, a cup of tea or ended the session and even discussed their continued involvement. If the participant

became significantly distressed or declared suicidal thoughts, the researcher was ready to ensure they sought support from their keyworker. It was ensured that the participants acknowledged the risks before being accepted to participate in the research.

The participants' anonymity and confidentiality were protected by not revealing any identifiable details in the report and having private interviews. The researcher continued to hold their information in confidence after the research was completed.

The participants were treated fairly and equally without prejudice to preserve the element of justice. After the research, when the researcher happened to make contact with the respondent through her work, she treated the patient as she would have whether they had participated or not by giving them the best clinical care she could.

The balance between respect for the human participant and efforts to gain rich and meaningful data (LoBiondo-Wood & Haber, 2011:156) was constantly addressed by ensuring the participant felt safe and not threatened by the research process.

The participants were included in the decision on how their contribution would be used in the research to give effect to their autonomy.

Thus throughout the research, and after the research, the rights of the participants were upheld to protect them from harm and facilitate justice.

1.12.2 Rights of the institution

The rights of the institution were protected by the researcher by maintaining research ethics.

The researcher did not intrude on the participants' work time, nor use her own work time to complete the research. The researcher did not use the resources of the institution. This was to prevent harm to the institution through lost productivity or loss of resources (LoBiondo-Wood & Haber, 2011:283).

The researcher obtained written informed consent to protect the institution from repercussions should a participant seek to complain that they were uninformed or unaware.

Ethical clearance to conduct the study was obtained from the Department of Health Studies, Higher Degrees Committee at UNISA. Approval for the research was also sought from the institutions' ethics committee, The Bay of Plenty Ethics Committee, as well as the regional ethics board, the Health and Disability Ethics Committee (see Annexure 2).

The research had the potential to reveal data that may harm the reputation of the institution. This was managed by not revealing the research report without prior discussion with and sanction from appropriate personnel at the institution. A further measure to protect the institution, which was not necessary, would have been to withhold the identifying data of the institution.

The rights of the institution were also upheld by explaining to the participants that their information would remain confidential, however if information revealing unsafe or illegal practice (e.g. unsafe parenting, cultivating marijuana, holding unlicensed firearms) was divulged, that this would be reported, as it was the duty of the institution (i.e. its' employees) to do so. The participants were assured that they would be informed before this occurred and that only the appropriate person/s would be informed.

The rights of the institution were maintained by the researcher respecting the institutions' time and reputation and by negotiated reporting of participants when necessary.

1.12.3 Ethics pertinent to this research

General ethical principles pertinent to all research were applicable to this research, e.g. confidentiality, non-maleficence, but there were also ethics unique to this research which needed to be addressed, e.g. potential for emotional harm and stigmatisation, and patient-clinician relationship.

An ethical issue pertinent to this research was that the topic of non-compliance may lead to stigmatisation and unpleasant emotions (e.g. feelings of inadequacy, shame, frustration and even anger) for the participants. This was discussed with participants during the selection process so the participants were aware and could make informed decisions about whether to partake and continue. They were also referred for support when necessary.

The researchers' own feelings regarding non-compliance had the potential to bring up issues in herself, e.g. Am I a good clinician? Why don't the patients listen to me? It could have brought up feelings of anger (because there are so few resources) and frustration (when the researcher has explained the benefits and made it practically possible, and the patient still did not comply). Thus the meanings which the researcher had developed within the social contexts she lived/worked, were addressed, i.e. the researcher engaged reflexively (Finlay, 2002:211) by using her feelings as part of the data, not as judgement.

The researcher was aware that if she were told by a participant that their keyworker (a colleague of hers) was not doing all they could to engage a patient, it may bring up feelings of resentment and judgment in her which she would need to identify and bracket as far as possible, and consider reporting to their supervisor.

The issue of patients' not taking responsibility for their health (including complying with treatment) also had the potential to bring up feelings of frustration within the researcher. The researcher believes that patients have the right to negotiated treatment but also have the responsibility to commit to the treatment till they can adequately justify (with knowledge) why they should discontinue/alter treatment (a subjective concept in itself). This addressed the issue of reflexivity, and the researcher scrutinised the impact her experiences, preconceptions, decisions and interpretations had on the research (Pringle, Hendry & McLafferty, 2011:12).

The researcher anticipated knowing most of the potential participants and this may have caused some unease since they worked together in their regular work. The researcher addressed this by not including any of her regular patients in the study. Some of the participants who knew the researcher might have tried to please the researcher by giving answers they thought the researcher wanted to hear. Other participants may

deliberately have wanted to sabotage the research and thus withheld information or not given the truth. The researcher concentrated on remaining neutral and listened without prejudice. She ensured they felt comfortable to do the research, felt comfortable to leave the research at any point, spent time with them debriefing, assured them of confidentiality, ensured they were aware that her function was a researcher and not a judge or therapist and that their participation in the research would not affect their regular treatment. The researcher was careful to examine her own prejudices and frustrations regarding the patient.

Some of the participants might have wanted to use this forum as a place for counseling and/or splitting, and this would have impacted on the researcher/participant relationship. The researcher consistently clarified boundaries by clearly stating the purpose of the research and firmly steering the interviews toward that purpose.

The researcher needed to have clear boundaries herself in that her usual role is one of counselor, and she could see she might easily slip into this role during the interview if she was not diligent enough. This would be confusing for the participant and also cross the line of treating another clinician's patient without their knowledge or consent.

Participants were chosen using purposive sampling, thus not all people had an equal opportunity to contribute and have their experiences heard, studied and thus addressed. The burden and benefits of the research were felt by a few (LoBiondo-Wood & Haber, 2011:246). The researcher addressed this by ensuring the few participants that did participate in the research were heard accurately and in-depth.

The patients who have been compliant with treatment may have been more likely to participate, thus the data may be slanted. Using volunteers as participants will affect the profile of the respondents (Nieswiadomy, 2008:204). Psychiatric patients may feel obliged to participate as they may not acknowledge their right to decline. This was addressed by the researcher by adopting a non-threatening and non-pressurised approach when discussing potential participation so as not to put undue pressure on the patient.

Using hermeneutic research, there were certain assumptions and this may have affected this study and the way the researcher related to the participant, conducted the

research and analysed the data. An assumption that we affect others and others affect us leads to the assumption that the researcher can influence the participant, thus the researcher used that influence judiciously, i.e. by asking neutral questions in a non-threatening manner and facilitating the participants' story to flow. The way the researcher related to the participants was hallmarked by respect, caring and honesty to ensure that the participant felt comfortable to give full and accurate data. That there are many truths was acknowledged by the researcher by including all data and data she did not agree with.

1.12.4 Summary

There were considerations on both sides of the risk/benefit debate of this research leading to pertinent ethical considerations/dilemmas. The risks for the patients were that they may have unpleasant emotions while reliving their experience of non-compliance. Another risk for the participants was that they may feel exposed when revealing information and may fear judgment. The benefit was that they may contribute to uncovering knowledge that may lead to clinicians responding to them in a manner that fosters therapeutic compliance, which would enhance their quality of life.

1.13 CONCLUSION

This chapter outlined the overview of the study, the lived experiences of patients with BPD. The background to the research problem was discussed, namely the poor compliance of patients with BPD. The aim of the study was stated, namely to gain insight into the lived world of patients with BPD. Key concepts were elicited. A broad outline of the research methodology used was given. Ethical considerations addressed during the study were detailed, e.g. the issues of beneficence, non-maleficence and confidentiality.

CHAPTER 2

PHENOMENOLOGY: A GUIDING FRAMEWORK

2.1 INTRODUCTION

This chapter will outline the framework supporting the study, namely hermeneutic phenomenology. Phenomenology was used as it is effective when studying how people experience the world in which they live (Polit & Beck, 2008:222), and specifically to this study, the world of living with BPD. Phenomenology is a field of enquiry that explores people's experiences by describing phenomenon as the participants see them. It is essentially a narrative and descriptive account of the phenomenon being studied (Streubert & Carpenter, 2011:72).

A frame work for the study is important as it gives focus and direction to the study, and is included in this research report so the reader can follow the structure of the study and the paradigms involved. The phenomenological framework was used as it was seen as the best methodology to explore the lived experiences of a patient with BPD.

In this chapter, phenomenology, the frame work used to structure this study will be described, and how it helped reach the objective of the study, namely to explore and describe the lived world of the patient with BPD.

2.2 PHENOMENOLOGY DEFINED

Phenomenology is one of the qualitative research approaches of enquiry, encompassing the interpretivist tradition. (Tashakkori & Teddlie, 2010:47). Interpretivism seeks to provide an answer to the meaning of the phenomenon being studied.

Phenomenology is “the study of experiences (as it is lived)” (Hoepfl, 2007:2). Phenomenology attempts to decipher what the phenomenon “is”, what it is like for the person living it. Phenomenology does not try to decipher what caused the phenomenon being researched, nor weather it is ‘good’ or ‘bad’, purely what “it is”, i.e. the experience

of the phenomenon and the meanings attributed to the phenomenon (Giddings & Smythe, 2010:58). Phenomenology is also seen as “the study of essences”, e.g. the essence of perception or the essence of consciousness (awareness) (Streubert & Carpenter, 2011:72). Hermeneutic phenomenology is a qualitative research approach where the emphasis is placed on gathering data (descriptions) as well as interpreting the meaning given to those descriptions.

The focus of hermeneutic phenomenological research is not the phenomenon *per se*, but how the person interprets the phenomenon (Cohen *et al.*, 2000:5). A phenomenological researcher studies how people interpret their lives and gives meaning to what they have experienced (Cohen *et al.*, 2000:6). Interpretation of meaning is an ontological (the nature of the persons reality) standpoint to conducting research by exploring “being in the world”. The awareness of this “being” is termed “consciousness”, where one is aware of being in the world, and exploring others’ consciousness. The core of phenomenology is the intentionality of consciousness, i.e. directing consciousness toward understanding the world (Sadala & Adorno, 2002:283). The role of epistemology (study of what counts as knowledge) in phenomenological research is to broaden the extent of knowledge, particularly acquaintance knowledge, i.e. familiarity of a subject (Pringle *et al.*, 2011:10), rather than developing an abstract theory.

Phenomenologists pay a lot of attention to language as they see meanings of words being important. Language is seen as the primary way we express our experiences and their meanings, and is the vehicle to help us understand aspects of human existence (McCloughan *et al.*, 2011:102). Language is the way we share our realities; when one understands another, one grasps what is said to the point that it becomes one’s own. We are not beings that merely use symbols, but beings that create and are created by their use. Gadamer stated (in Laverty, 2008:10) that “language is the universal medium in which understanding occurs, and understanding occurs in interpreting”.

Experience in itself seeks and finds words that express it (Friesen 2009:14). Language co-exists with experience, one cannot express experience without language, and language is created to express experiences. Language gives people the ability to disclose the world they live in. Intersubjectivity, the belief that others share a common

world with us is an important tenet in phenomenology (LoBiondo-Wood & Haber, 2011:134). This intersubjectivity is expressed in language.

Interpreting the data is more than acting on the literal meaning of words used by the participants in their descriptions. The focus must be on the deep structure of meaning rather than surface/concrete presentation (Laverty, 2008:19), i.e. read between the lines to elicit the characteristics of the phenomenon and gather what is really being said.

The focus of this phenomenological hermeneutic research was to explore the experience of living with BPD and what meanings the patient attributed to their experiences of BPD, especially regarding engagement with treatment, to arrive at the essence of compliance.

2.3 THE MAIN SCHOOLS OF PHENOMENOLOGY

Franz Brentano (1838-1917) and his student Carl Stumpf (1848-1936) reformed philosophy to gain answers that organised religion could not provide. Brentano strove to make psychology purely scientific by introducing a descriptive element. Stumpf founded experimental phenomenology which uses experimentation to discover the connection between the elements of what is being perceived (Cohen *et al.*, 2000:7).

Husserl (1859-1938) is described as the father of phenomenology, and argued that experience is the core of the meaning of knowledge. Heidegger further developed phenomenology, into what is known as Hermeneutic Phenomenology, by asserting the need to interpret the experience to gain knowledge (Streubert & Carpenter, 2011:74). Other key figures driving Hermeneutic Phenomenology were Dilthey (1883), Gadamer (1922), Sartre (1940's), Marcel (1951), Merlau-Ponty (1962), Spielberg (1965) and Wagner (1983).

2.3.1 Husserl's school of phenomenology and its' attributes

Husserl (1859-1938) developed phenomenology because he and other philosophers were questioning the empirical view/positivism, especially when studying human science. Husserl proposed that in order to understand one's fellow man, one needs to look at the quality of their experience, and as such placed great emphasis on

consciousness. Husserl described phenomenology as a science of consciousness (Pringle *et al.*, 2011:8), thus being and meaning are seen by Husserl as reciprocal. Husserl developed descriptive phenomenology, emphasising descriptions of human experience (Polit & Beck, 2008:228). Husserls' philosophy is epistemological (study of what knowledge is) in nature as he believed that experience is the core of the meaning of knowledge (Van Der Zalm & Bergum, 2000:212). Phenomenology as seen by Husserl is a return to the lived world, the world of experience (Sadala & Adorno, 2002:283), which includes being descriptive rather than explanatory. He saw that focusing on the things means turning to the world of experience by taking into account that before any objective reality (empiricism) there must be a subject who experiences (Sadala & Adorno, 2002:283). He thus suggests that knowledge has its origins in experience.

Husserl outlined phenomenological reduction, i.e. how to describe with scientific exactness, the life of consciousness, namely to "go back to the things themselves and discover awareness" and discard previous knowledge and preconceptions of the phenomenon. The term 'bracketing' was defined, urging researchers to identify their own consciousness and experiences and set them aside as far as possible and remain neutral (Cohen *et al.*, 2000:7). Merleau-Ponty (1962) strongly opposed the notion of reduction, as he postulated that people cannot distance themselves from their experiences. Bracketing was to help the researcher achieve transcendental subjectivity, i.e. that the researcher constantly monitored their impact on the inquiry and neutralised any bias and preconceptions (Lopez & Willis, 2004:728).

2.3.1.1 *Husserlian assumptions*

In developing his philosophy, Husserl put discussed or forward several concepts and assumptions, e.g. essences, intersubjectivity, bracketing and intentionality. These will be discussed below.

2.3.1.1.1 *Essences*

Husserl put forward that the essence of something is the very nature of what is being studied pre-reflectively and without bias or pre-understanding. Essences leads to the identification of the concepts that give a common understanding to the phenomenon

under investigation, i.e. common meanings given by different people to a single entity (Cohen *et al.*, 2000:7). Husserl describes achieving identification of essences as stripping the phenomenon of all unessential detail (Sadala & Adorno, 2002:285), returning to the things themselves.

2.3.1.1.2 *Intersubjectivity*

Husserl also described intersubjectivity, a collection of shared common experiences which make up a community sharing a collection of shared common experiences which creates a community sharing a common world, a world of shared lived experiences (LoBiondo-Wood & Haber, 2011:134). Husserl contends that this can be achieved once the essence is found.

2.3.1.1.3 *Bracketing*

Bracketing is the process where the researcher attempts to let go of their preconceived ideas and biases in order to be objective/reductionist (Pringle *et al.*, 2011:11). Bracketing means being aware of the phenomenon without processing it in the context of ones' own experiences or understandings, i.e. disconnecting from ones' experiences. Bracketing encompasses putting aside one's own beliefs so the phenomenon can be seen as the person experiencing it sees it (Parahoo, 2006:68), allowing the researcher to receive uncontaminated communication. Attempts at moving toward bracketing can be achieved through avoiding evaluation, avoiding forming opinions, avoiding comparing (namely your insights to others) and careful listening to others' stories by paying close attention to what is being described (Streubert & Carpenter, 2011:81).

Heidegger, Gadamer and Crotty (amongst others) felt bracketing could be difficult to achieve and proposed an alternative, "the lived view" where the researcher is part of the research process and data; they felt that to give credence to the data, cognisance must be given to how the conclusions are reached (Pringle *et al.*, 2011:11), e.g. by continuous self-reflection, therefore including one's own understanding in the data itself.

Bracketing is linked to the assumption that consciousness is intentional. Intentionality is an activity of consciousness directed at an object, not some causal relationship to an object, therefore Husserl contends that bracketing can and should be attained in the

pursuit of truth and knowledge as it is a method to maintain rigor through objectivity (Yegdich, 2000:32).

2.3.1.1.4 *Intentionality*

Husserl's put forward the concept that the mind is directed toward objects, and this directedness is called intentionality. This is based on the assumption that we are aware of that consciousness. Husserl described intentionality as "Knowing what conscious experience is like" in an effort to understand the world/phenomenon (Leher, 2011:6). Through intentionality of consciousness, all actions gain meaning. People experience the same phenomenon differently, due to their lived experience of that moment; this causes the phenomenon of "plurality of objects", where one object/phenomenon is interpreted differently/means something different to different people. What needs to be distinguished is what components are the experience and what are the interpretations. The similarities and disparities of the experience between people must be established (Sadala & Adorno, 2002:283). Consciousness, through intentionality, is understood as the agent that attributes meanings to objects. Without these meanings it would be impossible to talk about an object/phenomenon or its' essence. Thus the hermeneutic researchers' task is to analyse the experiences of the consciousness in order to perceive how the phenomenon is given meaning and to arrive at its' essence.

2.3.2 Heidegger

Heidegger (1889-1976) was a student of Husserl and together they developed phenomenology, although they had major differences in opinions (namely in description versus interpretation of phenomena as a method of uncovering knowledge) (Laverty, 2008:21), the ability of a researcher to remain neutral or unbiased/without preconceptions (Zahavi, 2002:672) and pure consciousness vs being aware of the world (Mohamed-Patel, 2002:15).

2.3.2.1 *Heidegger's Hermeneutic Phenomenology*

Heidegger developed phenomenological philosophy to incorporate interpretive phenomenology, known as hermeneutic phenomenology (Polit & Beck, 2008:229). He stressed that it is important to understand the human experience, not just describe it,

i.e. to go beyond only factual accounts, thus his emphasis was on interpretation. According to Heidegger, “being in the world” precedes all our thinking of the world, and being here, “Dassein”, should be the focus for all questions about being in the world (Laverty, 2008:20). He postulates that we are totally immersed in the world and yet separate as well (ex-ist), never quite stable, and always changing due to our experiences; his was thus existential-phenomenology (Owen, 2004a:268). He saw that individuals realities are invariably influenced by the world in which they live, and that individuals cannot separate themselves from the world.

Heidegger claimed that nothing can be examined/studied without reference to one's background. He believed that one could not separate the experience from pre-understandings and bias and thus proposed that when seeking knowledge, to adopt a reflexive attitude. Reflexivity refers to acknowledgement by the researcher that their own actions, decisions and views impact on the meaning of the experience being studied (Horsburgh, 2008:308). Husserl described reflexivity as the ongoing conversation about the experience that the researcher has with the participant while simultaneously living in the moment, actively interpreting the experience and questioning how those interpretations came about (Laverty, 2008:22).

Heidegger believed it was not possible to describe something without interpreting it. This led him to describe the relationship between consciousness and objects, that they each have an influence on each other (Schneider, Elliot, LoBiondo-Wood & Haber, 2003:194), therefore, in his view, both descriptive and interpretive elements became important in understanding.

Heidegger explored the ontological question of the nature of reality and “being in the world”, thus bringing the notion of the individual and his experience as co-existing, unable to exist without the other (Laverty, 2008:14). He thus saw pre-understanding affecting experience and vice versa. He sought to understand how a phenomenon is understood through the experience of the phenomenon.

The interpretation of texts will reveal something about the social context in which they were formed, but also provide the reader with a means to share the experiences of the author. The reciprocity between text and context is part of what Heidegger called the Hermeneutic circle.

2.3.2.2 The Hermeneutic Circle

The hermeneutic circle depicts the interplay between the understanding of the individual texts and the whole text, and also the interplay of the whole text on the individual texts. It depicts that it is important to understand the whole text (e.g. interview) in terms of its' parts (i.e. sentences/paragraphs) and the parts in terms of the whole, to fully understand what is being communicated (Polit & Beck, 2008:229). This is depicted in the following figure.

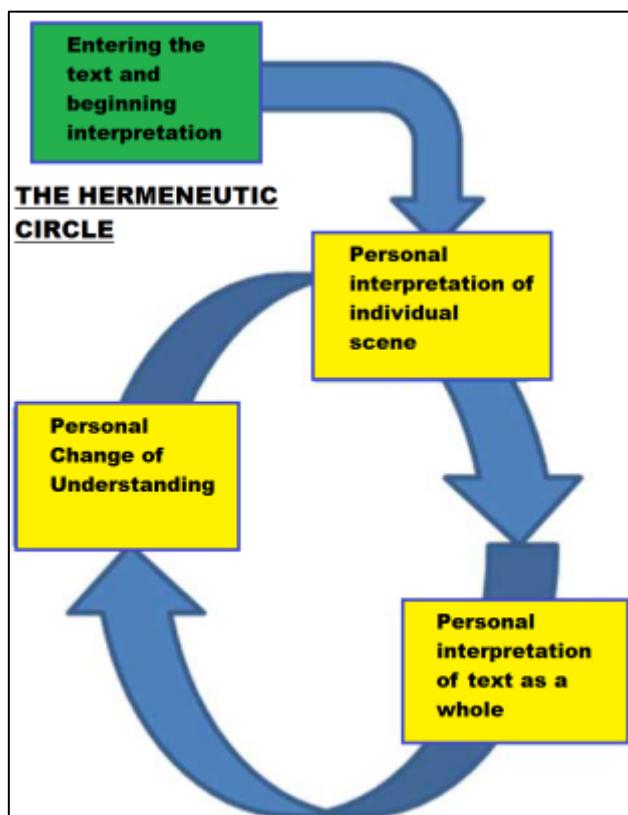


Figure 2.1 Hermeneutic circle

(Dennies, 2012:2)

2.3.2.3 The process of Hermeneutic Research

The researcher used the following process to ensure she conducted the study engaging in the hermeneutic research guidelines.

2.3.2.3.1 *Naïve reading*

In this step, the researcher read the text as a whole to become familiar with the information/text and began to explore meanings in the text for further analysis (Streubert & Carpenter, 2011:85).

2.3.2.3.2 *Structural analysis*

Here patterns of meaningful connections were explored by labeling meanings that were identified. Continuous comparison between the text as a whole and part of the text will be made as well as comparing the parts of the text to the text as a whole (Streubert & Carpenter, 2011:85), this is known as identifying the hermeneutic circle. As individual texts and the whole text were explored, the researcher grew in understanding and individual texts and the whole text were revisited, creating an ongoing circle of understanding.

2.3.2.3.3 *Interpretation of the whole*

This step involved the researcher reflecting on the initial reading along with the interpretive reading to gain a comprehensive understanding of the findings (Streubert & Carpenter, 2011:85). Shared meanings were identified and analysed.

2.3.2.4 *Heidegger and compliance*

Heidegger's assumptions were evident in this study, namely pre-understandings are part of the study and the attention to the interplay between the parts and the whole.

Heidegger's assumption that we always come with a pre-understanding of the phenomenon which cannot be eliminated, causes the need for the researcher to reflect on her own pre-understandings of compliance and observe how they influence the collection and analysis of the data, i.e. make it part of the data.

Heidegger's assumption that the part influences the whole and vice versa, caused the researcher to look at the individual texts on compliance given by the participants, study

the text as a whole and individual sentences/paragraphs and let each reflect off each other to give better understanding of compliance. It caused the researcher to be observant of the influences the participant felt regarding compliance and their consequent reaction and explanation/interpretation of their reaction.

Compliance, seen through Heidegger, will encompass the way the person experiences and interprets the process of engagement, i.e. the benefits and arguments against it, the way they see compliance as they have lived it, what is going on regarding compliance and why it is happening.

Heidegger saw that individuals have freedom of choice, but their freedom is not absolute because humans live in the world constantly being influenced by social, cultural and political contexts of their daily lives. He labeled this situated freedom. Heidegger believed that one is constantly faced with choices, even though the outcomes that will result from the choices are not obvious (Lopez & Willis, 2004:729). Compliance can be seen through this assertion.

In the foregoing section, discussion centered on the main schools of phenomenology, namely Husserl and Heidegger. The various assumptions, especially those held by Heidegger, were discussed as they give insight into how the research problem was studied, namely studying parts (individual sentences) and the whole (whole interview) to understand and interpret the experiences patients gave to living with BPD.

2.4 PHENOMENOLOGY AS A PHILOSOPHY AND THE RESEARCH APPROACH

In the subsequent discussion, the focus is on the meta-theoretical assumptions of phenomenology and the methodological assumptions of phenomenology, the philosophical approach used in the research.

2.4.1 Meta-theoretical assumptions

Meta-theory is a critical exploration of the theoretical frameworks that provided direction (to the research), and mainly includes identifying assumptions of the framework.

There are several assumptions upon which qualitative research was founded. The assumptions are those described by Glaser and Strauss in 1967, and listed by Corbin and Strauss (2008:5).

The main assumption of phenomenological research is that our internal and external world is created and recreated through our interactions (Corbin & Strauss, 2008:6). We do not act in isolation, our actions affect others and other people affect us and thus shape/affect our actions as we too affect/shape their actions. This assumption appears to pertinent when examining non-compliance in that non-compliant patients are often influenced by others/society in terms of engagement in treatment, and also have a high rate of relapse and becoming dependent on others thus literally affecting them (Byrne & Deane, 2011:285). A further assumption is that people behave from a social world that they have experienced, which may or may not be evident to the people they are interacting with, supporting why when a patient decides to discontinue treatment, others may not understand why.

A group of related assumptions also appears to be pertinent when studying non-compliance. Interactions are associated with meanings specific to the people interacting at that time. Actions are embedded in past present and imagined future interactions. Actions are specific to the present, in that a person may behave differently if different circumstances were to prevail or if new experiences have been encountered (Denzin & Lincoln, 2005:27). Predicted consequences direct many actions. Actions carry meanings and have emotional aspects, and may generate new meanings and emotions. Compatible interactions occur when there is shared meaning between individuals. Interactions may be followed by reflection on those actions with potential consequent new behaviour (Corbin & Strauss, 2008:7). Actions are not necessarily rational, and rational behaviour can sometimes be perceived by others as irrational. Even if the end result of certain actions is desirable, the actions themselves may not be justifiable, i.e. the end does not necessarily justify the means (behaviour). These assumptions again appear to be pertinent when studying non-compliance in that the patient and the clinician needs to agree on compatible actions to foster compliance (Jorgensen, Freund, Boye, Jordet & Andersen, 2013:305). The patient may see stopping medication that is making him shake/put on weight as rational, whereas the health professional may see patients deliberately putting themselves at risk of psychosis as irrational.

Hermeneutics is an approach that follows the assumption that interpreting the data, as opposed to just reporting the data/facts is the means to getting to the truth (Denzin & Lincoln, 2005: 27). Meaning and understanding are interconnected. There are however varying and diverse realities for patients and clinicians as they live and experience the world of mental illness, and BPD in particular. Participants' believe all clinicians want to do is over-medicate, and clinicians believe that patients only comply when they get it/have learnt the hard way (Saxon *et al.*, 2010:14). The focus is not to gain information per se but to gain an understanding through interpretation (Fleming *et al.*, 2005:117). Hermeneutic research has its' focus on understanding rather than facts, thus relies heavily on interpretation to build "knowledge" (Grant, 2002:17). Hermeneutic research demands that data collection moves from the "stories" to interpretation of the experience/phenomenon described, thus moving from "What is happening" to "How has it affected you?".

Hermeneutic research is also based on the assumption that there are multiple and competing views as well as multiple "truths" or multiple realities (Grant, 2002:13). Each person has an understanding of reality from an individual perspective (Erlingsson & Brysiewicz, 2013:94). This can be seen in the phenomenon of compliance. Patients often see compliance as "giving in", "being controlled" and illogical, while the clinician sees compliance as "getting it" and "being responsible" (Jin *et al.*, 2008:269). An assumption of Gadamer's hermeneutic approach is that we can only reach the truth by understanding our experiences: experiences are not fixed, but interpreted differently at different times under different circumstances (Pascoe, 2009:1311), therefore clinicians need to understand their own as well as the patients reactions to compliance and non-compliance as it affects the patients' and clinicians' responses at that particular time.

A further assumption of hermeneutics is that understanding is not gained through manipulation and control, but through openness, participation and dialogue (Pascoe, 2009:1311). The research attempted to uncover what meanings patients gave to their world of living with BPD, especially how it relates to compliance, without pre-empting or co-ersion. Meanings are created when language is shared and interpreted (Cohen *et al.*, 2000:6), and the researcher listened attentively to what was really being said to gain an accurate interpretation. A solid relationship was built with the participants to foster rich, relevant, complete and accurate data.

Another assumption of hermeneutics is that prior understandings and prejudices hinder, or at least affect, the interpretive process (Pascoe, 2009:1311). Hermeneutics assumes that experience and interpretation cannot be divorced, as they are always evident and linked. This means that scientific neutrality is impossible as we always interpret in the light of our anticipatory pre-judgment which in itself is constantly changing through the process of considering a phenomenon (Pascoe, 2009:1311). It is not possible to loose pre-understandings, but it also is through pre-understanding that understanding is possible. We move between shared understandings and interpretations and our own interpretations; each influences the other, e.g. we influence others and others influence us (Pascoe, 2009:1311). Understanding changes over time and interpretation itself changes understanding.

Research is inevitably the search of knowledge, which then at some point could be seen as “truth”. Epistemology is concerned with how individuals determine what is true (Streubert & Carpenter, 2011:362). Mouton (1998:47) states that research done in the epistemological dimension is regarded as the pursuit of valid knowledge (truth).

Some current epistemological assumptions held regarding compliance are:

- compliance usually benefits the patient in that it raises the quality of life of the patient and minimises distress (Phillips & McCann, 2010:579)
- compliance is linked to certain practical considerations, e.g. finances, availability of services, other commitments (Byrne & Deane, 2011:85)
- compliance is linked to the confidence and relationship the patient has with the clinician (Deegan & Drake, 2006:1636)
- compliance is linked to age, gender, severity/type of illness and beliefs regarding illness (Brohan *et al.*, 2010:3)

Applying the assumptions of qualitative research and hermeneutics to research, the patient and the clinician both come from their individual and combined lived worlds. Both have some degree of positive and negative influences on each other which affect both of their behaviours, including those related to compliance and non-compliance.

2.4.2 Methodological assumptions

Methodological assumptions consist of the assumptions made by the researcher regarding the methods used in the process of qualitative research (Creswell, 2009:33).

The methodology that was used is phenomenological research because the aim of the research was to develop a deeper understanding of compliance and non-compliance. The researcher attempted to examine the phenomenon living with BPD, particularly regarding issues of compliance and non-compliance, from the participants' perspective, and explored how the participants experienced compliance and non-compliance, and the meanings they gave to compliance and non-compliance.

Hermeneutic phenomenology focuses on how people go about understanding the world in which they live. In the study the emphasis was not on the structure of the phenomenon, but on how the phenomenon was interpreted by the respondent. The researcher concentrated on finding the participants' interpretation surrounding non-compliance rather than just relating what they say, by asking sensitising questions (Corbin & Strauss, 2008:72), i.e. questions that lead to an understanding of what the data might be indicating. Examples of sensitising questions that were asked were "Why do you see that as influencing non-compliance?" and "Why do think that was done to manage non-compliance?". The research questions were framed in hermeneutic style, seeking to interpret what is happening and understand the participants' experiences. The questions attempted to uncover rich narrative data, not an empirical answer to a cause and effect question.

The methodology required that the researcher does constant comparison of the data throughout data collection and analysis. The interpretations and conceptualisations were offered to the participants for their input. The results were measured against those from existing literature, as well as the researchers' own and peer understandings.

The researcher acknowledges that she had preconceived ideas regarding non-compliance and integrated these ideas as data, because she realised that all is data and she could not be separate from her beliefs and experiences (Pascoe, 2009:1310). The researcher explored ideas that she agreed with as well as those she did not agree with.

Meta-theoretical assumptions were discussed, namely that we do not act in isolation and that interactions are associated with meanings, and these have an influence on the manner in which patients experience BPD and consequent decisions regarding engagement with treatment.

2.4.3 Rationale for this phenomenological study

In this section, the reasons for choosing phenomenology as a means to study the lived experiences of patients with BPD will be highlighted; mainly that phenomenology is an appropriate approach when studying experiences of humans. The decision to use the interpretive hermeneutic approach in this study was guided by the reach question (seeking clarification on experience) and that the topic was very subjective and not easily measurable.

Human life experiences are best studied using phenomenological research (Streubert & Carpenter, 2011:87). Phenomenological inquiry requires that the whole be explored and that fits in with the holistic approach of modern nursing practice. Qualitative research combines the scientific and artistic aspects of nursing to enhance the understanding of the human health experience (Wilkin & Slevin, 2004:51). It is through phenomenological enquiry that practicing nurses have the opportunity to understand and find meaning in everyday situations patients' experience (Van Der Zalm & Bergum, 2000:217).

Non-compliance and compliance as experienced by patients (humans) appear to suit phenomenological research. The world and non-compliance are very complex and there are no simple explanations. Behaviours, including non-compliance, are the result of multiple factors. Experience cannot be divorced from the person, and the meaning a person gives to a phenomenon affects their experience of that phenomenon. The individual affects the social world and the social world affects the individual. This made phenomenological research appropriate for this study.

Non-compliance is complex and is the result of multiple factors coming together in unpredicted ways, therefore a framework to study compliance will itself need to be complex. Phenomenological research can capture the multiple perspectives of non-compliance and thus can be seen as a good fit.

Phenomenology discards the Cartesian philosophy of the separation between the body and the mind, as does contemporary nursing understanding. Phenomenologists and nurses also defy objectifying human behaviour (Yegdich, 2000:31); therefore using the phenomenological approach in a human centered nursing study appeared to be appropriate.

The phenomenological methodology appeared suitable because the researcher has chosen a qualitative research methodology to study human subjects (Denzin & Lincoln, 2005:4). A phenomenological research approach suited this research as it incorporated the multifactorial influences of society on people, including the subject (the patient with BPD). The aim of the research was to explore the experiences of patients, including that of non-compliance, by understanding their perceptions and attitudes towards non-compliance, an aim that could be achieved through phenomenological research.

The researchers' personal philosophy caused her to see situations as multifactorial and embedded in the influences of society at the time. She enjoyed seeing phenomenon from different angles as a researcher using hermeneutic research needs to. The researcher holds the concept that man is mind and body, not an inanimate object, an assumption of hermeneutic research (Pascoe, 2009:1311). Thus hermeneutic research does fit her way of thinking.

Considering that the research topic, research question, research methodology, research method and researcher's philosophy all complement and support each other, there appears to be internal consistency for the use of a phenomenological approach to this research.

2.4.4 Critique of phenomenology

There are criticisms for both quantitative and qualitative research. In this next section the criticisms of phenomenology will be identified as well as a short description of how the criticisms were overcome in this research. Further details can be found in the section describing limitations (see Chapter 7.3)

The primary arguments held against phenomenological research are the lack of generalisability and the absence of empirical measures. The counter argument to that critique is that phenomenology is an approach meant to be used to study abstract, value-laden experiences in a certain context in a certain time and should be presented and understood as such (Horsburgh, 2008:308).

The intuitive (ability to acquire knowledge without inference or the use of reason), inductive (reasoning that takes specific information and makes a broader generalisation), subjective (influence of personal feelings, tastes, or opinions) and impressionistic (general feelings or thoughts rather than specific knowledge or facts) nature of phenomenological research leads to the criticism of lack of credence/rigor by some readers (Pringle *et al.*, 2011:16). Intuition in this research was justified by the researcher as she has 30 years of experience in psychiatric nursing. Inductive reasoning was addressed by relating it as such and giving verbatim quotes. Subjectivity was addressed again by giving verbatim quotes and asking respondents to check interpretations. Impressionistic influence was curbed by qualifying all statements and conceptualisations.

While the reader may not necessarily agree with the researchers' interpretation, they must be able to follow how the researcher arrived at their interpretation, which is how the phenomenologist gives defense to and upholds vigor in the methodology.

2.5 CONCLUSION

Freud (1856-1939) noticed that every behaviour and every experience has a hidden meaning, which at first remains hidden from consciousness and self-observation. Phenomenologists posit that researchers must avoid focusing on too much actual behaviour itself but instead explore how the phenomenon is perceived and experienced by the individual (Mohamed-Patel, 2002:38).

Phenomenological research leads to descriptions involving feelings and thoughts about what was experienced and the perception/interpretation of that experience through reflection on its' meanings and its' impact on peoples' lives. This interpretation and reflection is intended as the catalyst to increase the understanding of the phenomenon under scrutiny.

Keeping to a phenomenological framework, the question of what the experiences of a patient living with BPD could be answered by hearing their story and understanding their perceptions.

CHAPTER 3

RESEARCH METHOD

3.1 INTRODUCTION

In this chapter, the research method will be described, namely the way the study was structured to gather and analyse information, from population sampling, data collection through to data analysis. The purpose of the study was to explore and describe the lived world of patients with BPD in order to develop supporting guidelines to improve non-compliance of patients with BPD. The research method, i.e. choosing the appropriate respondents, researcher-participation, data collection and data analysis was important to study the problem of poor compliance by patients with BPD. Poor compliance, as stated previously, leads to decrease in quality of life and increased risk of safety.

The research methods used will be discussed, namely purposive sampling, data collection obtained in interviews using an interview schedule and memos, and data analysis by interpreting and categorising data to uncover emergent themes. .

3.2 RESEARCH SETTING

In keeping with phenomenological research practice, especially regarding attention to vigor, the research setting will be described, so that the readers can examine the data in context for themselves. Also in keeping with qualitative practice, the research was done in the real world, with no control or manipulation of the environment.

The research was conducted in Whakatane, a town in the Bay of Plenty, a district in the North Island of New Zealand. Whakatane has approximately 20 000 people and is characterised by having a developed urban area with extensive rural surroundings. The towns' infrastructure is built on farming (dairy and dry stock), forestry (cultivation of pine trees) and the mill (to process the harvested wood), as well as tourism (motels and holiday parks). The climate is moderate. The current political climate has significant socialist aspects. This setting was chosen as it was accessible to the researcher and

also because it was anticipated to yield participants that would give rich and relevant data.

The site for the study was the Whakatane Mental Health Service. This service comprises of inpatient and Community Mental Health Services, and 5 allied sites, namely Recovery Program, Family Support, Disability Resource Centre, Peer Advocacy Service and Assisted Accommodation (all under the helm of the Bay of Plenty District Health Board). The services provide mental health treatment for those 18 years of age and above. The cost for all services is free, except for a \$5 dollar fee per medication script. The patients can self-refer or are referred by other agencies, such as medical specialist, family or concerned person and at times the police or courts. An intake worker and multi-disciplinary team screen the referrals to determine the best fit for the patient with a clinician. The access to the service was designed to be accessible, i.e. on the bus route, and has discreet signage for confidentiality. According to Phil Camish, the CEO of the Bay of Plenty District Health Board, there is an adequate number of staff as set out in the District Health Board workforce schedule; however there is a high rate of turnover of staff (Camish, 2011:2).

3.3 RESEARCH DESIGN

A research design is an overall plan for addressing a research question (Polit & Beck 2008:765).

The research design used in this study was qualitative, with naturalistic, descriptive, narrative, intuitive, interpretive and emergent elements (Parahoo, 2006:184), and is detailed below. The research design is participant centered and the researcher adopted an interview style hallmarked by listening, reflection and interest that drew out the narrative from the participants.

3.3.1 Qualitative research design

This qualitative research was underpinned by the assertion of the socially constructed nature of reality. This approach holds the premise of studying a phenomenon by interpreting the meaning people give to it in their specific context (Denzin & Lincoln, 2005:6). A phenomenological method was used to learn and construct the meaning of

human experience through directed conversation. The qualitative research design has several characteristic elements which will be described below.

3.3.1.1 *Naturalistic element*

The naturalistic element dictates that the study must be done in the field. The study was done in the natural setting (in the real world) with no control or manipulation of the environment, so as to minimally disturb the field of study (Streubert & Carpenter, 2011:22) to preserve the authenticity of the data collected.

3.3.1.2 *Descriptive element*

The descriptive element pertains to the participant's own story. The aim was to collect rich data from the descriptions given by each participant. The premise of qualitative research is that the participant is the one best able to describe the phenomenon in their own words, so the researcher was attentive to how they told their story (Holloway & Wheeler, 2007:6). The data was collected by eliciting the participants' description of the phenomenon, facilitated by the use of an interview schedule containing open (and closed questions) and by ongoing prompting.

3.3.1.3 *Narrative element*

The key to the narrative aspect is the story of the participant, told in their words, prompted by the researcher. The primary characteristic is the first person account of the experiences (Merriam, 2002:9). To achieve this, the researcher placed verbatim quotes in the text of the research report to verify their personal account.

3.3.1.4 *Intuitive element*

Intuition involves developing one's consciousness through looking and listening. This occurs when one is immersed in the subject being studied. The researcher considered herself as intuitive because she was collecting data she was familiar with and concentrating on, using her 30 years of experience.

Intuition is reached by contemplating the details given by the participant, thus representing knowledge without reasoning. It requires the researcher to become totally immersed in the phenomenon being studied (Streubert & Carpenter, 2011:81). The researcher listened attentively to the descriptions given by the participant, strove to see the descriptions from the participants' perspective and reflected on what was said and left unsaid.

3.3.1.5 *Interpretive element*

A characteristic of qualitative hermeneutic research is that the data is not only described but also interpreted, i.e. the meanings respondents give experiences must be uncovered. An assumption of naturalistic enquiry is that behaviour goes beyond what is observed by the investigator. Thus interpretation is required to investigate behaviour further (Krefting, 2001:214). This was achieved by searching for the meanings the respondents gave to the phenomenon of living with BPD, and how they constructed their reality around that phenomenon, i.e. their epistemological perspective.

3.3.1.6 *Emergent element*

It is characteristic of qualitative research that studies change as they are being implemented. Because the goal is to get inside a social phenomenon in a specific social setting, it is impossible to construct a rigid design at the outset of the study (Hatch, 2002:9). Thus a qualitative study needs to emerge/adapt as it develops to take into account all aspects of the phenomenon. Thus the researcher informed the participants that this may happen and constantly checked consent for the study to continue. Emergence also caused the researcher to seek answers to new questions uncovered during the research.

This phenomenological study examined human experiences through the descriptions provided by the people involved, i.e. lived experiences. The goal of this study was to describe the meaning given to the experiences by the participant (Nieswiadomy, 2008:172). A qualitative, phenomenological methodology was chosen because it is particularly well suited to study human experiences of health (LoBiondo-Wood & Haber, 2011:141).

3.4 POPULATION

Population is a collection of objects, events and individuals with common characteristics that the researcher is interested in studying (Polit & Beck, 2008:761).

A portion of the population needs to be identified for research to be practical (not all people can be accessed) and useful (not all people will offer data related to the study). This means a group of people who fit certain criteria pertinent to the research topic need to be identified, i.e. the target population. A target population is the entire population pertaining to the research topic (Polit & Beck, 2008:337).

The population sample and selection are important aspects of research as they influence the nature and scope of the study. The sample and selection method ultimately have an influence on the findings of the research (Burns & Grove, 2011:294), therefore the sampling method was chosen with care to fit the research topic, methodology and research aims.

In this study the target population consisted of all compliant and non-compliant patients with BPD in Whakatane. There are an estimated 20 000 people living in Whakatane. There is one Mental Health hospital in Whakatane with allied services, e.g. Recovery Program and half way homes. The prevalence of BPD in New Zealand (and also Whakatane) is estimated at 2% of the population (Bateman & Krawitz, 2013), thus a rough estimate of 400 patients are diagnosed with BPD in the Whakatane district.

An accessible population is a subset of the target population that consists of those who are available to the researcher to participate in the study yet reflects specific characteristics in respect of age, gender etc. to uphold representation (Lunsford & Lunsford, 2005:106). The population that is both eligible to participate (fulfills the criteria) and those accessible to the researcher are known as the study population (Burns & Grove, 2009:344). Thus the study population were patients who had a diagnosis of BPD, who had accessed the Whakatane mental health service and who were traceable.

3.4.1 Sample and sampling procedure

A sample is a subset of the population that is considered for actual inclusion in the research (Goodwin 2008:135). Sampling is the process of selecting a portion of the population to represent the entire population in the study so that accurate inferences can be made (Polit & Beck, 2008:339).

The selection of the appropriate sampling procedure in qualitative research is important to obtain information richness. Qualitative research explores subjective meanings of actions in the context of the research, therefore central to the quality of qualitative research is whether the participant's views have been authentically represented, and this starts with a robust sampling procedure. Two key considerations are necessary, namely appropriateness and adequacy (Fossey *et al.*, 2008:726). Identifying appropriate participants (those who can best give reliable and useable data), and adequacy (ensuring there is sufficient information to develop a full description of the phenomenon being studied) are essential to maintain the credibility of the research. Qualitative sampling is described as purposive when it aims to target known sources that may reveal specific data pertinent to the study topic (Fossey *et al.*, 2008:726).

Non-probability, purposive sampling was used to select the sample because it allowed the researcher to handpick participants to be included into the sample (Lo Biondo-Wood & Haber, 2011:228). The advantage of purposive sampling is that information rich cases are sought, increasing the likelihood that the sample will deliver appropriate and concentrated data, thus the research process is streamlined and the inclusion of irrelevant data is minimised (Hoepfl, 2007:6). The researcher sought out potential participants from the known patients with BPD from a list of patients who were treated in the service, and asked them, one by one, in a non-judgmental, non-pressurised manner, if they would consider volunteering to participate. If the person showed an interest, the researcher gave the person an information sheet and answered any immediate questions. Assurance was given that the participation was completely voluntary and that their decision to participate or not would not have consequences on their treatment. The potential respondent was given time to consider and discuss with support people. After each set off interviews with a respondent, the selection from the list continued until saturation was noted.

A purposive sample of 10 participants eventually participated in individual semi-structured interviews, making up the study. The 10 were chosen as they were the first respondents replying to the request to become a participant as they were deemed to fulfill the inclusion criteria, were available and were seen as being able to provide data that would be useful in the study. Ten became the number of respondents used as by then, several elements of saturation were observed, namely, repetitive data, data that was found not relevant to the study and a collection of emergent themes had been revealed.

After the 10th participant, data were saturated. . In qualitative research, the sample is expected to be small as it is anticipated that each participant will reveal rich data and the researchers' memos (notes of observations and potential further avenues of questioning) taken during interviews will add to the data source.

3.4.2 Inclusion and exclusion criteria

To obtain a robust and representative sample, inclusion criteria were formulated. The patient-participants included were patients who:

- Had a diagnosis of BPD – fitting the criteria for BPD according to the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders).
- Both compliant and non-compliant patients – to pursue a representative sample.

To further ensure an appropriate sample was obtained and to recognise ethical considerations, the following exclusion criteria were proposed:

- Patients who were acutely unwell
- Minors under the age of 18 years
- Mentally handicapped patients
- Patients engaged in treatment with the researcher

3.5 RESEARCHER-PARTICIPANT INTERACTION

Researcher-participant interaction refers to the relationship participants have with the researcher. The relationship is developed by trust and openness and evidenced by the influence each has on the other and the measure of full and true information given by the participant (Streubert & Carpenter, 2011:28).

One of the characteristics of qualitative research is that it involves a close relationship between the participant and the researcher. The term participant reflects the nature of the interaction, namely one of mutually active inclusion, rather than object/subject relation (Streubert & Carpenter, 2011:28). Participants are viewed as “knowers”, as they have experienced the phenomenon first hand. In conducting research with humans, the researcher must come with an attitude of caring and genuine interest (Schneider *et al.*, 2003:196) to build a good relationship with the participant that fosters rich and accurate data. If there is poor researcher-participant interaction, the study could become compromised as true and full data will not be revealed, therefore this section will describe optimal researcher-participant interaction and the steps the researcher toward this.

According to Creswell (2009:75), the researcher needs to have both self-awareness and awareness of the participant. Qualitative researchers need to be able to create an atmosphere that allows safe sharing of experiences and feelings, fostered by developing the participants’ trust, respecting the participant and authentic caring and interest in the participant.

The researcher’s initial communication and ongoing rapport-building with the participants will strongly affect the participants’ decision to participate and remain involved (Grove *et al.*, 2013:374). This is important as attrition will negatively impact on the research in terms of data richness as those who have valuable information are not included, and in terms of data authenticity (committed and safely engaged participants will reveal the most authentic data). The researcher must also exhibit characteristics that will draw out the data the participants have, e.g. have the ability to communicate clearly, help participants feel comfortable disclosing their experiences, be able to connect with the varied participants and treat the participants with courtesy and respect (Streubert & Carpenter, 2011:89). Thus the researcher must show the capacity for empathetic understanding and interpersonal communication. This will be managed in

this research through the transference of psychiatric nursing skills into research interviewing skills.

To understand the lived experience of the participant, the researcher took into account her own beliefs and feelings. The researcher must “dwell with the participants’ descriptions in quiet contemplation” (Nieswiadomy, 2008:173). The researcher must be reflexive, i.e. be aware of their influence on the research process, from methodology selection, through data collection, to data analysis.

In nursing the aim is to heal. Research may have a healing property in itself in that the reflection of the story, being heard by a caring person, being understood (someone gets it) may be therapeutic. Nurses are legally and ethically obliged to protect the health and welfare of their patients, therefore when the patient is compromised by the research, the role of the nurse always takes precedence over the role of researcher. Nurse researchers, especially psychiatric nurses, must not become counselors as this may cause splitting between their therapist and researcher, the researcher unethically interfering with another clinicians’ therapy and confusing the patient regarding the role of the researcher (Streubert & Carpenter, 2011:65). The interview is not primarily therapeutic and researchers must be cognisant not to ask questions that may cause participants to give more information than they consented to or feel safe to. However the research may have secondary benefits in that the participant gets a space to reflect, receive an interested listening ear and feel that someone does understand.

The researcher has specific responsibilities regarding the collection and analysis of the data. Reinhartz (cited in Streubert & Carpenter, 2011:88) describes five steps phenomenological researchers must follow during their research process, namely (a) transform peoples experiences into language, (b) transform what is heard and seen into an understanding of the original experience, (c) transform what is understood about the phenomenon into concepts, (d) transform those concepts into a written document, reflecting the participants descriptions, thoughts and actions, and (e) transform the written document so that it can clarify the preceding steps).

Researchers should remain neutral and ask questions that help participants describe their lived experience without leading the discussion; the discussion should be led by the participant. The participant should also be put at ease so that their disclosure will

remain confidential and will not be used against them, e.g. via ridicule or ostracization (Watson, McKenna, Cowman & Keady, 2008:285).

The researcher thus has to have several skills including philosophical understanding (understanding the underpinnings and assumptions of the research philosophy used), attention to detail, interviewing skills, a caring attitude, intuitiveness and the ability to write descriptively.

The researcher became a tool for data collection by coming to know the participants in a personal way (Streubert & Carpenter, 2011:65). The researcher became thoroughly aware of the social and cultural context of the environment where the data was collected. To accurately and comprehensively collect data, the researcher was intensely involved in the field, yet not in a way that altered the environment by her “being” in it. The researcher used perceptiveness and sensitivity in relation to the data, i.e. read between the lines and got the concept of what was being said, to get the real meaning the participant conveyed; and was aware of the subtleties of the meaning of the data. These interpretations were presented to and verified by the respondents (Hoepfl, 2007:5) and discussed in the findings (see Chapter 5).

The researcher tried to bracket her own experiences and bias as far as possible, but identified that this is not always completely achievable, and thus included and acknowledged the bias in the research as data itself. Hermeneutic research requires that the researcher become immersed in the data, so that the lived experience is more reliably identified (Streubert & Carpenter, 2011:91). This was implemented as the researcher is a practicing psychiatric nurse who works with patients experiencing BPD.

The researcher thus tried to build a comfortable and open relationship with respondents to foster the free flow of full and true narrative. This was largely achieved evidenced in the amount of data obtained from the respondents, the consistency of each of their stories over the interviews and the stated expressions of feeling safe and listened to.

3.6 DATA COLLECTION

Data for this research were collected through interviews using a semi-structured interview schedule. The participants were interviewed 3 to 4 times and the interviews

were audio-taped and transcribed in order to capture as much data as possible and maintain accuracy. Memos were taken during and after interviews to supplement the data collected in the interviews.

3.6.1 The oral interview

A research interview is a verbal interaction between participants and researchers for the purpose of collecting valid and reliable data to answer particular research questions (Nieswiadomy, 2008:240).

An interview could be structured (following a strict order), or unstructured (more conversational), or take a semi-structured stance (having both structure and flexibility) (Nieswiadomy, 2008:240). This study followed a semi-structured approach, fitting a qualitative approach, and characterised by some flexibility in the order and wording of the questions to foster free flow of data and allow probing (Parahoo, 2006:329).

3.6.1.1 *The interview process*

The process started at the setting up of the interview, through to building a rapport, to the working phase (i.e. getting the story), to the ending of the interview and the writing up of the transcript.

3.6.1.1.1 *The preparatory phase*

The initial step of the interview process was the preparatory phase. The researcher selected an appropriate venue with each respondent, considering availability (booking, payment), accessibility (primarily for the participant, but also for herself), comfort (seating, quiet, lighting, heating, ventilation) and privacy (both in access to the venue and while the interview was in progress) (Nieswiadomy, 2008:243). Comfort of the participant was considered (an office setting may create a power dynamic, a hospital setting may evoke painful memories), therefore most interviews were held at the respondents home, ensuring their comfort and confidentiality, and eliminating cost and need for booking venue.

3.6.1.1.2 *The introductory phase*

The next phase of the interview was the introduction. Here the participant and researcher got to know each other and started communicating in a superficial “safe” manner. The researcher introduced herself fully to the respondent (not assuming the respondent remembered her) and presented herself showing caring, openness, and interest. The research and the purpose of that particular interview was clearly explained to establish expectations and boundaries. This was to start the process of building a rapport to foster trust and openness (Watson *et al.*, 2008:285). Any initial questions from the participant were addressed.

3.6.1.1.3 The working phase

As the participant started to feel more comfortable and familiar with the process, the interview progressed to the working phase. Here the data started to flow as the participant told their story, prompted by the questions from the researcher.

Throughout the interview, the researcher used language that was clearly understood and talked in a respectful and conversational manner. Assurance was given that there were no wrong or right answers. No pressure was used to elicit answers. Sensitive questions were broached later in the interview when a rapport has developed (Nieswiadomy, 2008:245). At no time during the interviews did the researcher observe participants becoming distressed with the interview.

The hermeneutic circle, characteristic of this research, was evident during data collection (as well as data analysis). The questions alternated from general to more specific questions (e.g. Tell me how you experience everyday living? What does BPD mean for you? What is your experience of receiving treatment? What is it like for you when you have therapy?) so that the big picture could be enhanced by the specific detail, and vice versa. The participants were explained beforehand that at times the questions may appear repetitive, general or specific, but all responses were important and there were no wrong or correct answers..

3.6.1.1.4 The termination phase

The termination phase of the interview was reached when the time limit set for the interview was reached. The researcher ensured that the participant felt comfortable and safe, especially if unpleasant recollections were evoked. Time to de-brief or a referral to their keyworker were options if the researcher had concerns. Reassurance and thanks for their input built rapport and ending on a positive note helped ensure further participation. During and at the end of the interview, the researcher asked the participant if they had any questions.

3.6.1.1.5 Documentation

Memo writing and transcription of the interviews were completed as soon after the interview as possible while the researchers' memory of the interview was still fresh (Polit & Beck, 2008:401).

3.6.1.2 Rationale for using semi-structured interview

A semi-structured interview was chosen because it fits with phenomenological research, namely that the objective of the interview was to get rich narrative data. It is also the method of choice for data collection when dealing with subjective topics and humans (LoBiondo-Wood & Haber, 2011:302).

3.6.1.3 Advantages of a semi-structured interview

One of the main advantages of a semi-structured interview is that it is possible to prompt the participant to assist the flow of the story (Polit & Beck, 2008:400). This way details and rich/full data can readily be elicited. It also allows for delving into areas that show to be potentially pertinent. Another advantage is that non-verbal responses can be included in data, which could not be done in, e.g. a self-administered questionnaire. A further advantage is that the response rate to all the questions is high; however attention must be given to accuracy and completeness of responses (due to the dynamic of the face to face contact). Qualitative research rigor can be preserved by quoting participants responses verbatim.

3.6.1.4 Disadvantages of a semi-structured interview

Interviews are very time-consuming. Arrangements for the interview and the interview itself demand a lot of time. The transcription of the interview is also very time-consuming (Nieswiadomy, 2008:245).

Interviews deny the participant ambiguity. Respondents may be reluctant to answer questions they feel are private or may cause them to feel exposed, embarrassed or uncomfortable. Participants may be influenced by the researcher, i.e. intimidated by their status. They may respond by giving vague and socially acceptable answers or ones they think the researcher will want to hear (Nieswiadomy, 2008:245). This was overcome by taking time to develop a good rapport with the participants and structuring the questions so that the less overwhelming questions were asked first, and constantly assuring the participant that there were no right or wrong answers nor any consequences for any answers. This was to foster accurate and full data.

Interviewer/participant bias may occur, affecting the relationship and ultimately the authenticity and detail of data given. The relationship may also affect the way data is collected and analysed, affecting the authenticity of the research (Nieswiadomy, 2008:245). Because of the face-to-face contact, the response rate to questions is high, but as explained, may lack authenticity and detail unless a trusting/open/safe rapport is built and the participant is specifically guided to respond in detail.

An interview may elicit uncomfortable/distressing emotions (Polit & Beck, 2008:400). This was addressed by the researcher being observant to signs of stress and fatigue, and offering a break and offering time to debrief.

3.6.2 Interview schedule

An interview schedule is a measuring instrument comprised of a set of questions that broadly cover the topic being studied. The schedule is used as a framework to conduct the interview and includes both open and closed ended questions. The interview schedule used in the research was semi-structured and did not require strict adherence to the wording or order of the questions (Parahoo, 2006:329). The initial number and type of questions were the same, but as each interview progresses, the question order was changed to allow free flow of the conversation, additional questions to be asked to probe new avenues, seeking clarification or gathering more comprehensive details (i.e.

allowed perspectives and topics to emerge) (see Annexure 5). The researcher was guided by the responses of the participants to allow further questions to develop.

The interview schedule used in this study was set out in a manner to prompt conversation/narrative and yet also allowed for some consistency to protect the rigor of the study. Its' main aim was to elicit rich descriptive data, and is thus suited when doing qualitative research.

3.6.2.1 Advantages of an interview schedule

An interview schedule gives the researcher a frame work to work from. An interview schedule characteristically allows the story to flow through the use of open ended questions, yet also captures some definitive data through closed ended questions. It allows for a balance of standardisation (to maintain rigor) and flexibility (to allow emergence of rich authentic data) (Parahoo, 2006:330). It gives the interview a structure, yet does not constrict the flow of the story.

3.6.2.2 Disadvantages of an interview schedule

A disadvantage of an interview schedule is that the questions may be perceived with ambiguity if not worded with care. Questions that are long and with multiple sections may be overwhelming for the participant and potential data may not be captured (Nieswiadomy, 2008:242). Another disadvantage is that face-to-face verbal response denies the respondent anonymity, and this may compromise authenticity and completeness of responses. A further disadvantage of interview schedules is that the lack of consistency of the questioning may lead to poor rigor and generalisability of the study. Lastly, the ability of the researcher to ask additional probing questions may cause the researcher to lead the participant.

These disadvantages were addressed by the researcher by constructing clear questions, and the interview schedule was offered for peer review prior to the study. Lack of anonymity was overcome by rapport building and assuring the participant that no identifying data would be included in the research report. The researcher was cognisant not to ask leading prompting questions.

3.6.3 Memoranda

Memoranda, or memos, are informal notes written by the researcher during and after an interview to supplement the data in the recording and to capture any ideas developed during the interview (Streubert & Carpenter, 2011:134).

Memos can include:

- Jots to remind the researcher of details not captured on the recording, e.g. body language.
- Reflections and insights the researcher has, e.g. patterns in the data, relationships between categories and emergent conceptualisations.
- Cues for new avenues to pursue questions.
(Polit & Beck, 2008:524).

The advantages of memos are that they serve as reminders and prompts for the researcher and can fill in details not capture in the recording, e.g. body language (Burnard, 2011:462). A disadvantage of memo taking is that the researcher has to take their attention off the participant and may miss some details. The participant may feel neglected as the researcher makes the notes (particularly relevant when working with patients with BPD who are particularly sensitive and easily perceive being “ignored/abandoned”) and this may compromise the participant-researcher relationship. In this study, the researcher compromised by negotiating with the participant that there would be times that note taking would be unavoidable, but they were still very important to the researcher and encouraged them to pause their story or restate anything they felt the researcher missed while writing. After taking a note, the researcher was diligent in making comfortable eye contact to reconnect with the participant and show attention.

3.7 PILOT STUDY

A pilot study is an opportunity to evaluate and refine the research plan, e.g. the interview schedule, to ensure that the research will run smoothly (Polit & Beck, 2008:67). The data gained from the pilot study is not included in the research data.

After compiling the interview schedule, the researcher asked a peer to partake in a role-play. The researcher conducted a mock interview to attempt to identify any ambiguities

or problems with the interview schedule or any issues with her interview style. A peer was used as opposed to a patient to protect the patient from going through an interview and it not be used. The researcher was cognisant that not as much would be learnt this way, but weighed up the risks and benefits.

One suggestion following the pilot study, relating to the interview schedule, was some minor changes in the order of the first questions, and this was applied. They felt the questions were applicable and would yield data toward the research topic. The questions were found non-offensive and gave room for the respondent to tell their story. The response regarding the researchers' interview style was that they felt comfortable, safe and respected.

3.8 DATA ANALYSIS

Qualitative data analysis is a process of interpreting data to describe and explain the phenomenon being studied, i.e. inductive data analysis (Fossey *et al.*, 2008:728). Data analysis starts while collecting data and continues as new data is collected. In this study the phenomenon was the experiences of living with BPD, particularly those experiences affecting their decisions regarding their ongoing care.

Phenomenological data can be analysed by searching for themes, patterns or trends. Themes, concepts and commonalities can be drawn from the data. Themes are then clustered together to define the characteristics of the phenomenon. The themes are then put together to describe the “essence” of the phenomenon. Findings can be presented in the form of verbatim quotes, describing emergent themes and positing new concepts and understandings.

The steps of data analysis in qualitative research include:

- Thorough reading, with sensitivity, of the entire transcript.
- Identifying shifts in participants' thoughts/understandings by dividing the transcript into sections and by comparing initial interview with subsequent interviews.
- Highlighting particular significant phrases in each thought segment, using the participants' words.

- Examining each significant phrase to identify its' core meaning in the researchers' words.
 - Grouping together similar core meanings to formulate themes
 - Analysing themes and extracting essences of the phenomenon.
 - Combining the essences to describe the lived experience.
- (LoBiondo-Wood & Haber, 2011:146).

Analysis in this study started with the researcher studying the whole transcript of the interviews. The interview transcripts were examined to find the participants' fundamental expressions of the phenomenon, looking for meanings (interpreting the responses) and gaining an understanding of the transcript as a whole. Analysis continued by examining the individual parts of the transcript (i.e. sentences). Sentences were interpreted by interpreting the meaning of the words, i.e. reading between the lines, and comparing the findings of the sentences and the entire transcript to see what interpretations could be made (Fleming *et al.*, 2005:118). Thus the understanding of the whole transcript helped the researcher to understand individual sentences, and understanding individual sentences helped the researcher to understand the transcript as a whole (Fleming *et al.*, 2002:118). This aided the discovery of the meanings the events had for the participants who experienced them. This facilitated the identification of commonalities and themes. Consistencies of themes were evaluated, but stand-alone data was also acknowledged. The themes were then offered to the participants and peers for comment, and the researcher also challenged her own pre-understandings against the data (Fleming *et al.*, 2002:118).

Dimensions of the phenomenon of living with BPD were studied and interpreted when analysing the data. The dimensions included frustration, helplessness, and satisfaction. Characteristics (significance) of the phenomenon (e.g. tolerability, level of interference) were also examined during analysis (Morse, Stern, Corbin, Powers, Charmaz & Clarke, 2009:95).

Analysis, as described earlier, can appear linear, but the researcher noted several steps occurred simultaneously with different pieces of data, and the data was re-examined after initial analysis. Analysis also guided subsequent data collection (Hoepfl, 2007:10) and hence further analysis.

The rigor of the analysis process was monitored by checking the transcripts with the participants, having peers check the conceptualisation, and checking the findings with participants, literature and peers. The researcher invited a Maori elder to assist her with the interpretation of the data captured from the 3 Maori participants. The researcher analysed the data consistently using comparative analysis and acknowledged all data (Bruce, 2007:51). The rigor of the study was further enhanced by using the participants own words and having excerpts from the transcripts in the research paper so readers could follow the analysis and conceptualisation process (Morse *et al.*, 2009:209). The researcher analysed all the data, even the data she did not agree with and she described what was done with the data that were not used. The researcher described how she incorporated her own views as data. She proposed that the research findings not be used outside the specific research situation as the theory will be substantive and not open to generalisation. She examined weather the findings offered any new explanations or insights. Ethical considerations, e.g. confidentiality and sensitivity were addressed to maintain the rigor of the study (Stige, Malterud & Midtgarden, 2009:1508).

The researcher devised an audit trail, i.e. a method of identifying data according to their speaker and context, by including quotes. She identified how she determined the categories and how they were linked, so the reader can follow her analysis (Hoepfl, 2007:9). The audit trail was included to enhance the readers understanding of the conceptualisation process, allow them to follow the analysis process and interpret its' authenticity (Polit & Beck, 2008:392).

The data were analysed by constant comparison at each stage of data collection. The data from each interview were compared with other interviews. The data from the transcript as a whole were compared to the sentences. The sentences and paragraphs of each interview were compared. (Bryant & Charmaz, 2007:277). The constant comparison of data generated theoretical properties, such as dimensions and characteristics (Morse *et al.*, 2009:95), both revealing comparative relationships to other data. The aim of the analysis was to interpret the subjective meanings of the experiences of the respondents by gaining an understanding of the meanings the participants gave to their experiences of living with BPD. The interpretation process of the data is presented in Chapter 5.

3.9 VARIABLES IN THE RESEARCH METHOD

Qualitative research methods are always subject to variables as the research is done by humans (who are not accurate machines and prone to subjectivity) using tools (interviews and interview schedules) that are difficult to replicate. This section will outline some of the variables and how the researcher attempted to eliminate their effect.

- **Research setting**

Using different settings will add a variable that is difficult to eliminate. The researcher stated that the research findings were only to be used in the setting that the research was conducted.

- **Population sample**

If different respondents were chosen the data collected could have been different. The researcher tried to overcome this by adhering strictly to the inclusion and exclusion criteria and ensuring a representative sample.

- **Researcher-participant interaction**

If the respondent was not feeling well on the day of the interview, the data captured on that day could have been compromised. The researcher was careful to get an accurate feeling of how the respondent was feeling and offered time to ground themselves or offered a new appointment.

If the researcher was struggling herself, e.g. feeling unwell or stressed, she could become less attentive than desired, and thus the accuracy of the data collection could be compromised. The researcher was cognisant to use time prior to the interviews to focus and ensure that she was fully “there”.

If the researcher and participant had any transference issues (biases toward each other) it may have affected the study. The researcher was very observant of biases and set boundaries and clear expectations to minimise any poor relationships. Time was taken to earn trust and respect to improve relationships.

- **Interview and interview schedule**

As questions were asked in a different order, data collection is not able to be replicated. This variable was minimised by the researcher by asking the same questions and recording their answers verbatim.

- **Data analysis**

If the researcher was not strict in following hermeneutic phenomenology assumptions, different means of data analysis could be used, e.g. not using data she did not believe in, not trying to interpret the data.

As hermeneutic phenomenological research is human driven, there is a propensity for variables to affect the research, so close attention must be paid to try to minimise those that can be, or state clearly in the research what variables were noted.

3.10 TRUSTWORTHINESS

Trustworthiness, a term akin to vigor, is a concept that is strived for in qualitative research in order for the research to be believed and taken seriously in the field (Morse, Barrett & Mayan, 2008:13). Trustworthiness contains aspects including credibility, transferability, dependability confirmability and authenticity (Morrow, 2005:253); these are specific methodological strategies to evaluate qualitative vigor in order for the research to be considered worthwhile and for the reader to develop confidence in the research. This section is included so that the reader may follow the steps taken to ensure trustworthiness, and determine to what extent the research is robust.

3.10.1 Credibility

The rigor of a qualitative study is judged by its credibility. Credibility is the measure to which others in the discipline judge the research to be accurate (Lo Biondo-Wood & Haber, 2011:158). To develop credibility, the research questions (interview schedule) were offered to 2 peers in the field of mental health nursing (both having experience with patients with BPD) to give comments on the potential credibility of the research. To

further enhance credibility, the transcripts of the interviews and the conceptualisation of the data were offered to the participants for comment on their accuracy as advised by Healy and Devane (2011:34). The findings were also given to the peers for comment on the credibility of the research. A qualitative and descriptive design was used as this appeared to be the best fit for the topic which studies humans. The most appropriate research method, e.g. selection process, was chosen to foster credibility (Dibley, 2011:14), i.e. patients from all groups were selected to cover a wide base and ensure data from a wide source.

The credibility of the research was established by including measures that increased the probability that credible findings would be produced (Streubert & Carpenter, 2011:48), e.g. prolonged contact with participants and prevention of attrition. Attrition has a negative impact on credibility because it introduces many extraneous variables (Xia, Adams & Bhagat, 2009:290), e.g. the data from the non-compliant patients who do not continue with the research will affect the result as they are not included. Therefore the researcher explained the research process thoroughly to all potential participants to prevent startling surprises and stress which could result in attrition. She built a good relationship with the participants to foster trust and reduce attrition (Xia *et al.*, 2009:285). However the researcher was mindful of creating an atmosphere where it was comfortable for the participants to exit if they should choose, to respect their wishes and because an unwilling participant is often likely to give responses that will negatively impact on the credibility of the data, e.g. unreliable or incomplete responses (Xia *et al.*, 2009:296).

Credibility was also enhanced by building trust through being open, honest, trustworthy and maintaining confidentiality to promote detailed and credible responses from the participants.

The credibility of a quantitative research report relies heavily on the confidence the readers have in the researcher's ability to be sensitive to the data and to make appropriate decisions in the field in regarding interpretation and analysis. Credibility was addressed by using applicable open ended questions (which have been checked by peers), and by ensuring good rapport with participants (to minimise attrition and enhance honest and full responses).

3.10.2 Confirmability

Confirmability is the degree to which the findings of the research reflect the implementation of credibility (Lo Biondo-Wood & Haber, 2011:372). To achieve confirmability, the issues that enhance credibility must be demonstrated. To implement confirmability, the peers the researcher approached to comment on credibility were senior practitioners with experience with patients with BPD, and their comments were acted on, again to enhance credibility.

Confirmability was dealt with in this study by returning to the participants at all stages of the research, to check on interpretations made during analysis of the data (Fleming *et al.*, 2005:119).

Confirmability also refers to the degree to which the researcher can demonstrate the neutrality of the research (Hoepfl, 2007:14). The researcher demonstrated this by providing an audit trail showing reasons for interpretations and conceptualisations.

All data were checked against each other repeatedly and compared and contrasted again to enhance trustworthiness. Findings were compared to literature to validate the findings (Corbin & Strauss, 2008:299).

Triangulation, where data from different sources are collected, has been shown to enhance confirmability (Tobin & Begley, 2008:388), hence the researcher used multiple sources to obtain data, i.e. varied selection of participants and use of interviews and memo taking. Triangulation was implemented by using patients who have been compliant and non-compliant and from all groups. Data from the transcripts of the interviews with participants and memos taken during interviews were used to widen the field of data collection to effect triangulation (Kirkman, 2008:70).

Findings from the research were compared to literature findings on the topic to validate the research findings (Cutcliffe & McKenna, 2009:379). The researcher was aware that the possibility existed that even though the research findings and literature findings were similar, they both may be incorrect. To enhance confirmability from literature findings, the researcher used multiple literature sources when seeking to validate resource findings, as advised by Anthony and Jack (2009:1174).

3.10.3 Transferability

Transferability refers to the extent to which qualitative research findings can be generalised or transferred to other contexts or settings (Polit & Beck, 2008:768), notwithstanding that the aim of a qualitative study is not the generalisability of the findings. Transferability depends on the degree of similarity between the original (research) environment and the environment to which it is being transferred to, as well as the research methodology used (i.e. sampling method) (Hoepfl, 2007:13). Rich, accurate data is the hallmark of qualitative research as opposed to generalisation.

To aid transferability, the researcher described the situation (where the study was done what the circumstances affecting the study were, e.g. the economic and political climate), the sample, the research methodology and the data analysis process as fully as possible to give an indication of the research context and process. Other researchers can then appreciate the context and structure of the research and judge for themselves to what extent the findings are applicable outside the research.

Stakeholder participation will enhance the relevance and direction of the research as stated in the research by Macaulay, Jagosh and Seller (2011:45). To this end, the researcher asked the respondents and peers as stakeholders to evaluate the questions and interpretations to monitor the process of the research to establish transferability.

Assumptions the researcher has, e.g. that treatment should be negotiated, was described in the research to help the reader make an assessment of the researchers' influence on transferability.

Transferability was addressed by describing the context of the research, the population sample, data collection methods and the data analysis process, so that the reader is able to judge how the data may be used outside the study. However the researcher cautions that the focus of the research was not the generalisability of the findings, but its rich detailed data.

3.10.4 Dependability

Dependability is a criterion for evaluating whether the findings remain consistent throughout the study, i.e. referring to the stability of data over time and differing conditions. Dependability is comparable to objectivity (unbiased) and reliability (consistency of measurement). The ability to replicate a study increases the study's dependability (Polit & Beck, 2008:751). One way the researcher attempted to increase the dependability of the research was to detail the context within which the research occurred. The manner in which the researcher approached the study was described to foster dependability as the integrity of the research can be evaluated.

The researcher enhance dependability by defining and documenting concepts (e.g. compliance, non-compliance, treatment) so that terms were seen universally and were not ambiguous (Coombs, Curtis & Crookes, 2011:368). A list of concepts was defined under the heading “Key concepts”.

The researcher strove to generate a representative sample by ensuring a mix of compliant and non-compliant participants across age, gender, ethnic and social backgrounds as this was found by Anthony and Jack (2009:1178) to enhance the dependability of a research study.

The researcher established an audit trail to enhance dependability. The process of the research was documented, so that it can be traced and authenticated. The researcher documented data objectively and explained the method of the research, e.g. the population sample, population selection, data collection process and the steps in the analysis of the data. Statements of logic regarding the decisions made during the research process were offered (Streubert & Carpenter, 2011:93). An effort was made to make strong logical links between the data and the analysis, and evidence was given to support any claims made. Sufficient detail (e.g. including actual respondents' statements and the steps in the interpretation process) were included to verify the findings, as it is important that the research process becomes traceable.

Reflexivity is important when assessing the dependability of any research. Reflexivity is the awareness of the researcher of the influence they have on the research and how the research affects them by giving them a new understanding of the phenomenon under

study and their new responses to the phenomenon (i.e. a constant evolution of the topic and the researcher) (Elliott *et al.*, 2012:433). This in essence will affect the dependability of the research as the findings will not be consistent due to the continual evolving of the topic and the researcher, but cannot be avoided so must be described in the research report to address dependability. The researchers' preconceptions, pre-knowledge, bias and own personal experiences relating to the study topic were documented in the research so the reader can see how this may have influenced the research and thus access dependability. By declaring her stand point, the reader can see how the phenomenon has been studied from the researchers' perspective.

Stability in data, i.e. consistent findings, will enhance dependability (Miyata & Kai, 2009:319). The researcher will document the process of the research so that dependability of the research can be assessed by the reader. She also documented her influence on the research by addressing reflexivity.

3.10.5 Authenticity

Authenticity is the measure of genuineness and legitimacy; it is the extent to which the qualitative researcher fairly and faithfully shows a range of different realities (Polit & Beck, 2008:748).

The authenticity of this research was enhanced by methodological accuracy and consistency. The research was implemented as described by authors and experts in hermeneutic research methodology, e.g. as described by Schunemann, Fretheim and Oxam (2006:25).

To establish authenticity, the researcher described the process of data collection and analysis via an audit trail so the reader can clearly follow the process and judge the authenticity of the research for themselves (Streubert & Carpenter, 2011:93).

The researcher represented the various realities surrounding compliance and non-compliance by interviewing a wide range of patients who have had different experiences regarding the topic. Compliant and non-compliant patients with different social, ethnic, economic and geographical back grounds were included to respect inclusion and representation to augment authenticity.

Transcription and interpretations of data was checked with the participants. The researcher asked peers for comments on the conceptualization process and asked for their comments on the robustness of the research process and whether the findings appeared to be believable.

The researcher detailed all the data, even the data she did not agree with, because including all data enhanced the authenticity of the research (Corbin & Strauss, 2008:298). All negative data was also acknowledged, e.g. respondents who do not have an answer or do not wish to answer. Appropriate data (data that pertains to the topic) will be sought to prevent inclusion of non-relevant details that will detract from the authenticity of the research.

To get authentic data, the researcher must have an honest and deep relationship with the participants (D'Arcy, 2009:175). If a good relationship is not developed, the data may not be complete or honest. The researcher spent time building a good relationship by showing caring, interest, consideration, treating the participants with dignity and respect and maintaining confidentiality. She anticipated that this would take time and be difficult especially with the patients who have BPD, notwithstanding whether they were compliant or not.

To enhance authenticity, the researcher identified and described her involvement and its' potential to affect the findings (Horsburgh, 2008:309), e.g. that patients knew her and may want to please her by giving answers they think may be helpful but not quite accurate. No research is free of bias, and the researcher detached herself as far as possible from the data, but acknowledged her own prejudices (e.g. compliance should be linked to receiving sickness benefit) and insights to allow the reader to establish the degree of authenticity of the research as they read it.

The researcher used her exposure in the research field as a psychiatric nurse to get a good interpretation of the research field, i.e. the lived experience of patients with BPD, particularly regarding non-compliance, to enhance the accuracy of the data collection and analysis.

In summary, trustworthiness was addressed through methodological rigor (using sound practice in the conduct of the research) as well as interpretive rigor (interpreting the data accurately and having the interpretations verified by the participant's and peers). It was acknowledged that generalizability of the findings is limited to the context of the research. Trustworthiness was enhanced by describing the circumstances in which the study was done, documenting the conceptualizations process, verification of the findings through peer and literature review and building a rapport with the participants.

This section discussed the trustworthiness of the research and what the researcher did to uphold the rigor of the research. Research vigor was upheld by addressing credibility (by seeking peer review), confirmability (by checking interpretations with participants), transferability (acknowledging that the research results were not generalizable), dependability (creating an audit trail, e.g. verbatim quotes) and authenticity (attention to methodological detail).

3.11 CONCLUSION

In this chapter, the research method was described, including the research setting, research design, sampling, data collection, data analysis and trustworthiness.

The setting for this research was Whakatane, New Zealand. The site included inpatient and Outpatient services as well as 5 allied services. The research design used was qualitative, with naturalistic, descriptive and narrative, intuitive, interpretive and emergent elements. Sampling was done using non-random, non-probability sampling, namely purposive sampling. Data collection was done using face-to-face, audio recorded interviews guided by a semi-structured interview schedule. Memos supplemented the data collected during interviews. Data analysis was hallmarked by constant comparison, contextualization and description of emergent themes. Measures to protect and enhance trustworthiness of the research was discussed, namely credibility, confirmability, transferability, dependability and authenticity.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

4.1 INTRODUCTION

In this chapter an outline of how the data that was collected from the respondents was analysed and prepared for presentation.

Data analysis refers to “the process of breaking down, examining, comparing, conceptualizing and categorizing data” (Lincoln & Cuba 2000:214). Data analysis is based on the research questions and guided by the theoretic framework of the study. Data analysis was conducted on the information/narrative that the ten participants revealed and described in this chapter.

Data analysis grounded in Heidegger’s hermeneutic phenomenology dictates that both descriptive and interpretive functions are performed on the data collected in an effort to gain an understanding of the participants world view. This was done by the researcher in order to provide a robust narrative study of the experience of the patient living with Borderline Personality Disorder.

Data were obtained through interviews with participant in order to co-construct reality with the participant, to see how they make sense of their reality of living with BPD. The goal of analysis was to accurately interpret the narrative to portray the meaning of the lived experience of the participant with BPD (Cohen *et al.*, 2000:72). The data resulted following examining the main research question:

- What are the lived experiences of a patient with Borderline Personality Disorder?

Ten (10) verbatim transcripts from the tape-recorded interviews became the raw data for analysis. This was done in plain text format and direct quotes were given in the discussion of the findings in Chapter 5.

In hermeneutic phenomenological research, the analysis of data for interpretive purposes is both similar to and different from content analysis. The process is similar in that the data looks for pertinent themes via coding and categorisation. It is different because the premise on which interpretive research is based is that there are multiple meanings and that the clue to those meanings needs to be found in the interpretation (Holroyd, 2007:117). One important aspect of analysis used in this study was to gather and interpret meanings of the phenomenon as elicited by the participant through the understanding and analysis of their language as described by Kvale & Brinkman (cited in Sloan & Bowe, 2014:1292).

4.2 ASSUMPTIONS UNDERLYING THE DATA ANALYSIS

During analysis, there were several assumptions that stemmed from general hermeneutic phenomenology, e.g. interpretation, as well as the researcher's own personal assumptions, e.g. that patient's with BPD have unique needs regarding compliance. These assumptions will be discussed below.

4.2.1 General hermeneutic assumptions

During the analysis, the researcher was cognizant of the following assumptions pertinent to hermeneutic phenomenology:

- Every experience has a meaning which at first may be hidden. Good listening and robust analysis of the data will foster the illumination of the true meaning of the phenomenon for the participant (Lye, 2008:15).
- That people are not merely passive participants of life, but interact with their environment, and give meaning to these interactions. We share a reality but also have our own personal reality. Our existence as beings is affected by our situation, our tools with which we manipulate and articulate the world, our pre-understandings and our prior experiences (Lye, 2008:25)
- Interpretation leads to the unfolding of contextual meaning given by participants to the phenomenon. This interpretation can only be valid when the researcher is

immersed in the phenomenon and taking the background/context into account (Huang, Kellet, St John & Lee, 2006:49).

- Perceptions and understandings change over time, with introspection/reflection, discussion with others and additional experience (Owen, 2004b:349). We thus constantly revise our understandings and adjust our personal reality over time. This was evident as the participants who had had a long experience with compliance often changed their view/understanding of the phenomenon of compliance.
- There is a clear distinction between things “in themselves”, e.g. how they appear physically, and what we project onto things, i.e. what they mean to us (Zahavi, 2002:678). Hermeneutic phenomenology dictates that interpretation to access meaning is essential in analysis. Adjunct to this assumption is that there are multiple realities; each person experiences their own reality, which is unique but may have some common elements with other people’s realities. The analysis of this study sought to uncover these realities and find common themes. As such, the assumption led not to “the answer” but to uncovering the meaning of experiences for the participants.

4.2.2 The researchers’ personal assumptions

Phenomenological research requires that the researcher does not concentrate on bracketing (denying) their own understandings and biases, but acknowledging them and including them as data. This is to enable the study to become more trustworthy as the reader can follow the researcher’s view and influence on the subject (Polit & Beck, 2008:228). To respect this, the personal assumptions of the researcher will be described.

- Patients with BPD are subject to similar issues to other patients that affect compliance, e.g. accessibility, time, trust. (Paris, 2009:62). The patient also has issues affecting compliance that are unique (e.g. fear of abandonment) or far more substantive (e.g. trust).

- The patient with BPD has unique characteristics which impact on compliance, e.g. impulsivity, fear of abandonment, difficulty in making and sustaining relationship's (including with clinicians), as also described by Binks *et al.* (2009:20). Patients come to clinicians with common cognitive distortions, e.g. black and white thinking, labelling, anger, catastrophizing and generalization (Clarkin & Lenzenweger, 2006:49). These will affect rapport building and compliance.
- The patient with BPD will need more time to develop rapport and trust with the clinician who will affect at least initial compliance as also found by Banerjee, Duggan, Hubbard and Watson (2006:387).
- The treatment plan for patients with BPD is characteristically a long process, thus compliance is important to stay the distance and get the benefit of treatment (Waldinger, 2007:163).
- The patient with BPD inevitably tests the clinician for honesty, trustworthiness and understanding; this may be evidenced in compliance as stated by Clarkin and Lenzenweger (2006:53).
- Treatment should be negotiated and adapted regularly to attain maximum compliance, while maintaining firm understood boundaries as discussed by Friedel (2004:152).
- Unconditional compliance is not advocated, but rather a negotiated, co-constructed treatment plan with flexibility and basic boundaries is deemed most therapeutic and successful as also seen by Wijnveld and Crowe (2010:1379).

It is acknowledged that the assumptions stemming from hermeneutic phenomenology and the researcher's own pre-understandings affected the analysis and interpretation of the data.

4.3 DATA ANALYSIS AND INTERPRETATION PROCESS

In order to provide congruence between the study's philosophical underpinning and the researchers' methodological process through which study findings were interpreted, the researcher was obliged to use or develop an approach for textual analysis. As a result, the basic elements of Heidegger's hermeneutic interpretive approach, influenced by the hermeneutic circle as described by Sloan and Bowe (2014:1296), guided the data analysis and interpretation process in this study.

In line with research strategies which concentrate on the context of understanding events and meanings, every interview text was documented sequentially, as were follow-up interviews. This resulted in a series of documents for one participant. For example, participant 1's transcription of the first interview was ES Int. 1 and the initial analysis of this transcript resulted ES IA 1. The follow-up transcript, if any, resulted in ES Int. 2 and the analysis thereof was ES IA 2. These were all sequentially numbered and filed for the purpose of auditing and providing an audit trail.

Data analysis occurred simultaneously with data collection. Initial data collection led to initial data analysis which in turn guided further avenues for data collection, then more data analysis, thus a cyclical process ensued (Beagan, 2000:180). The researcher thus moved back and forth between data collection and data analysis in order to uncover and explain findings.

Analysis is the process of ordering and interpreting the data, so that it makes sense, becomes rational. The data from the interviews needed to be analyzed to create a comprehensive picture of the information collected. Rationality is the process in which we can share our world, that we can make things understandable to each other, and that experiences can be made intelligible (Sloan & Bowe, 2014:1292). It gives an insight into the complexity of people's experiences as they engage with the world around them.

To be able to engage in the process of analysis, the researcher applied skills of reading texts (i.e. the transcripts), intuition (to be able to interpret the text) and isolating themes, as described by Sloan and Bowe (2014:1292). The themes were then written as interpretations of the lived experience.

The process of the application of hermeneutic phenomenology was thus followed, i.e. the examination of the texts, reflection on the content, exposing something meaningful and describing themes. Once the themes were identified, the themes were rewritten by interpreting the meaning the participant had about the experience, as described by Hoepfl (2007:529). Thus content analysis was conducted (i.e. reading the text) followed by interpretation and identification of themes.

Data analysis began with data collection, as the researcher listened and thought about the meaning of what was said as it was revealed (Cohen *et al.*, 2000:76). As the data emerged, interpretation occurred (a process of analysis) and new avenues of data were revealed for further data collection, thus data collection and analysis was not a linear function, but a back and forth process as described by Lindseth and Norberg (2004:147). This process of understanding was documented as a testament to the analysis process for verification and evidence of trustworthiness as detailed by Cohen *et al.* (2000:74).

Notwithstanding the contention that hermeneutic phenomenological methodology has not been derived from statistics, the analysis must still be robust and authentic. The following stages of analysis were used to achieve this.

4.3.1 Stages of analysis

There were 5 stages that the researcher progressed through to analyze the data, from data gathering and verification to writing and rewriting the narrative (Cohen *et al.*, 2000:76).

4.3.1.1 Stage 1: Data gathering and verification

The first stage occurred as the researcher listened. Possible themes emerged, e.g. the theme of the participants seeing themselves as bad. These themes were validated by reflecting them back to the participants, i.e. a participant said he “*was not lovable*”. I then verified its’ meaning that he felt that he was a bad person and affirmed this and justified it by saying “*that was why everyone rejected me, I am a bad egg*”.

This showed analysis of the individual statements of the individual participants. During the interviews constant attention was placed on interpreting the statements and discovering/clarifying meanings to engage in hermeneutic phenomenological analysis as described by Hoepfl (2007:5). Common meanings to the participants' experiences were soon revealed.

The verification of the interpretations of statements was an integral step as it filtered out researcher misunderstanding, communication errors, researcher opinions and researcher speculation (Sloan & Bowe, 2014:1299). Verification also increased the trustworthiness of the research process.

The interviews became quite emotional for the researcher as she heard their story and felt their pain. She made this work by showing empathy and developing a rapport to get rich data, but had to be cognizant to remain true to being a researcher and not get into a therapist role.

The 10 participants' interviews became the data to be analysed.

The interviews were read and reread to move from naïve reading to being able to grasp some meanings and understanding.

4.3.1.2 Stage 2: *Transcription and immersion*

More thorough analysis of the data was done by transcribing the interviews verbatim. Personally transcribing the transcripts helped the researcher become immersed in the data and reflect on the data. She then read the transcripts and her memos several times, i.e. getting further immersed in the data. Reading entailed going back and forth between the sentences, paragraphs and the whole transcript to get a contextual understanding of the sentences, paragraphs and the complete text. In this stage intuition developed as the topic became more familiar to the researcher.

4.3.1.3 Stage 3: Data transformation/reductions

This stage encompassed data organization by eliminating irrelevant details (i.e. digressions, changes in topics), simplifying spoken language and compacting sentences, being mindful not to lose context or meaning.

4.3.1.4 Stage 4: Coding and thematic analysis

Line by line coding of the transcripts enabled more data organization to occur. The text was then divided into smaller parts, known as meaning units. A meaning unit contained aspects related to each other through their content or context, and conveyed one central meaning (Erlingsson & Brysiewicz, 2013:98).

Codes were established by defining words, groups of words and their properties (i.e. characteristics, scope and limitations). Clear definitions were developed for each code so it could be applied consistently and to build trustworthiness due to the transparent process of coding.

Once the overall texts were understood, phrases of the texts were underlined and more themes identified. Recurring patterns of data were identified and tabled as themes and sub-themes. A theme is a re-curing thread of meaning that is found in various text parts, it conveys an essential meaning of lived experience, e.g. guilt (Lindseth & Norberg, 2004:149). These themes and sub-themes were then compared and differences and commonalities were identified. Common themes were grouped together. Relationships between the various themes were identified to start forming a contextual picture.

Each theme's significance was understood through noting the emphasis the participant placed on it. The significance of each theme was also rated by noting the how often each participant mentioned the issue and the number of participants that mentioned the issue.

These themes were then discussed with the participants and peers to gain confirmation and detect any poor /unfounded interpretations as suggested by Cohen *et al.* (2000:83).

Themes remained flexible; as more data was revealed the researcher constantly modified the themes.

4.3.1.5 Stage 5: Writing and re-writing

This process was crucial in staying true to hermeneutic phenomenology as it fostered further interpretation of the data to occur. It enabled comparison of themes, the identification of relationships between the themes and the development of a coherent picture of the phenomenon. The analysis will then presented as a system of linked themes, described in Chapter 5. The way the data will be presented is in the form of a series of themes, categories and sub-categories, answering the research questions of:

- What are the experiences of the patient living with Borderline Personality Disorder?
- What are the contributory factors leading to treatment of non-compliance in patients living with BPD?
- What meaning do patients with BPD attribute to treatment of non-compliance?

The researcher adhered to the above five stages of data analysis to ensure that a robust and consistent application of analysis was upheld to facilitate the integrity of the research.

As well as following the stages of analysis set out above, the researcher used the hermeneutic circle, studied isolated thematic statements, used inductive reasoning, interpreted, checked and compared, sought essences and was aware of appearances to facilitate effective data analysis. These will be described below.

4.4 HERMENEUTIC CIRCLE

The hermeneutic circle describes a process of analysis that involves studying the whole text and comparing it to the small parts of the text, and then studying the small parts of the text and comparing it to the larger text in order to get a contextual understanding of the data (Fleming *et al.*, 2005:18), i.e. moving between the parts and the whole text.

The researcher used the process of the hermeneutic circle and this increased the understanding of the data, e.g. sentences in an interview with a participant depicted the participant was angry at the clinician, but the large picture (from the large text) showed the participant as being angry at most people he came into contact with, as well as himself and even inanimate objects, thus putting the participants' anger at the clinician in perspective.

4.5 ISOLATED THEMATIC STATEMENTS

Some isolated statements that were made were pursued to see if they would bring up any new themes. At times they did (e.g. family influence, detailed later), and other times they remained isolated, e.g. "*I use my intellect to try figure things out*" remained an isolated statement despite asking other participants how they integrated BPD in their life; by contrast, all other participants reflected they relied on others or it was just too hard.

4.6 INDUCTIVE REASONING

Inductive reasoning is a step in the analysis process. It is the process of reasoning from detailed facts, progressing to the more general picture (Sloan & Bowe, 2014:10). Inductive reasoning requires the researcher to have some knowledge of the topic to be able to begin interpretation.

To be able to apply inductive reasoning, the researcher must be immersed in the phenomenon, allowing the data to speak for itself. Inductive reasoning helps construct a description of the experience which can then be interpreted by the researcher (Osborne, 2009:81).

The researcher adhered to this process by being immersed in the phenomenon of compliance and non-compliance by patients with BPD, both through her normal work and through the intense connection she forged with the participants. The researcher also is a trained psychiatric nurse and has a working knowledge on the subject of BPD and compliance issues.

4.7 INTERPRETATION

The hermeneutic process requires both descriptive and interpretive elements (Streubert & Carpenter, 2011:84). The descriptive element was obtained through listening acutely to the story of each participant and reading the transcripts several times. Interpretation occurred while uncovering the meaning given to the phenomenon of compliance by the respondents.

Interpretation already began in the data collection phase, i.e. the interviews. Through hearing the participants' story, the researcher already started forming insights and uncovering themes, and this in turn prompted further questioning (Sloan & Bowe, 2014:1296). Interpretation is what makes hermeneutic phenomenology (Van Manen cited in Sloan & Bowe, 2014:1299). However, it is argued by Lindseth and Norberg (2004:147) that all description is innately interpretive. As experiences and information are shared, there is inherently an ongoing process involving interpretation, this includes interpreting the language used.

The interpretation of the data included examining the participants views on compliance, what impact the phenomenon of compliance had on the participant, feelings and habits around compliance and consequences compliance and non-compliance had, in order to understand the phenomenon from the participants perspective and what it meant to them (Cohen *et al.*, 2000:80).

Interpretation was not a linear process. As the researcher gained more understanding, it lead to further questioning and data collection and then more interpretation, incorporating the new data. The researcher had not focused on the impact the family had on compliance, but as one participant stated how her mother had tried to convince her to stop taking her medication, the researcher then added this by going back to participants to collect data on this avenue of investigation, and then put the data up for analysis.

The interpretation process involved moving between the sentences and the text as a whole several times to accurately get the context of the whole and the sentences.

Interpretations cannot be accurate unless the data is viewed with the understanding of pre-conceptions, time (as understanding changes over time) and context (Polit &

Hungler, 2008:530). Thus the entire story of each of the participants was listened to carefully to get a contextual framework from which to interpret the data.

Using hermeneutic methodology, bracketing was not a tool that was required in this analysis. Instead, acknowledging the researchers' pre-conceptions and bias kept the interpretation trustworthy as readers could follow her interpretations.

The robustness of analysis, i.e. the interpretation, was supported by transcript extracts for external analysis and audit trail as proposed by Hoepfl (2007:9). Further, the interpretations were checked with the participant and peers to ensure the accuracy of the interpretations.

4.8 CHECKING AND COMPARING

During the analysis process, there was continuous checking and comparison of the data to ensure authenticity of interpretation.

4.8.1 Checking

The researcher constantly checked that she had understood the participant and received the intended message/information by reframing or asking the participants to clarify or comment on her interpretations.

The participants were invited to read the transcript and check the content and findings. The researcher also checked that her interpretations were correct by reflecting her interpretations to the participants for verification. This is known as member checking, described by Sloan and Bowe (2014:91).

The researcher also checked with literature and colleagues as the data emerged to confirm interpretations and themes.

4.8.2 Comparing

Comparisons were done to discern similarities, make connections and discover patterns.

The individual sentences were compared to the main text and the main text was compared to the individual sentences to affirm context. The various texts were compared to each other to form themes.

In this study, after analysis of the transcripts, 3 main themes emerged with 11 categories and 28 subcategories as indicated in Table 5.1, which will be presented in Chapter 5.

4.9 RELATING THE DATA ANALYSIS TO THE PHILOSOPHICAL UNDERPINNINGS AND THE GUIDING FRAMEWORK OF THE STUDY

As the study was done using hermeneutic methodology, some underpinnings of the methodology will be discussed, such as terminology and assumptions.

4.9.1 Being in the world

“Being in the world” is a concept that refers to the hermeneutic phenomenological belief that all activities are internalised/constructed by the person through their own perceptions based on their experience and knowledge (Streubert & Carpenter, 2011:77).

This study, through robust hermeneutic analysis, sought to see things “as they *are*” to the participant, not how they *seem* (Dinkins, 2012:157).

Heidegger asserted that the individual and experience cannot be separated; they are co-existing and unable to exist apart. He proposed that human experiences are more than knowing, it is experiencing as well as giving the experience meaning, thus Heidegger stressed the ontological focus of the meaning of being (Dowling, 2007:134). This study sought to describe the experience, from the participant’s world view, and sought to interpret how they gave the phenomena meaning (Laverty, 2008:15) after having lived it. This meant raising consciousness of the phenomenon first (i.e. by asking what they understood by compliance/non-compliance) then exploring what it feels like/what it means. The Cartesian conundrum (of the relationship of mind and body) was

upheld in that the phenomenon itself was explored but also the relevance the participants place on it, i.e. the effect it has on them.

Understanding the patients' "being in the world" seeks to find the essences of the phenomena, e.g. that therapy is more than the interaction between the patient and the clinician, but the way the patient feels about the relationship with the clinician, e.g. issues of trust and respect. It seeks to find the meaning of the phenomena, e.g. interpreting the why, not so much the what.

As people experience the world, they change, constantly "becoming" as they reflect on phenomena (Owen, 2004b:349). This was shown in compliance where traditionally the patient did exactly what the doctor ordered because they were seen as knowledgeable/trustworthy. Over time patients have come to question this and use other sources for reflection (e.g. family, internet), hence compliance with treatment has changed as they receive differing advice (Bender *et al.*, 2010:1176).

Getting in touch of the participants state of "Being in the world" fosters contextuality to the experience and thus accurate interpretation/analysis can occur (Owen, 2004b:349).

4.9.2 Language

Language (verbal and non-verbal) helps define and disclose the world in which we live, it allows expression and understanding (sharing) of the meaning we give to phenomenon in our world (Holroyd, 2007:1). The better we understand the language of the participant, the better we can analyse the data (what is being said).

In this study, part of analysis was getting to the core of what the participant was really saying, getting past the literal word, reading between the lines by observing the language used and listening to what is left unsaid (Osborne, 2009:85). An example is one participant said

"everyone always rejects me".

When the researcher looked past the words, she heard that what the participant was really saying was how overwhelming rejection is (this was checked with the participant).

The participants' language needs to be understood to get the real meaning of the experience for the participant. The researcher did this by reflecting and asking for clarification of language used. Close scrutiny of language used by the participants gave the researcher content as well as meaning.

4.9.3 Essences

Analysis of data includes the understanding of the actual phenomenon itself, the nature of the thing itself, its' essence, and this leads to the understanding of the meaning of the thing (Sadala & Adorno, 2002:283).

Phenomenology of essences involves searching the data for common themes or essences and establishing relationships (Streubert & Carpenter, 2011:82).

In this study, compliance was the essence of the phenomenon itself, i.e. if the participant took their medication and came for therapy. How compliance and non-compliance made them feel and what it represented to them was the interpretation of the phenomenon.

4.9.4 Intentionality

Intentionality is a way of knowing reality (Mamabolo, 2009:48). Intentionality is seeking to know more than simply the exterior or obvious, to want to know more than the description of the phenomenon (Leher, 2011:5). Intentionality strives to explain how "it is", what meaning it has, what impact it has on the participant (Osborne, 2009:80).

Identification of intentionality was demonstrated by the researcher during analysis by striving to find out how the phenomenon impacted the participant in terms of compliance.

4.9.5 Appearances

Analysis of the data includes examining the data for appearances by observing different ways the same phenomenon presents itself (Sloan & Bowe, 2014:14). In this research,

appearances were challenged, e.g. the loss of self-esteem presented in some participants as a motivation and laziness, while in other participants it presented in passive aggressive behaviour. Challenging appearances ensured authentic interpretation of data.

4.10 CONCLUSION

In this chapter, the data analysis and the interpretation processes employed were discussed. Data analysis, using hermeneutic phenomenology, involved progressing from the field, i.e. where the data was collected, to the interpreted text. As more data was collected, the narrative was re-examined and the data was re-interpreted and re-written (Cohen *et al.*, 2000:76).

The aim of the analysis was to understand the phenomena, and was achieved by listening attentively to the data and then interpreting the meaning it had for the participant.

The analysis process, hermeneutic circle, studying isolated thematic statements, inductive reasoning, interpretation, checking and comparing, seeking essences and being aware of appearances all contributed to accurate data analysis. The findings, i.e. themes, categories and sub-categories that emerged from the data analysis will be presented in the next chapter, Chapter 5.

CHAPTER 5

PRESENTATION OF THE FINDINGS AND LITERATURE SUPPORT

5.1 INTRODUCTION

The previous chapter outlined how the data were analysed, and in this chapter the findings will be presented by highlighting the themes, categories and sub-categories that emerged, supported by literature. The literature references were included to enhance the robustness of the research. Literature references were also included to allow the reader to follow what findings have been revealed previously on the topic, compare those findings with this study, reflect on the trustworthiness of the research and examine the potential for generalisation of the data.

The structure of the data after analysis consisted of three themes, eleven categories and 28 sub-categories and is featured in Table 5.1. The themes became the headings for the presentation of the findings. The presentation of the themes aims to relay the lived experience of patients with Borderline Personality Disorder captured in the data, particularly regarding engagement with treatment. This will help understand how the patient perceives the various elements of compliance and help understand their reaction towards compliance.

5.2 PARTICIPANT PROFILES

To allow the reader to follow and make their own interpretation of the data, short participant profiles have been included here, near the findings, for ease of reading. Care has been taken to maintain anonymity as discussed with the participants, and to this end codes were created to identify participants only to the researcher.

The participant profiles were collected as an ice breaking exercise, enabling the researcher and participant to start forming a rapport, which is important to foster full and accurate data collection during each interview. In order for the reader to have a glimpse

of the participants in order to follow the analysis process, a brief description of each participant is hereby presented.

5.2.1 ER

ER is a single 32-year-old female who has had 22 years of contact with Mental Health Services. Her contact has traditionally been on a crisis-only basis and she has had many admissions (+/- 30) under the Mental Health Act for safety following suicidal behaviour. ER is currently living alone and is unemployed, having been dismissed from her employment as a Social Worker due to her self-professed “*poor people skills and panic attacks*” Her perception of experiences with Mental Health Services has been that clinicians do not care and find her too difficult to manage. She sees clinicians as only doing enough to get their pay and lying to her on a continual basis so has no trust in any clinicians and responds to this with non-compliance and frequent reporting to authorities.

5.2.2 EH

EH is a divorced lady, aged 58. She previously was a midwifery student, but “*could not cope*” according to her, and did not complete. She lives with her mother and works as a cab driver on occasions. These issues all contributed to her poor self-esteem and feeling unworthy of clinician contact, yet she was also painfully aware of her right to treatment. EH first presented to Mental Health Services 38 years ago with panic attacks, anxiety, poor sleep and overdosing.

EH often finds herself contemplating “*why don’t people want to help me*”. She often experiences narcissistic pain and reacts by getting angry and withdrawing, including from clinicians, thus engages in a passive aggressive manner.

5.2.3 EW

EW is a 25-year-old electrician in a *defacto* relationship. He has been enrolled with Mental Health Services for 1 year. He has a volatile relationship with others and this has been noted in his relationship with clinicians, and he confesses that is why his partner has chosen not to get married. He finds himself to be very sensitive to the responses of

others, e.g. the way they look at him, what they say to him, not being included by others in group activities; and thus describes himself as having huge trust issues and avoids people contact where possible, evident in his lack of attendance at appointments. What also affects his engagement is that he does not want to seek help or talk about his illness to save others from worry, and EW feels no one will understand or can help. He feels he should be able to do it on his own and has to “*be strong*”, this he says has enabled him commit to the pressures and discipline of work.

5.2.4 ED

ED is a 53-year-old mother of 3 who lives on a farm with her 3rd husband. She is a retired dental technician. She has had contact with Mental Health Services since the age of 20 for recurring overdoses and anorexia. Her core presentation is trying to please everyone by being the good wife, mother, friend, employee and patient. She rarely feels she achieves this, and thus withdraws and is not open with people/her therapist, telling them what she thinks is right. However needing to be “good” enabled her to weather the pressures of work. ED often asks others for help, then rejects it as she “*should do it on my own*” and tries to find ways to help them instead. This causes her to miss appointments and use group sessions exclusively to help others.

5.2.5 EA

EA is a 56 year single lady who lives alone and regularly attends the local Mental Health Recovery Programme and is a Consumer Advocate. She did not finish school. She was placed in a children’s Mental Health Unit at the age of 10 as she had severe dissociative episodes that her family were not able to deal with. She has grown up with a strong conviction that she is a bad person and has compensated for this by deliberately going out her way to be nice to people and admits that is the reason she is a Consumer Advocate. EA attends appointments, but only “*to be a good patient*”.

5.2.6 ES

ES is a 51-year-old divorcee who is currently going through transgender therapy (from male to female). She has been living in a lesbian relationship, which has been characterised by turmoil, as are all her relationships with her family and clinicians. She

has recently been terminated from her job due to insubordination and poor work productivity. This shows how BPD has impacted all areas of her life. She has had Mental Health input since her teens when she presented with overdoses. Her core emotions are of anger and entitlement, and this is expressed in being quite demanding and volatile in her interactions with others and regular reporting of people to authorities, including her therapists. Her previous contact with Mental Health Service was characterised by crisis interventions or when she needed medication or a medical certificate to sickness benefits.

5.2.7 EM

EM is a lady of 53 years. She entered university after school but could not cope with the pressure of performing and interpersonal contacts. She first had contact with Mental Health Services from the age of 16 when she presented with cutting, overdose and attempted hanging. She has been married for 3 years, showing she is now able to make and maintain relationships. EM works as a Mental Health Support Worker, showing she has reached a place where she can understand others needs as opposed to being consumed with her own anger, grief and narcissistic pain. She often queries what is real and what is not and this affects her relationships with all clinicians as well as others.

5.2.8 AZ

AZ is an 18-year-old scholar living with her parents, her dad suffering from schizophrenia and her mother from depression. She was first seen by mental health at the age of 7 with poor sleep, intense moods, impulsivity, anxiety, persistent negative thoughts about herself and low frustration tolerance. She does not like "*not knowing*" and thus often sits for hours at her computer reading and persists at school despite finding interactions with others stressful. She will not stop a debate until she is satisfied she has won the other person to her way of thinking; AZ also carefully chooses people, namely those that will accept her need to be right. This impacts on the way she relates to clinicians and her compliance. She also finds herself intensely experiencing anyone else's pain, to the point of living their experience and becoming tearful, thus does not attend groups.

5.2.9 HS

HS is 54-years-old and was a solo mother of 1 child, the father of the child having abandoned the family. HS now lives independently and works as a Mental Health Support Worker. She has had Mental Health treatment since the age of 10 when she presented with cutting and poor socialisation skills at school. HS does not like being alone, this influenced her decision to persist in employment. HS admits to not being able to make and maintain relationships as a young woman, and thus never married. She often did not feel worthy of treatment, and thus did not attend appointments, but also often demanded attention by self-harm behaviours.

5.2.10 EN

EN is a 35 year old man on a benefit. He is separated from his partner and taking care of their 3 young children. EN was witness to his mother's psychotic episodes, in which he was often a target, e.g. "*the evil one who she had to get rid of*".

He left school early as he could not cope with the social pressure or the academic requirements due to severe anxiety, panic attacks and depersonalisation episodes.

EN has had several jobs but finds he cannot cope with the pressure, namely having to interact with others and concentrate. His main concern is that he does not want his "*bad side*" to come out, namely uncontrollable anger and labile mood. He also related this to why his partner left him. He keeps himself isolated by not answering phone calls or texts and not opening the door to visitors or his clinician. He pretends all is well and never talks about his illness as he feels embarrassed about not coping and being "*a bad egg*", this leads to poor compliance.

The participants represented a cross section of the population, coming from different ages and diverse backgrounds. The sample consisted of 10 participants who represented patients at various stages of illness, ages, genders, socioeconomic status, occupational status and living situations, and all had been non-compliant as well as compliant at some point. There were 2 male, 1 transgender and 7 female participants in the sample. This reflected the higher prevalence rate of BPD in females, and the gender identity crisis experienced by patients with BPD (Clarkin & Lenzenweger, 2006:267).

The participants' ages ranged from 18 to 58 years, the average age being 44.1 years. This was concurrent with BPD becoming evident in adolescence, and showing signs of becoming less pronounced in the 50's and 60's (Friedel, 2004:75), but also noting that 18 was the inclusion criteria for this study. The average age of first contact ranged from 7 to 25, the average being 14.9 years. There were varying length of years of treatment, namely from 1 to 46 years; this was in line with the comments made by Gunderson and Hoffman (2009:36) that therapy requires a long term commitment by patient and therapist. All had in-patient and out-patient experiences, and all had been compliant and non-compliant to some degree at some time during their treatment.

5.3 THEMES THAT EMERGED

The data will be presented through an outline of the themes that emerged. These themes led the researcher to develop guidelines to improve compliance amongst patients with BPD. These guidelines will be detailed in Chapter 6.

Through the giving of rich data, participants unwittingly helped the researcher uncover themes; this made the research process true to hermeneutic research by encouraging co-creation of reality (Moleki, 2008:104). This was done by uncovering how participants made sense of their reality, namely what living with BPD meant to them and how it affected them. Close note was taken of what the participant wanted to say and what was left unsaid. The researcher constantly checked how focussed she was on the participants' story to ensure she was getting their perspectives.

After analysis of the transcripts, three themes emerged.

These were:

- Relationship with clinician
- Feelings of being overwhelmed
- The futility of the treatment regime

The structure of the data consists of 3 themes, 11 categories and 28 sub-categories, featured in Table 5.1.

Table 5.1 Table of themes, categories and sub-categories

| Themes | Categories | Sub-categories |
|--|--|---|
| 1 Relationship with clinician | 1.1 Compliance 1.2 Needing a say in treatment 1.3 Building a rapport | 1.1.1 Restrictive and limiting compliance 1.1.2 Clients' rights 1.1.3 Motivation/reason for compliance 1.3.1 Initial contact with clinician 1.3.2 Not being understood 1.3.3 Lack of caring 1.3.4 Attitude of entitlement 1.3.5 Help from clinician 1.3.6 Untrustworthy clinician 1.3.7 Attitude toward clinician 1.3.8 Qualities sought in a clinician |
| 2 Feelings of being overwhelmed | 2.1 Inability to change the situation 2.2 Life too hard 2.3 Feeling scared 2.4 Feeling of tiredness 2.5 Feelings of anger 2.6 Being bad | 2.2.1 Feelings are extremely difficult to discuss 2.2.2 Too difficult to ask for help 2.3.1 Panic attacks 2.3.2 Scared of self 2.5.1 Anger at illness 2.5.2 Anger at perpetrator 2.5.3 Anger at clinician 2.5.4 Generalised anger 2.6.1 Memories of abuse 2.6.2 Being unlovable 2.6.3 Having to pretend all the time |
| 3 The futility of the treatment regime | 3.1 Disillusionment 3.2 Ambivalence in compliance | 3.1.1 Hopelessness of treatment 3.1.2 Can't see improvement 3.1.3 Lack of hope 3.2.1 Pain vs potential help 3.2.2 Engagement seen as dependence 3.2.3 Entitlement to help |

5.4 DISCUSSION OF THE FINDINGS

The themes that emerged, namely relationship with clinician, feelings of being overwhelmed and the futility of the treatment regime, are discussed using participant quotes and literature evidence.

5.4.1 Theme 1: Relationship with clinician

The relationship with the clinician was reported as having a great impact on the respondent, manifesting in compliance if the relationship was sound, and non-compliance if the respondent felt threatened, unsafe or not understood.

5.4.1.1 Category 1.1: Compliance

This theme revealed that there were often negative experiences of compliance amongst the participants.

5.4.1.1.1 Sub-category 1.1.1: Restrictive and limiting compliance

This sub-category illustrated the perception of participants that compliance for them was very restrictive, limiting and prescriptive. This was evidenced by statements such as “*they get to tell me what to do*”, “*I have to do exactly what they say*”, relating to appointments, medication, admission and discharge. Further evidence was stated specifically by ES stating “*Don’t cause a fuss, don’t take overdose, don’t AWOL, don’t cut*”.

EM recalls getting the message from clinicians to “*come only when scheduled and then get out quickly*”. ES was particularly affronted when she was “*told*” to “*guarantee my safety*”. These observations were in keeping with findings shared by Moskovitz (2001:91) where he recounts patients were particularly sensitive to “*instructions*”. ER was very vocal in her account of being told to “*be satisfied with what you get*”. She was very angry and her response was “*be grateful for what?*”.

Another participant (ES) clearly recalls being given the message to “*shut up, don’t ask for anything*” and similarly became very angry because as she put it “*I don’t get what I’m entitled to*”. This attitude was also found by Kriesman and Straus (2001:69) where they found

patients with BPD had an ambivalent need to be controlled and punished, yet they also had a narcissistic need to dominate, be in control and have their needs met.

Participants revealed that clinicians and family often confronted them about playing games, namely their non-compliant behaviour (e.g. acting out, deliberate actions of self-harm, manipulation and splitting). EM showed some insight, but also frustration and narcissism when she challenged clinicians with “*I know some of my behaviour gets under peoples skin, but you are the professionals and you need to deal with it*”. ER responded to challenges about her behaviour by saying “*You think I play games, you should see the games you play*”. The game playing, although having a negative connotation, expresses the behaviour patients with BPD engage in to fulfil their need to get what they feel they deserve, a statement concurred by Fonagy, Gergely, Jurist and Target (2006:364).

5.4.1.1.2 Sub-category 1.1.2: *Clients' rights*

A question asked by many participants related to what they could do especially in conjunction with their clinician and their treatment was “*What are my rights?*”.

They felt frustrated at having to comply on the clinicians' terms. Participants felt they had the right to proper treatment, to be treated with respect, as well as have control over what was happening to them. When they felt their rights were not met, they related they had various responses to asserting their rights, summarised by letting the clinician know how they felt, not attending appointments, storming out of sessions and AWOL from hospital. Even though they were asserting their right, they expressed dissatisfaction/anger at not getting what they needed. These rights were explicitly expressed by ER when she did not show up for an appointment, phoned an hour later stating she needed to see her clinician immediately and wanted admission. When admission was not organised, ER overdosed and was transported to hospital; half an hour later she discharged herself. Participants expressed they had the right to be seen when they felt they needed support or were in crisis. ED regularly would not show up for her appointments and a short while later she would phone and demand to be seen immediately. This behaviour was also documented by Moskovitz (2001:88) stating that this is an expression of the narcissistic element of the patient escalated by unrealistic disillusionment (see key concepts).

ER, ES and HS regularly used the complaints process available to them to make their grievances known. This, however, often left them feeling more lonely and aggrieved. This scenario was also reported by Gutheil (2004:250) where he states that patients with Borderline Personality Disorder are often prone to question the quality of their care, but the end result of expressing their complaints often incurred consequences and left them feeling more abandoned and rejected than before, compromising their therapy. ER used the complaints process when she felt she was not given the medication she wanted and felt she deserved. She demanded a hearing with the District Inspector, however after the inquiry, she felt he was conspiring with her clinician and became very angry and disillusioned and stopped all her medication in protest. She then became acutely unwell (with panic attacks and insomnia) and also felt embarrassed and guilty at her behaviour, and this made re-engagement with her clinician difficult and tense.

The participants were regularly found to have dismissed their clinician and demanded a new clinician in an effort to express their right to gain the attention they felt they deserved. The patient often cannot tolerate any ambiguity, and their thinking is black and white, so any real or perceived flaw in the clinician causes the patient to see the clinician as entirely “bad” and needing replacement. This was also opined by Clarkin, Marziali and Munroe-Blum (2002:210) where they explain how patients with BPD cannot tolerate inconsistencies or perceived faults in others. ER reported that she had been seen at 7 different hospitals in the area and regularly dismissed her clinicians in an effort to feel that her rights to proper treatment by a “*decent clinician*” had been met.

5.4.1.1.3 Sub-category 1.1.3: Motivation/reason for compliance

The participants were asked why they did comply and also why they did not comply. There was a group of replies. Often the first reply was “*Why comply*”, “*it doesn’t work*”, “*it doesn’t help*”.

A response that was always deeply emotional was that they did not trust the clinician and had no rapport with their clinician. Linked to this was a common feeling that the clinician did not understand them. The constant reflection by the patient on whether and how to engage with mental health services was described by Clarkin *et al.* (2002:210) who say patients should be encouraged to consider negotiated compliance as compliance regardless of whether it is warranted or not. Clarkin *et al.* (2002:210) also

state that reasons for non-compliance are to be addressed, but with boundaries and explanations from the therapist, e.g. using this as an opportunity to negotiate, teach the patient reality testing and assertiveness and understand the patients' needs.

Regarding therapy, the response was that it was too painful to reveal all the feelings they were experiencing. ED expressed it most succinctly, saying "*It hurts too much*". Moskovitz (2001:89) concurs with this finding, describing how patients at times can become paralysed with fear and the therapist ought to be observant of this and remain caring and supportive to create a safe space for the patient to share.

They felt guilty at being such a bad person and were also scared of letting their emotions "*boil over and explode*", expressed most clearly by EN where he said "*I am so scared to let the bad side out*". This fear was also found by Moskovitz (2001:137) who states that anger issues need to be identified and assertive expressions of feelings need to be taught to help the patient maintain control.

The side effects of the medication were another major deterrent in compliance, namely the weight gain (EM shared she had more than doubled her weight) and the sedation (ER was angry at "*always feeling like a zombie*"). These common complaints were addressed by Friedel (2004:135) where he explains how anticipatory warning of potential side effects is essential, as is appropriate monitoring of the medication which could lead to early intervention, e.g. reduce, stop or change medication. It was also stressed that medication is only a part of the treatment regime and should not be relied on its own; psycho-social skills were advocated to ultimately replace medication.

Some participants revealed that they felt they did not deserve the clinician's time. This was due to their feeling so bad and not worthy. They had not tried hard enough previously and that there were sicker patients than them. ED stated that she had so much input from clinicians she felt she did not deserve any more time, especially as she did "*not do as they advised*". EW echoed this sentiment in that he "*should be like my dad, help others and not rely on people*". This ambivalence in their perception of whether they should be allowed clinician time was documented by Clarkin *et al.* (2002:215) and they caution clinicians to be aware of this phenomenon and build a solid therapeutic relationship so the patient can relay and overcome these misperceptions. Other patients felt they should be able to do it on their own. The denial of the severity of their illness, and the

overreliance on themselves need to be addressed to encourage them to engage in therapy, especially when self-harm thoughts are at risk of becoming overwhelming (Clarkin et al., 2002:207). ED constantly told her clinician she was fine and would skip appointments, but when she experienced stress, she quickly regressed to previous behaviour of overdosing and needed ICU admissions.

A few participants revealed that they did comply because they felt they had no choice, people were expecting or forcing them to comply. Moskovitz (2001:72) concurs with this relating how family, friends, police, courts and staff apply some form of pressure to comply, i.e. issuing punishment (ostracization), withholding privileges (access to accommodation, car, money) or via the Mental Health Act. HS stated that the only reason she complied was when it compromised access to her daughter.

Some respondents conceded there was something to gain from compliance, namely medication for anxiety/sleep, sick note, skills and support; and despite any negative issues related to compliance, they did comply, however often on their own terms. ED noted quite proudly that "*I know how to use the system; I will come to see the doctor when I need medicine*". This was also found by Binks et al. (2009:4) where they state that some patients arrive at a point of resignation that some form of therapy is inevitable and comply to some or other degree.

5.4.1.2 Category 1.2: Needing a say in treatment

Despite the feeling they are worthless, participants frequently stated that they wanted a say in their treatment plan.

HS, amongst others, expressly described her need to have a say or she would not comply. EN was more specific stating that he wanted to "*discuss medication, decide where to go on respite, or when to go on the ward and when to leave – I want to say what I need*".

ES lamented that she had to fight for a say in what she needed and deserved. She stated she had taken "*drastic measures*" to be heard and cited she had complained, AWOL'd, chosen what medication she would take/not take, what treatment she would participate in, in an effort to be heard. ER specifically stated "*I get told my options but they never work*". This caused her to become non-compliant on many occasions. This

scenario was also described by Ben-Porath (2004:255) when he noted the necessity for inclusion and commitment from a patient in order to secure compliance.

Participants revealed that they felt helpless against the power the clinician had over them, e.g. MHA (Mental Health Act to commit), medication (amount and type), admission and discharge. The participants noted that the power was abused, and this made them very angry, e.g. not dispensing medication they wanted or committing them in an act of punishment. The abuse of power may have a basis in reality, as presented by Moskovitz (2001:88) when the clinician was exasperated by the patient. The use of Consumer advocates and legal representation may be appropriate, once the facts are established and the patients blurred reality and imperfect perceptions are cleared.

Some participants cited that the clinicians ganged up against them. They felt the doctors, nurses, psychologists, occupational therapists and social workers were conspiring to make it as difficult as possible for them. They felt they had no hope of getting what they needed/wanted. This perception of collusion was also noted by Martino, Menchetti, Pozzi and Berardi (2012:184) when they found that an apparent alliance amongst staff often had a negative effect as opposed to being seen as unified and supportive of the patient.

ER used Email/notes/texts in an effort to be heard. If she did not receive the attention she desired, she would cut her wrists or take an overdose “*then they listened to me*”. She also sought to gain control over the clinician by reporting the clinician “*it gives me some form of control; I get what I need then*”. The phenomenon of gaining control over the clinician was also described by Gunderson and Hoffman (2009:50) where they explain the patients’ need to feel in control of events and emotions.

5.4.1.3 Category 1.3: Building a rapport

5.4.1.3.1 Sub-category 1.3.1: Initial contact with clinician

The swing between idealisation and total abhorrence towards the clinician begins very early on, and makes it difficult for the patient with BPD to build a solid rapport with the clinician. The initial contact with the clinician is thus instrumental in starting the process

on a therapeutic footing (Forsyth, 2007:38). EM stated she always gave the clinician the benefit of the doubt because “*they were the professionals who knew best and supposedly cared*” and then was disappointed when the clinician did not live up to her expectation. EA always thought, “*this clinician would be the one who would be able to help*”.

SW experience of first contact was “*the staff treat me ok in the beginning, but once they know me they get rid of me, things change*”. The importance of the first contact in regard to sustained compliance was also expounded by Gunderson and Hoffman (2009:28) as well as Martino *et al.* (2012:184).

Most participants declared they hated change, even the clinicians they stated were “*against them and didn't do what they should*”. It was revealed that this was because the initial contact with an unknown clinician was seen as significantly more stressful than continuing with a known clinician - despite their flaws, as they had to tell their story again.

5.4.1.3.2 Sub-category 1.3.2: Not being understood

A common theme was that the respondent felt that the clinician did not understand them, EH put it as “*they don't see my real struggle, they don't know*”. This left the participants questioning the logic in continuing treatment with the clinician. This was expressed in statements such as “*the clinician doesn't know what to do with me, can't cope with me*”, “*the clinician is scared of me and gets frustrated and angry*”. Barlow (2009:375) opines that the basis for misunderstanding the patient with BPD is due to the fact clinicians often overestimate the patients' competence and they do not get the help they need (because the clinician deems them capable); or clinicians are felt to dismiss their fears/problems (done in an effort to bring them to calmness), but the patient interprets this as further invalidation because they should be able to cope and they don't really have a problem.

EH related that the clinician shows they have no idea when they say things like ER says “*I feel you could do different/better, you are manipulative, you are playing games*”, “*I sometimes put things out there to test reactions, see what they know; they always fail*”. The experience that the clinician did not understand was similarly recorded by Friedel (2004:151) who states that this perception may have some basis in reality (particularly when the clinician is not

schooled or experienced with patients with BPD), but also may stem from the patients' innate inability to engage with people, especially in the area of building trust.

5.4.1.3.3 Sub-category 1.3.3: *Lack of caring*

An experience often running parallel to the lack of understanding by the clinician is that “*they don't care*”. This was verbalised by HS who stated “*they leave me at the first opportunity*”.

ER experienced that “*clinicians only do the least possible to not get in trouble and cover their backs*”. EH felt that “*a patient is seen as a necessary inconvenience at best – otherwise a pest*”.

ES reported “*I am seen as hard work and some clinicians are not up to the task, quickly putting me in the too hard basket because they can't be bothered*”. This perception again may have a basis in reality, as not all clinicians are up to the challenge of the testing and splitting the patient delivers. Gunderson and Hoffman (2009:28) elaborate on the commitment the patient with BPD needs from the clinician, and cautions clinicians to expect unrelenting labile responses from the patient, varying in quick succession from idealisation to hate, as their responses will be felt acutely by their patient.

5.4.1.3.4 Sub-category 1.3.4: *Attitude of entitlement*

The narcissistic element of BPD was demonstrated by participants stating that they were not given the necessary treatment or courtesy/respect. They felt their requests for change in treatment/clinician, review of medication, admission and discharge were consistently ignored. They felt they did not get decent or adequate treatment, something they clearly stated they were entitled to. This narcissism was also demonstrated by Clarkin and Lenzenweger (2006:293) when they discuss how narcissism affects patients' compliance due to their inflated self-worth, arrogance and egocentricity. ES portrayed this regularly in her interviews, stating “*they don't give me what I deserve, I should have a decent a clinician, they're never there when I need them*”.

5.4.1.3.5 Sub-category 1.3.5: *Lack of help from clinician*

Respondents showed an overwhelming sense of futility in continuing with treatment because they perceived that the clinicians were not able to help them. They saw the

clinician as being overwhelmed, scared and frustrated at not knowing what to do. This sense of futility was also reported by Moskovitz (2001:91) where he correlated a poor outcome for sustained engagement with lack of confidence in the clinicians' ability. ER exhibited this most clearly when stating "*they can't help me, some try, but never manage, I'm still messed up*".

5.4.1.3.6 Sub-category 1.3.6: *Lack of trust in clinician*

The participants all related their mistrust of clinicians in some way. The main way it was expressed was "*they don't do what they promised to do/what I am entitled to*".

Some respondents noted clinicians abused their power. This was mainly due to their characteristic perception of people, one of either black or white (good or bad), which ultimately affected their engagement style with people, including clinicians. This scenario was also reported by Bornovalova and Daughters (2007:925) who note that a common interaction style by patients with BPD is one of no trust in people/the therapist. ER was most vocal in this stating "*they weren't honest with me, they kept lying to cover their backs*".

EM was weary of clinicians as she felt they put on a false façade of caring and thus could not be trusted. This again stems from reality as she was molested by her clinician after apparent grooming, but also from the core feeling of "*I am too bad to be liked so they must be lying*". This was also related by Kreisman and Straus (2001:69) who described that the hall mark of BPD is the inability to form interpersonal relationships due to a combination of an inability to read others and a damaged ego structure.

ER often made statements regarding the reliability and trustworthiness of clinicians, characterised by "*they say we play games, you should see the games they play*".

5.4.1.3.7 Sub-category 1.3.7: *Attitude toward clinician*

Respondents often refer to clinicians as "they", emphasising the disconnect, giving the sense that they felt the clinician was the enemy, or at least the opposition. In this study, the word "they" has been used to indicate the participant/patient, something to reflect on. Forsyth (2007:34) describes ways to bridge this disconnect, emphasising the need

to build a therapeutic relationship with clients, e.g. treating the client as a human being with respect, honesty, caring and interest .

Participants regularly expressed exaggerated responsibility of clinicians, e.g. “*they need to give me better treatment*”, “*I’m not getting better because I don’t get decent clinicians*”, an attitude also described by Misal (2009:84) who attributes this to the patients’ narcissism.

5.4.1.3.8 Sub-category 1.3.8: Qualities sought in a clinician

When describing the qualities of a clinician that would foster engagement, respondents listed “*clinicians need to be authentic – real, trustworthy, open, honest*”. *Their attitude needs to be “non-patronising, non-judgemental, understanding, give me hope”*. EW succinctly stated “*knowing – when to push me, when to leave me, when to use humour, shows me you must like something about me*”.

These values were also described by Forsyth (2007:34) when he noted that some clinicians viewed certain patients as untreatable, not trying, and difficult, and thus creating an invalidating environment.

Box 5.1 Summary of theme 1: Relationship with clinician

The participants revealed that:

- the relationship was restrictive
- clinicians had accused them of playing games
- the lack of control they had was frustrating
- they were not getting what they were entitled to from the clinician
- they would assert their rights
- they would comply when it suited them
- compliance was affected by the rapport with the clinician
- clinicians need to be authentic and open

The findings noted above showed how engagement “was” for the respondents, and showed how they would react, i.e. not engage or comply only when it suited them.

5.4.2 Theme 2: Feelings of being overwhelmed

The intense feelings experienced by patients with BPD flowed over to the feelings experienced in regard to treatment and compliance, and often overwhelmed them, influencing engagement.

5.4.2.1 Category 2.1: Inability to change the situation

A characteristic of BPD is that the patient is not able to build on positive experiences, and this blurs their insight into their progress, thus they cannot compare where they are today from where they were previously, e.g. prior to treatment. What they are convinced of is that their future is always destined to be bleak (Bornovalova & Daughters, 2007:231). This was expressed by ED as “*I have to live with it*”, showing she felt broken and defeated. EM was convinced that “*I won’t make it, I will fail*”.

To them the future always looked bleak. The understanding that BPD never goes away was heart-breaking for the respondents, and was expressed as “*there is no future, I will always live a life of hell, there’s no getting better, I will never be happy, never have pleasure in anything*”. With this schema, respondents found it hard to become motivated to comply with treatment.

AZ expressed her outlook on life as “*life is unfair, people are cruel, and I can do nothing about it*”.

5.4.2.2 Category 2.2: Life too hard

This category seemed to refer to life in general and to treatment. The participants’ fractured egos found it difficult to believe they could succeed at anything they attempted (Clarkin et al. 2002:90), including succeeding at therapy.

5.4.2.2.1 Subcategory 2.2.1: Feelings are extremely difficult to discuss

Most respondents expressed that their past experiences, and especially their feelings related to the experiences, were extremely painful to discuss. It triggered very vivid and painful memories and flashbacks, causing them to relive the experience on multiple sensual levels. This has been documented by Friedel (2004:92) explaining how the brain pathways, specifically memory pathways, produce emotions. The events that are associated with strong emotions are often remembered more vividly and for a more extensive period of time.

AZ related how “*it hurts to be vulnerable*” and exposing these vulnerable feelings was traumatic. She acknowledges how she might raise an important topic and then avoid discussion by either changing the subject, becoming quiet or leaving the session. ER found it too scary to contribute in groups, therefore kept quite in sessions, thus used silence as a mechanism to avoid opening up her feelings. ED shared how “*therapy opens wounds that are very sore, I would rather not, brings back overwhelming memories and pain. Sessions are hard, it's real hard after a session too*”. Avoidance and silence as protective mechanisms was highlighted by Moskovitz (2001:91). EM explained that she “*was scared to feel happy as bad will surely follow*”, and this caused her not to commit to therapy “*because if I stay unwell, nothing more will happen – good or bad*”.

A characteristic of BPD is low distress tolerance. This is evident when noting how the participants avoid any discomfort, including exploring feelings. This was evident with EM who continually changed the subject, often telling a joke, and with ED who would not even come to therapy as her anxiety already increased in anticipation of the distress she was bound to feel during therapy. Bornovalova and Daughters (2007:926) stated that “distress tolerance, defined as the ability to persist in goal directed behaviour in the face of emotional distress, may be the key to understanding dropout rates”. Lingam (2013:139) concurred, noting that “therapy demands too much from the fractured ego”.

5.4.2.2.2 Sub-category 2.2.2: *Too difficult to ask for help*

The findings revealed that respondents found it very difficult to ask for help. For HS it was that it made her “*feel vulnerable and pathetic*”. For AZ it was “*people don't believe me*”, and for EN it was “*I'm so bad, I can't show you who I am, I'm a bad egg*”. ES related that when she had tried to ask for help she was always treated badly. EM felt the fear of being rejected and thus often did not ask for help. EW stated he lacked confidence to ask for help – felt

he had a label “*stupid, crazy, difficult, bad, lazy*”, and he felt ashamed he couldn’t cope on his own. ED felt others were more worthy of the clinicians’ time and she should be strong. EM was scared to ask for help as she then would get better and the clinician would discharge her; “*people put pressure on me to get well, it’s too scary*”. ES explained for her that “*compared to physical illness, no one punishes you, it doesn’t mess with your mind, you get better, no one criticises you, you get sympathy, you still are someone; so it’s easy to ask for help for a physical illness*”. The fears related to asking and turning up for help were also discussed by Clarkin *et al.* (2002:255). They noted that the fears encompassed fear of rejection, fear of vulnerability, fear of dependence and the need to be able to cope on their own.

5.4.2.3 Category 2.3: Feeling scared

The respondents regularly revealed that they experienced ongoing feelings of dread and panic, for regular events, for the probable negative events that life would surely present, for the rage and emotional lability they experience, but also specifically for the treatment and having to engage with the clinician.

5.4.2.3.1 Sub-category 2.3.1: Panic attacks

The respondents talked of ongoing distressing panic attacks. This is often linked to the innate inability of patients with BPD to tolerate distress, and they are thus easily overwhelmed with fear (Bornovalova & Daughters, 2007:936). The respondents often experienced extreme fear on leaving their home, and some felt unable to attend therapy sessions. Bornovalova and Daughters (2007:936) emphasise that distress tolerance is a crucial element in therapy to overcome panic attacks as well as controlling rage.

5.4.2.3.2 Sub-category 2.3.2: Scared of self

Respondents related to the rage and impulsivity, characteristic of BPD, and which is often directed at themselves or causes them to do risky behaviour (e.g. EM was scared of her reckless driving, alcohol binges and impulsive buying of razors to cut her wrists). Their main issue with rage and impulsivity was their inability to control it. This fear was also directed at clinicians by demanding more attention or by getting very angry at the clinician for not protecting them from themselves. An example of this was shown by ER. ER self-harmed on numerous occasions and told of her intense fear of herself, that she

may one day succeed. She then went on to report her clinician who had resuscitated her after an overdose which had caused her total respiratory arrest. This fear was also documented by Schiavone and Links (2013:134) where they caution clinicians to be aware of the patients' inability to keep themselves safe.

5.4.2.4 Category 2.4: Feeling of tiredness

A common theme was the feeling of being so very tired. This was exemplified by ES stating, “*I'm so tired of fighting and trying, Feel tired and very alone in the struggle, I'm so very, very, very tired of the daily struggle, I can't go on like this anymore, I can't anymore*”. HS was specific in saying “*I'm so tired of always putting on a brave face, tired of being unable to cope, tired of being a bad person/mother*”. EM commented on being “*tired of fighting memories - constant memories followed by guilt, anger - self-berating thoughts, so hard to ignore, have to fight memories each and every day*”. The experience of being tired was not attributed directly to lack of sleep, but poor sleep was described as making the “*struggle even more difficult and tiring*” (EN). Barlow (2009:373) attributes this chronic fatigue to the patients' intense emotional arousal and the slow return to their baseline emotions. The fatigue that the BPD patient is prone to is also described by Moskovitz (2001:127). He emphasises how exhaustion can make the patient more vulnerable to impulsivity, rage outbursts and mood swings and the patients' general level of functioning will deteriorate.

5.4.2.5 Category 2.5: Feelings of anger

Respondents were emotional when describing their anger, and found it impeded their relationships, including the relationships with their clinician. However they usually gave a justification for their anger. Gunderson and Hoffman (2009:50) note that the anger often was expressed by self-harm behaviour.

5.4.2.5.1 Sub-category 2.5.1: Anger at illness

Respondents referred regularly to being angry at having their illness, especially when comparing themselves to others and seeing the “disparity”. AZ stated it was “*unfair ... everyone else gets to lead a normal life*”.

Anger also stemmed from the realisation that they may not have caused all their problems but they have to live with it and solve them anyway. The anger at having an illness was also akin to grieving a healthy self as expressed by EA, who stated that “*as I grew older I became less angry ... I saw the bigger picture that everyone has a cross to bear ... I learnt how to cope*”. The coming to accept their illness was directly related to the intensity of anger they felt about their illness, as also opined by Gunderson and Hoffman (2009:109).

Anger at having to go through treatment was commonly recalled by respondents, hating to have to take medication (that made them feel worse) and sit through seemingly endless and purposeless therapy. EM was very angry at the weight she had put on, despite being warned of this potential side effect, and often stopped her medication. Gunderson and Hoffman (2009:71) mention the irony of giving a patient an “anger pill” which ends up making them angry in itself.

5.4.2.5.2 Sub-category 2.5.2: Anger at perpetrator

The anger shown toward the perpetrator of abuse was surprisingly low. EM expressed confusion saying “*he was my father, you’re meant to love your father ... he had a good side too ... my religious belief state that I need to love my mother and my father ... I must have tempted him /done something wrong, so it’s my fault*”.

Anger at the person/people who should have protected them tended to be more overt, HS repeatedly stated that her mother should have saved her, and as an adult cut off all ties with her mother. The anger, and the need to cover up the anger to be a good person (as EA did) was described by Friedel (2004:98), stating that the patient had a realistic right to be angry, but this was distorted and often misdirected by their diminished sense of reality due to impaired neural pathways. He further went on to detail the snow ball effect of anger and feeling that one is a bad person if one is not “nice” (Friedel 2004:98).

5.4.2.5.3 Sub-category 2.5.3: Anger at clinician

Often respondents shared how angry they were that the clinician was not doing what they should do, e.g. “*not giving me attention, dumping me, ignoring me, clinician is messing with me,*

not doing enough, not doing their best". Anger at not getting what they are "entitled" to was expressed regularly. This was sometimes based in reality, but also clouded by their poor perception of reality and their narcissism, when they felt their expectations had not been met, i.e. having the ideal clinician. This anger toward clinicians was described by Harris and Darby (2009:329) who state some expectation of clinicians is inevitable and realistic, but frank disclosure of expectations and boundaries need to be laid in order for the patient to overcome illegitimate anger towards the clinician when they do not fulfil unrealistic expectations.

Respondents verbalised anger at clinicians for "*not knowing what to do ... not being able to help ...not being able to fix it*". This may be a reflection of the clinicians' own frustration at the patients' behaviour, e.g. splitting, demanding or their true lack of skills; but again also the unrealistic expectations and the black and white perception the patient has of their clinician. This was explained by Roth and Friedman (2006:90) where they warn clinicians to be aware of this reaction, be consistent and teach coping skills.

The perception that clinicians can go home and "*have a great life ... live their perfect life*" was relayed in an aggressive attitude by several respondents. EH verbalised her anger by saying "*you salaried people (clinicians) should sponsor others who need help*". This was fuelled again by her narcissistic, black and white paradigm. This same scenario was depicted by Bornovalova and Daughters (2007:932) and they caution that anger may also stem from resentment at not being able to evoke feelings in the clinician. They guided their readers to be authentic yet have boundaries when revealing pieces of themselves in order to build a therapeutic rapport and limit the potential anger.

Findings show that respondents resent the control a clinician has over them, i.e. regarding access to clinician, medication, in-patient treatment and social benefits. Respondents were angry at the apparent collusion of clinicians with other multi-disciplinary health professionals and services, namely CYFS (Child Youth and Family Services), WINZ (Work and Income New Zealand), the legal services and police. ER stated "*I have to fight the whole system*".

Moskovitz (2001:169) describes similar findings, stating clear contracts and written rights and responsibilities should be available to patients to ensure they are aware of what their entitlements are and what the processes to access help are.

5.4.2.5.4 Sub-category 2.5.4: Generalised anger

Feelings of rage and anger were often elicited in interviews, but at times no specific focus was identified. Friedel (2004:96) contributes this to the previously mentioned disrupted neural pathways which do not allow appropriate experience of emotions, including anger, tempered by the narcissistic nature of the patient with BPD.

5.4.2.6 Category 2.6: Being bad

The findings when exploring this theme revealed that the participants had a profound negative image of themselves, which was often presented alongside their antipodal narcissistic traits. EN portrayed this by stating “*I can't show you who I am, I'm a bad egg. I don't want to be with others, they will see how bad I am*”.

It was noted that often patients were given the message that they are “bad” through being abused, ridiculed, rejected (real or perceived), and continued to give themselves this message for many years. EM portrayed this by stating 30 years after the abuse “*There is something very bad about me, that is why I was abused*”.

ER states she is so bad and justifies this by proclaiming “*my label warns staff to keep away, e.g. attention seeking, druggie, doesn't want to help themselves, intentional behaviour*”.

The findings show that this feeling of being so bad did impact on compliance. EA voiced “*I don't want to talk in therapy – it shows how bad I am*”. She did however participate in the groups where there was no expectation to share feelings/experiences, but a place where she could give, an opportunity to portray herself as “*not so bad*”. This was corroborated by Fonagy *et al.* (2006:13) where they state that abused and traumatised are often unable to accurately judge the actions of their abuser, voluntarily defending them, thereby sacrificing their own ego.

5.4.2.6.1 Sub-category 2.6.1: Memories of abuse

Data revealed that most participants had been abused, if not subject to severe trauma, similarly found by Friedel (2004:63). The participants related that their abuse not only

confirmed their “*badness*”, but that the world was unsafe because they deserved bad things to happen to them “*it always did*”.

The participants often expressed that they felt stupid for allowing the abuse, again emphasising in their mind how bad they are. The feeling of worthlessness was evident, particularly when EM stated that her internal dialogue was one of “*I must be nothing that this happened to me*”.

These findings were relayed by Moskovitz (2001:31) where he states that sexual molestation plays a causative role in the destruction of a healthy concept of self, and that the victim of abuse often misconstrues the actions of the abuser, taking on the blame themselves.

5.4.2.6.2 Sub-category 2.6.2: *Being unlovable*

Often mixed in with their sense of entitlement, participants believed that their clinician would not want to help them because they were not endearing. Their internal dialogue appeared to be “*I hate myself, so you will too*”. This appears to be carried over from the messages they perceived from family and friends. They had experienced hurt and rejection and rationalised it by determining they were not lovable. EA believed that “*no one likes me ... get rejected all the time ... hate and fear rejection, feel it intensely*”. Believing they are unlovable often resulted in another hurt, that of shame. This was also noted by Clarkin and Lenzenweger (2006:111) as well as Barlow (2009:377), where they concur how intertwined self-esteem, fear of rejection and guilt are.

Connected to not feeling lovable, the participants perceived that they did not deserve the clinicians’ time or effort. ED often mentioned that she did not deserve to be a patient; others were more worthy of the clinicians’ attention.

5.4.2.6.3 Sub-category 2.6.3: *Having to pretend all the time*

EA described the need to be liked, but felt this came with the price of always having to pretend to be nice. She felt if she did not pretend, she would not be good enough. She felt she never attained the sense she was good enough despite constantly giving away things, even to people she did not like, in order to be liked. EA continued this behaviour

with her clinician where she constantly brought gifts or offered to help, and described this as very scary and tiring, because the clinician was clever and would see through her pretence. This did impact on compliance, especially the honesty of the compliance. This was also described by Roth and Friedman (2006:23) who described pretending as an un-therapeutic coping mechanism often adopted by patients with BPD.

Respondents reported “having to pretend” all the time that they were “ok” and coping to show that they were not such failures. Moskowitz (2001:93) explained the phenomenon, and cautions therapists not to overestimate the patients’ recovery as this leads to further trauma, in that the patient feels inadequate as the clinician seems to be indicating they should be coping but cannot, and then needs to pretend even more.

Box 5.2 Summary of theme 2: Feelings of being overwhelmed

The participants revealed that:

- their future is always seen to be bleak
- talking triggered very vivid and painful memories
- they felt the fear of being rejected and thus often did not ask for help
- they had been treated badly by clinicians
- their fears encompassed fear of rejection, fear of vulnerability, fear of dependence and the need to be able to cope on their own.
- the main issue with rage and impulsivity was their inability to control it

It was noted that:

- fear was often directed at clinicians by demanding more attention
- there was confusion about the feelings of anger
- anger was sometimes based in reality, but also clouded by poor perception of reality and narcissism
- the respondent had unrealistic expectations and a black and white perception of their clinician
- respondents resent the control clinician has over them
- participants had a profound negative image of themselves which was often presented with narcissistic traits
- low self-esteem and fear of rejection both fuelled each other

Findings from this theme were that respondent's feelings were often overwhelming and kept them from engaging as they believed they were unworthy of clinician time.

5.4.3 Theme 3: The futility of the treatment regime

The respondents recollected how they had tried treatment, often telling of various strategies clinicians used, but never found treatment to be successful.

5.4.3.1 Category 3.1: Disillusionment

The respondents revealed that they were generally very discouraged by their life, reflected in statements such as "*everything is dark ... life is hell ... I can never be normal ... will always have to suffer*". HS put it "*if things improve, it will only be for a while*". ES was more vocal and stated "*my life is messed up for ever ... what's the use ... lost everything, family, friends, job, home; I'll never get them back*". Barlow (2009:373) put the patients' intense emotional responses, and the very slow return to their base line emotional state, as the cause for this chronic feeling of unhappiness.

5.4.3.1.1 Subcategory 3.1.1: Hopelessness of treatment

Alongside the feeling that the clinician cannot help, the respondents did not have confidence in the treatment as such, expressed by "*it doesn't help, can't see it helping, didn't work before, why will it work now? previous attempts ended in failure*". ER reports that she was "*given options that don't help/work*". ES was frustrated at getting "*clichés, options, platitudes - none helped*". ED appeared the most disillusioned when saying "*hospital/treatment is just delaying the inevitable*". The futility was summed up by AZ when she reflected that "*you can't change the situation or the treatment received from your clinician, you have to put up with it*".

This sense of cynicism (cynicism that may be justified at times), was also noted by Roth and Friedman (2006:47) when they stated that the BPD patient often gives up hope in people (clinicians) and treatment. The feeling of hopelessness was also commented on by Bornovalova & Daughters (2007:930), encouraging clinicians to stay focussed in the moment as opposed to looking to the past or future, as patients with BPD are unable to compare present with past nor visualise their future due to their intense feeling of despondency.

5.4.3.1.2 Sub-category 3.1.2: *Can't see improvement*

Linked with hopelessness of treatment, respondents were not able to see improvement in what was happening for them, e.g. in terms of feeling better, relationships and their social situation. They were so intensely captured in the feelings of the moment; they were not able to embrace any accomplishments. The respondents ascribed this to the intense pain they felt and they were not able to think clearly, similarly reported by Moskovitz (2001:78). The respondents also mentioned that they feared that if they got better that the clinician may discharge/abandon them, or they were too scared to believe they were getting better, captured by EM declaring that “*when anything good happens, bad is sure to follow*”.

5.4.3.1.3 Subcategory 3.1.3: *Lack of hope*

The main essence of the lack of hope was loss of hope for a particular future they had envisioned. This was again tempered by their narcissistic paradigm of “I deserve more”. Chapman (2010:388) concurred saying that a prime treatment goal must be to help the patient identify how they fit in the world, and to temper their narcissism, to enable them to weather the interaction with others more successfully and thus feel more hopeful and peaceful as they successfully navigate their future.

The feelings of hopelessness were exacerbated by the labels they carried, e.g. “*druggie, attention seeker, acting out, not trying, failure*”. Bornovalova and Daughters (2007:930) stress the instillation of hope as a critical element against dropout, and as such negative schemas (including labels) need to be addressed.

A poignant quote from ER illustrates the deep sense of hopelessness “*The future is like looking at the horizon, knowing there is no such thing really, when you get to the horizon there is another one further away*”. The deep sense of hopelessness was also documented by Moskovitz (2001:78) when he describes how a patient with BPD cannot draw on the past for consolation or hope, because they cannot recognise good memories. Bateman and Krawitz (2013:30) found that patients who had some hope were more likely to persevere with treatment, hope in fact kept patients going and contributed to saving lives.

5.4.3.2 Category 3.2: Ambivalence in compliance

The characteristic black and white thinking caused the respondents to feel very ambivalent about many facets of life in general, and also specifically of treatment and clinicians. They are not able to conceptualise that a phenomenon or person can have both flaws and admirable qualities. They thus then either extol the virtues of a person and see no wrong or totally abhor the person. They are extremely angry when their overvalued idealisation is proven wrong, even if only in a minor manner. This was also found by Roth and Friedman (2006:54). ER had an unrealistic idealisation of her therapist, and the first time she was 5 minutes late for a session, the therapist was deemed “*totally uncaring, absolutely untrustworthy and completely useless*”.

5.4.3.2.1 Sub-category 3.2.1: Pain vs potential help

The respondents often found themselves having to choose between two difficult options, e.g. continue as is and experience the ongoing distress, or risk the hurt and pain of working through the issues causing the distress. The dilemma comes from needing to take risks, e.g. the risk of being judged vs being listened to as one submits to therapy. This ambivalence was acknowledged by Ben-Porath (2004:252) where he states how important it is to identify and address “therapy interfering behaviour”.

The respondents expressed that they wanted gentleness and concern from clinicians, but even when they did receive it, they found it difficult to believe it was genuine or sustainable, and this compromised their decision to comply or at least comply authentically (i.e. they **pretended** to be the good patient to continue receiving the desired positive attention). This caused them intense anxiety in seeking help, a potential place for reaching a sense of peace. This irony was highlighted by Ben-Porath (2004:252) as he relayed how opposing forces can prevail as patients consider committing to treatment.

The ambivalence of wanting to engage with clinicians vs not trusting them was particularly salient for EM who did develop enough trust in her clinician to commit to treatment and was ultimately abused by her clinician.

5.4.3.2.2 Sub-category 3.2.2: Engagement is seen as dependence

Data showed that many respondents felt that engagement was a sign of weakness, vulnerability, failure and dependence, and this affected their decision to seek treatment. The ambivalent feeling that they should be strong, should be able to cope and needed to be there for others clouded their judgement. These antipodal feelings were seen as the cause of the delay noted in seeking help, as well as the frequent cancellation of appointments and lack of authenticity in therapy (Wang *et al.*, 2007:178).

5.4.3.2.3 Sub-category 3.2.3: *Entitlement to help*

A common ambivalence voiced by the respondents was that of feeling they were a bad person and thus not worthy of clinician time or good care versus that they were entitled to quality treatment. The ambivalence was further escalated in some when they contemplated the treatment they received (deemed as sub-standard) and whether to continue even though they were entitled to. A few verbalised this by making demands of their clinician, e.g. ER demanded admission and then AWOL'd within 1 hour, this occurred on more than 10 occasions; getting the treatment however often left a bitter taste in her mouth as she reflected “*why should I have to fight for it?*”

The concept that they need to be treated, i.e. change, was challenged by several respondents, seeing the dichotomy of them needing to change while others are wrong, why should I do the work/change?; behaviour change is seen as others responsibility. Morgan (2010:161) similarly illustrated this by challenging the clinician to understand the decisional balance and process.

The ambivalence to attend treatment was summed up by ED when she said “*When I don't come to therapy is when I really need support*”.

Box 5.3 Summary of theme 3: The futility of the treatment

Respondents relayed:

- a deep sense of hopelessness

- a chronic feeling of unhappiness
- they were not able to see improvement
- that engagement was a sign of weakness

It was noted that:

- respondents were not able to use past experiences to help them progress
- respondents were slow to return to their base line emotional state
- respondents did not have confidence in the treatment
- there was ambivalence of wanting to engage with clinicians vs not trusting them and feeling unworthy of the treatment

Findings from this theme were that respondents felt hopeless and entitled, and these issues were impeding on their commitment to therapy and thus engagement proved tenuous.

5.5 REFLECTIVE REMARKS ON THE FINDINGS

The core element reflected by respondents was hope, whether it was a hope set in a positive frame, i.e. hope for improvement, end to pain, a good clinician, or a negative hope, i.e. hope I get what I deserve. Relationships with clinicians also appeared very important.

The availability and affordability of mental health services were not mentioned as major issues affecting compliance (due to national health assistance providing free mental health services). In fact some respondents claimed they were not concerned regarding missing appointments as they were not going to be charged for a no-show.

Rejection did not appear as critical as feeling they were getting what they deserved.

The clinician is often referred collectively as “they”, putting them in an opposing side, defining a disconnect between the patient and their clinician/s.

Respondents often talked in generalisations, e.g. “*always, every one, never, they all*”, demonstrating their intense emotions and black and white thinking.

The themes tend to be present in day to day life of a patient with BPD as well as in the context of compliance, i.e. relationships with people in general (as well as clinicians), feelings of anger and despondency with life (as well as with clinicians) and futility of trying at all (as well as lack of futility in treatment).

5.5.1 Relating the classical meaning of the findings to the philosophical guiding framework of hermeneutics

To reflect on the data using a hermeneutic framework, the data will be examined how respondents give meaning to their experiences.

The concept of compliance, i.e. **its essence**, was seen by the respondents as one of dominance by the clinician as clinicians' yielded all the power, in terms of clinician time, access to services and treatment regime. It made them feel helpless and restricted, causing narcissistic injury, portrayed in behaviour such as passive aggression, withdrawal and self-harming.

Respondents often attributed meanings to compliance that were different to the clinicians', e.g. the respondent may come for medication while the clinicians' aim of **engagement** was to teach life skills.

The respondents' **perception of reality** was often clouded and their being in the world was not conceptualised, causing confusion (in relationships and in their own self-construct), and anger toward others when perceived entitlements were not met.

There were some indications of shared common lived experiences, i.e. the respondents shared the desire of the clinicians for a common bond, although the definition of the bond (relationship) was not always similar.

Intentionality was evidenced when respondents were conscious of their experiences, i.e. the pain of feeling vulnerable in therapy, and directed their behaviour accordingly by not attending therapy, going AWOL or stopping medication.

The patient does not act in isolation, neither does the clinician, each influencing the other, this was shown when the clinician was 5 minutes late and the patient felt very rejected by this. The respondents came to the mental health service with certain expectations (based on past experience and from their sense of entitlement), as did the clinician. When these expectations differed, as reported by the respondents, poor relationships were built, dissatisfaction and frustration occurred and non-compliance ensued.

Language used by the respondent was closely observed to ensure the underlying messages were understood. These included noting body language (to understand the intensity of the emotion), generalisations (to understand the enormity of the topic to the respondent), reading between the lines as well as hearing what was not said. The respondents were asked to comment on the researchers' interpretation of their language, to ensure accuracy, but also as a method of building a rapport, by showing she was really listening.

Respondents' actions were noted to be embedded in their **past experiences**, affecting their engagement with treatment. Most had had bad experiences (e.g. dealing with a clinician who they perceived as uncaring, untrustworthy) and thus were not motivated to comply, yet consequences of not complying (another experience, namely not getting attention, sick note or being ostracised) caused them to engage in one or other form.

5.5.2 Isolated thematic statements

There were many common statements as outlined above; there were also some isolated thematic statements reflected by only respondent, but significant enough to mention here in an effort to remain true to hermeneutic research and maintain research integrity.

Only one respondent, ER, revealed that she coped by using her intellect to "*figure things out*". Most other respondents declared they "*had to rely on others*". ED was the only one who mentioned how hard it was for her after the session, that after the session was when she felt the most distressed and knowing how she would feel after the session was what affected her decision regarding compliance most for her. Most respondents

reported that opening up during the session was the most traumatic and thus a major factor that influenced their compliance. Only one respondent, again ED, noted how a written spiritual text given to her by her clinician had had a positive influence on her decision to remain engaged. JK was the only respondent who stated her compliance was complicated by the negative advice from her family, saying she should not go for treatment. To put it into context, JK was brought up in a home that followed Maori traditions and values, and this included renouncing Western medicine and embracing traditional medicine, e.g. using *tohungas* (spiritual healers) and *rongoas* (traditional herbs).

5.6 SUMMARY OF THE FINDINGS

On reviewing the data, many commonalities amongst the data became evident. From the commonalities, three themes emerged, namely relationship with clinician, feelings of being overwhelmed and the futility of the treatment. These three themes with their categories and sub-categories gave insight into the experiences of patients with BPD, especially as it relates to compliance. These are depicted by the researcher in figure 5.1 below.

Central to the findings were the feelings of lack of hope, felt by the respondent via the lack of caring from the clinician and that they did not know how to cure them.

Lack of hope also stemmed from experience of previous treatment that they felt had not been beneficial as they could not recognise improvement.

The feelings often still overwhelmed them, compounded with the conviction that it never get better, made up their lived experience of living with BPD.

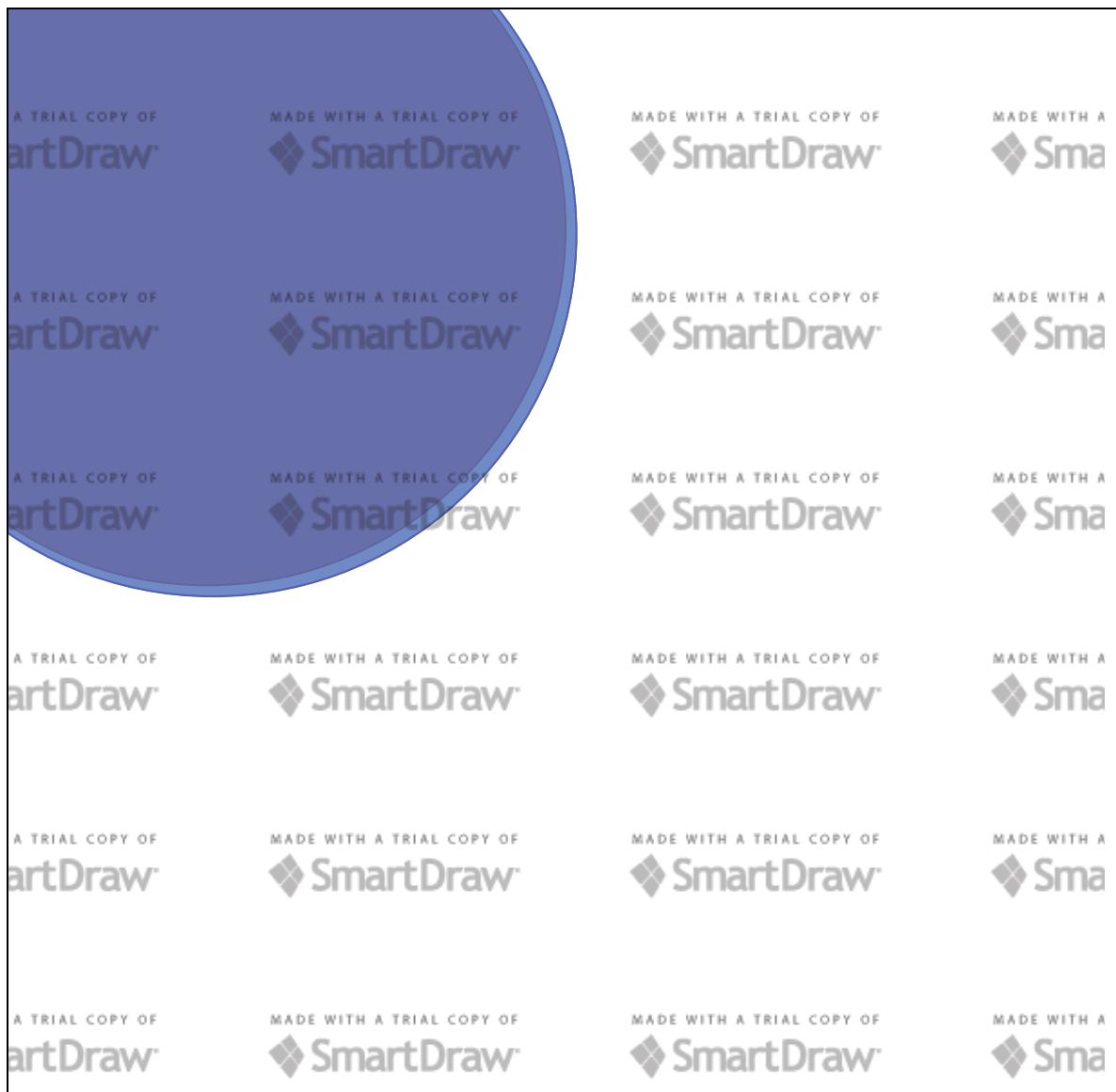


Figure 5.1 Summary of themes

The relationship with the clinician was important to foster commitment to compliance, demonstrated by the respondents' lack of engagement when they did not feel a bond with their clinician. The overwhelming feelings the respondent experienced, e.g. not feeling worthy, also impacted their ability to engage therapeutically. This was however tempered with their feeling of entitlement, which did lead them to engage in an untherapeutic manner. The sense of futility in the treatment (due to previous failed/distressing experiences) caused many of the respondents to question the rationale of going through treatment. In every theme the concept of hope was evident, hope that this was the clinician who could help and would not reject them, hope that the

overwhelming feelings would subside, and hope that there would be treatment that would prove to be helpful.

There appears to be very few practical issues in engaging patients with BPD. The main issues were of poor attachment and lack of hope. These were both seen as being impeded by the intense feelings characteristic of a person with BPD as well as their sense of entitlement.

5.7 CONCLUSION

The findings concurred with current literature and was referred to in the discussion of the findings.

The most outstanding findings were that the patient often felt distressed at being seen as further along the recovery process than they really were, causing them to pretend and feel despondent, and exemplified the schema that they were bad and confirming the label they were stupid/lazy. The need for hope, related as due to the perceived lack of hope they had received, became evident.

In this chapter the findings were presented, namely the importance of the patient-clinician relationship, the overwhelming feelings and sense of futility. In the following chapter, Chapter 6, the guidelines developed from the findings will be highlighted.

CHAPTER 6

DEVELOPMENT OF GUIDELINES TO IMPROVE COMPLIANCE OF PATIENTS WITH BPD

6.1 INTRODUCTION

In this chapter the guidelines developed from the findings will be presented. The development of guidelines is important in order to reach the objective of the study, stated in Chapter 1.5, namely to facilitate compliance in patients with BPD.

Guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (Sonnad, 1997:17).

The study findings have implications for the engagement, assessment and treatment of patients with BPD. The purpose of the guidelines, through using the findings, is to improve quality, maintain consistency, standards and reducing uncertainty and cost (Sonstad, 1997:17), so that clinicians may better engage the patient with BPD.

Resistance to guidelines was evidenced in many studies, and it was noted that education and social influence may not be sufficient to change physician behaviour and successful guideline implementation (Sonstad, 1997:17). Therefore the guidelines were written with the following in mind:

- Matching guidelines with the organisation's philosophy, including getting bureaucracy to support the guidelines.
- Guidelines to be clear, achievable, relevant and practical (Streubert & Carpenter, 2011:431).
- Change is often time-consuming and difficult, so gain collaboration of peers in the implementation of the guidelines.

- Dissemination of guidelines is important so all staff are to be given access to the information relating to the guidelines, e.g. seminars and in-service education (Nieswiadomy, 2008:348).

6.2 IMPLEMENTATION OF THE GUIDELINES

The implementation of guidelines involves the recipient who is expected to be the one benefiting from the guidelines, the patient in this case, the implementer, referring to the clinician, and the area where the guidelines are to be implemented, which in this study was the mental health service in Whakatane.

The difficulty with implementing these guidelines was defining where the engagement process ended and therapy started. The researcher believed it was cyclical and intertwined. As the patients built rapport, they were more open to learning new skills, and as they learnt new skills they became more open to building a deeper rapport. Engagement was seen to become more regular as treatment progressed. This was demonstrated by the respondents who tended to have a high rate of non-compliance in the earlier days of treatment, and slowly as time went on, even with different therapists, patients became more compliant.

6.2.1 The recipient

The recipient of the guidelines is anyone who benefits from the guidelines being implemented, primarily the patient with BPD, but also includes the patient's family, clinician and management.

The focal recipient of the guidelines in this study was the patient with BPD. It was anticipated that as the guidelines are implemented, the likelihood of compliance would increase. With more compliance, the patient would benefit as their risks were minimised and their quality of life increased.

The family are also recipients of the benefits of the guidelines and ensuing increased compliance, because as the patient improves they portray less risk and are easier to manage at home.

Clinicians will benefit from the implementation of the guidelines as they feel more satisfaction from their job (because their patients improve), they feel more supported (e.g. through regular supervision) and feel more competent (through in-service education). With increased compliance the clinician also benefits from less waste of their time through no-shows.

The unit co-ordinator and management also benefit from the implementation of the guidelines as they have a more productive and competent work force. There is also less wastage of staff time by no-shows and less waste of medication as the patient complies with their treatment. There are also fewer re-admissions, keeping costs down.

6.2.2 The implementers

There is a range of people who can be called on to implement the various guidelines, including the clinician unit, unit-coordinator and intake officer.

The skilled clinician is the primary person, with the proviso they get support, supervision and time to engage in ongoing education. The unit co-ordinator and management are also implementers as they need to facilitate time for clinicians to attend supervision and in-service education. The intake officer is called on to implement guidelines in that they need to be aware of the patients' needs and be able to link up the correct clinician for the individual patient. Other personnel who could implement the guidelines are general practitioners (as they motivate the patient to follow up on treatment), peer support advocates (encouraging and instilling hope), family (as they learn to support the patient and encourage them to comply), lawyers and consumer advocates (assisting patients with their rights) and police (when the patient is compelled to treatment).

6.2.3 The area

The area the guidelines are intended for is the mental health service, both at grassroots and management levels.

6.3 GUIDELINES FOR MANAGING COMPLIANCE IN PATIENTS WITH BPD

The guidelines were drawn from the findings as depicted in the presentation of the themes in Chapter 5. The guidelines aim to improve initial compliance as well as ongoing compliance.

6.3.1 Theme 1: Relationship with clinician

The guidelines to address Theme 1 reflects the understanding that engagement of patients with BPD is challenging, and the relationship between patient and clinician needs to be built attending to patient perceptions as well as best clinical practice. The guidelines also reflect the need for patients to have input into the treatment plan to enhance compliance and ensure that the treatment plan is effective.

Guideline 1.1: To improve compliance

The results derived from this theme were that respondents wanted to remain in control of the way they engaged and have a relevant reason to engage. This led to the conclusions that both respondents and clinicians needed to look at compliance issues and respondents needed hope. From the conclusions, the following guidelines are proposed:

- Clinicians to engage in constant reflective practice to monitor any dictatorial or controlling attitude that may hinder compliance. This reflection can be done either on their own after contact with a patient (e.g. as they write up the notes) or in peer discussions. Their practice should also be reviewed with their supervisor during supervision on an ongoing basis, e.g. monthly.
- Help the patient identify realistically what their rights are (e.g. by discussing the content in Annexure 6). Help patients assert their rights in a manner that they are successful, i.e. clarify appropriate grievance processes and assist in appropriate assertiveness (see Annexures 6 and 7). This could be carried out by a consumer advocate.
- Offer support, e.g. link up with consumer advocate, lawyer or second opinion, when appropriate through the referral process or as appropriate.

- Do not aim for nor advocate compliance regardless; teach the patient to listen to and question recommendations when deciding whether and how to engage.
- Clinician to give clear and unbiased information based on evidence and showing understanding of patients experiences and needs, in order to foster informed compliance.
- Address therapy interfering issues as soon as detected, e.g. poor attachment, unrealistic expectations, clinician burn-out; seek and listen to patients' input as to what is causing complication in engagement.
- Instil realistic hope in the efforts of compliance by exploring the positive gains the patient stands to enjoy and the control they can exercise.

Guideline 1.2: Inclusion in treatment planning

The results derived from this theme were that respondents demanded a say in their treatment and this led to the conclusion that given information and boundaries, respondents could contribute effectively to their treatment plan which would increase engagement. From the conclusion, the following guidelines are proposed:

- The clinician should construct a treatment plan in collaboration with the patient, yet helping them remain realistic (their narcissism may present some unrealistic expectations) as the patient is more likely to be committed if they have a part in creating the plan. This satisfies the patients' need to be helped, yet have a say/maintain some control. Start by identifying common goals and build the treatment plan on that foundation.
- Clearly state in the treatment contract the consequences of breaking the contract, so the patient can predict the consequences of their actions.
- Discuss with the patient their rights, and guide them through their responsibilities so they have a thorough understanding of how they can have a productive say in their treatment (see Annexures 6 and 7).
- Teach effective communication skills so the patient can have a successful input into their treatment, e.g. assertiveness, use of knowledge, based in a good self-image as opposed to cutting, swearing, threatening and withdrawal.

- Discuss the purpose, process and value of the multi-disciplinary team involved in the treatment plan, so the patient does not feel overpowered by numbers (Bateman & Krawitz, 2013:112).

Guideline 1.3: Build solid rapport

The results derived from this theme were that initial contact with a clinician was very important, as were clear boundaries and expectations which needed to be discussed regularly with the patient. This led to the conclusion that clinicians need to constantly portray caring, hope, understanding and trustworthiness to build and maintain a rapport that fosters engagement. From the conclusion, the following guidelines are proposed:

- Building a relationship based on understanding, respect, non-judgemental attitude, caring, interest, empathy, openness, trust and “knowing”.
- Help the patient identify that they see the clinician (and others) as either exemplary or detestable; help them wrestle with the confusion and how to try to see clinician with their positive and negative attributes to foster engagement due to having a realistic perspective of the clinician. The clinician must therefore have a consistent approach so the patient can predict their response.
- Link appropriate clinicians with patients, (often done on an *ad hoc* basis), i.e. clinician who is motivated to work with patients with BPD, has training and experience with patients with BPD. Similar guidelines were also advocated by Bhar, Brown and Beck (2008:175) who found that the more senior and experienced the clinician was, the less negative emotions were expressed and thus more therapeutic relationships tended to be built. This guideline can be achieved by having a intake worker/triage worker who has an understanding of the needs of the patient with BPD as well as a sound knowledge of the clinicians who they can refer to.
- Clinicians are to keep up to date (attend courses, reading professional journals), and be aware of burn out (use support, breaks and supervision) so the clinician can be fully “there” for the patient (Bateman & Krawitz, 2013:35). This needs to be implemented by management by facilitating the necessary time and resources.

- Patients need to have a clear understanding of expectations of the relationship so no unfilled expectations are encountered, i.e. clear boundaries must be set. This can be achieved by entering in a written contract, created together (Bhar *et al.*, 2008:173). This may mean the clinician has to address unrealistic preconceptions and the black and white thinking the patient often brings to the relationship, and the clinician must be aware how they are perceived by the patient to foster a therapeutic rapport.
- The clinician must manage the intense oscillating feelings the patient projects onto them (through countertransference) by expecting these reactions, remaining consistent and not reacting to the behaviour (by having a healthy self-esteem themselves and having a good understanding of the patient). Peer/supervisor support for the clinician (made possible by management) to help de-brief may be helpful to weather the emotions the patient draws out of the clinician.
- Clinician to be aware that the patient may present as being more capable than they are and thus needing more input than outwardly indicated. The true extent of the patients level of functioning can be assessed accurately if the clinician has a therapeutic relationship with the patient based on trust and openness.

6.3.2 Theme 2: Feelings of being overwhelmed

The guidelines from Theme 2 reflect that the patient is often paralysed with the intense feelings they experience and the need to address these feelings and other misperceptions the patient presents with. The aim of the guidelines is to assist the patient change ingrained schemas and to decrease anxiety and resistance regarding attending treatment. The respondents noted that they hated change but also felt helpless at not being able to improve their situation, so any anticipated change needs to be implemented slowly, and at the pace of the patient along with the patients input.

Guideline 2.1: To have some control over the situation

The results derived from this theme were that respondents often felt overwhelmed by their feelings, felt that there was no hope and that they were a bad person who could not ever be loved or deserve treatment. This led to the conclusion that affect regulation and instillation of hope were essential to engage patients. From the conclusions, the following guidelines are proposed:

- Clinician to be aware that patients can not readily derive pleasure from positive experiences or acknowledge progress, and the best practice is to stay in the moment to help the patient remain engaged and help them gain control “for now”.
- Teach what emotions are about – emotions to a certain intensity are normal, emotions have a life cycle (i.e. they will pass), awareness of emotional intensity and triggers, what helps, link between emotion and action, see things in the third person to limit emotional overload.
- Teach the patient how to accept things they can’t change, and empower them to change what they can by assertiveness, negotiation, using their skills and applying knowledge.
- Instil hope, i.e. enjoy the control/safety that they can obtain.

Guideline 2.2: Gain coping strategies

The results derived from this theme were that patients found it very difficult and painful to ask for help; thus they put on a pretence that they were coping better than they actually were and thus readily disengaged. This led to the conclusion that clinicians need to be aware of the struggle the patient faces when they do present for help and instil hope that treatment will be beneficial. From the conclusion, the following guidelines are proposed:

- Building resilience toward distress will help patients deal with the pressures of life and therapy.
- Clinician to be aware of this schema the patient has, and help them identify it for themselves and challenge it, e.g. challenge generalisations (e.g. always, every time, never).
- Clinician to show patience and consistency to make sessions a safe place to enable the patient to engage in therapy, something initially “too painful to do”.
- Clinicians to be aware how difficult it is for the patient to ask for help, by acknowledging it is painful for the patient to be vulnerable and to make it safe for the patient to take the risk to open up (i.e. be “there” for the patient, be understanding and caring).

Guideline 2.3: Promote feeling of security and allay fear

The results derived from this theme were that despite the bravado and insistence on control, the patient struggled with significant panic and fear and this led to the conclusion that coping strategies as well as instillation of hope were important to engage the patient. From the conclusions, the following guidelines are proposed:

- Address distress tolerance to help the patient manage the overwhelming feelings of being scared (Bornovalova & Daughters, 2007:936).
- The feeling of vulnerability needs to be acknowledged so the patient feels safe enough to engage in therapy.
- The fear of rejection innate in all patients with BPD must be addressed by showing nurturing, caring, respect and a commitment to stick with the patient. Clear boundaries must be included in the treatment contact so the patient knows what is expected of them to “not be rejected”.
- Clinicians need to assess the patient accurately in terms of risk of self-harm, by being aware of the patients’ unique early warning signs and sense of their own safety. Risk assessment tools may help, but primarily the clinician must develop a sound knowledge of the patient (to be aware of early signs of risk) and have an open rapport with the client so they will disclose accurately if/when they feel unsafe.

Guideline 2.4: Promote physical wellbeing

The results derived from this theme were that despite their often very active and physical reaction, they regularly if not constantly felt exhausted. This led to the conclusion that both physical and emotional elements of fatigue needed to be addressed. From the conclusion, the following guidelines are proposed:

- Ensure adequate diet/sleep and manage any physical illnesses to alleviate any non-BPD induced tiredness, e.g. referral to dietician, exercise, sleep hygiene, general practitioner follow-up.

- Teach emotional intensity modulation to reduce tiredness from their ongoing emotional arousal, e.g. live in the moment, grounding, distraction, self-nurturing so the patient is not too fatigued to contemplate and continue treatment.

Guideline 2.5: Manage anger

The results derived from this theme were that the respondents felt rage which was directed at themselves as well as others in repose to apparent interpersonal triggers. This led to the conclusion that rage would impede interpersonal functioning as well as the ability to engage in treatment. From the conclusion, the following guidelines are proposed:

- Teach anger/rage management (e.g. distraction, relaxation, grounding) so that treatment has the most likelihood of being effective, not just raging which leads to disengagement.
- Help patient identify narcissistic behaviour/thoughts and put in proper perspective to counteract anger, hurt, frustration and emotional dysregulation.
- Teach self-soothing as a method to achieve some peace (emotional regulation) and de-escalate anger.
- Teach them they have the right to be angry at the perpetrator/their “care giver”, but also how to express that anger therapeutically and put it in the frame they did not deserve the abuse.
- Anger at clinician can be managed by creating clear boundaries (e.g. contracts) so unfulfilled expectations may be avoided and sustained compliance fostered.

Guideline 2.6: Promote positive self-image

The results derived from this theme were that the respondents had a profound negative self-image and that engagement could only be fostered by encouraging them to believe they were worthy of clinician time. This led to the conclusions that patients need to develop a therapeutic and realistic self-image and new schemas to be able to contemplate engaging with a clinician. From the conclusions, the following guidelines are proposed:

- Clinician to help the patient identify how they themselves are continuing the negative self-concept and schemas that were started by the abuse/abuser.
- Identify unrealistic and exaggerated schemas and help program new realistic schemas to develop a healthy true self-concept.
- Identify the all or nothing concept they have developed of themselves (the totally bad or narcissistic fuelled grandiose concept), and help them acknowledge the balanced real version.
- Help them re-define what “bad” is, also what “good” is, and how to overcome their real flaws with the power of their positive characteristics. Help them define success realistically so success can be seen to be achieved in treatment to enhance ongoing engagement.
- Help patient counteract labels they have (either from themselves or others), through restorative purposeful action if the label is warranted (i.e. behaviour management), or challenge and disregard the label if it is unfair.

6.3.3 Theme 3: The futility of the treatment regime

The guidelines from Theme 3 reflect that the patients often do not comply due to experiencing the treatment as hopeless and seeing no improvement, as well as the varied ambivalent perceptions they wrestle with. The aim is to instil realistic hope and assist to clarify ambiguities to help them engage and remain therapeutically engaged in treatment.

Guideline 3.1: Manage disillusionment

The results derived from this theme were that the respondents lacked any hope to enable them to see a future, believe in treatment or believe they would improve. This led to the conclusion that alongside traditional therapies, emphasis must be placed on instillation of hope in order for them to contemplate entering and remaining in therapy. From the conclusion(s), the following guidelines are proposed:

- Clinician to instil hope, realistic hope. Help the patient prepare for the normal life disappointments/frustrations, including the disappointments therapy or clinician

could bring. Teach that there will be success and hurdles, recovery (and life) is not a success only journey, and they have the means to manage the hurdles.

- Help them acknowledge and manage their narcissistic position and help them see how they can fit into society successfully, i.e. instil empathy and tolerance (including toward the clinician).
- Help them live in the moment and enjoy an accomplishment, not expecting the feeling to endure, but hope and strive for another to follow to help sustain them through the dark periods.
- Help them place realistic hope on outcomes of treatment, to minimise unmet expectations and disillusionment, and ensuing poor engagement.
- Prescribing clinician to give sound warnings of side effects of medication so this is anticipated and treated as early as possible and the patient gains confidence in the treatment. Explain that medication is not the only aspect of treatment, to avoid unrealistic expectations of medication.

Guideline 3.2: Gain balanced perceptions

The results derived from this theme were that the respondents had ambivalent thoughts of the meaning of treatment and hence ambivalent of when and how to engage. This led to the conclusion that their thought processes regarding deciding taking the risk to engage was very difficult and time consuming. From the conclusion, the following guidelines are proposed:

- Clinician to address black and white thinking by helping them understand there are positive and negative qualities in almost all they encounter, teach them to weigh up positive and negatives to make sound choices including engagement in treatment.
- Help them take safe risks, e.g. open up slowly in therapy once they have built up some trust.
- Help them see engagement as an empowering process, not dependence or failure to foster initial and continued compliance.

6.4 ANALYSIS AND EVALUATION OF THE GUIDELINES

The guidelines were drafted, and were sent to peers for review and opinion of their credibility and practicality.

Feedback given included the agreement on the stated necessity for clinicians to clearly define boundaries of engagement to enable a solid foundation to be formed, which would then be able to withstand testing behaviour and foster continued engagement.

Peers supported a robust screening process to be able to link up the patient with the most appropriate clinician. They also commented that they also saw the need for ensuring that the clinician did not get burnt out, and thus saw that the guideline for supervision, even for experienced staff, was valuable.

Peers found that it would be beneficial/helpful to define more clearly who would carry out the guidelines. This was implemented by adapting the guidelines to reflect this.

It was suggested that more clarity was given to how the guidelines were to be carried out. The researcher then amended the guidelines with this in mind, expanding on how each guideline was to be accomplished.

The feedback of the guidelines from peers also noted the grey area of where relationship forming and engagement in treatment ends and skills training (therapy) starts, but acknowledged that as the one develops, the other is also likely to develop, so stated that both relationship building and skills training were needed.

6.5 CONCLUSION

The guidelines were drawn from the data gained from the study. The aim of the guidelines is to improve initial engagement and sustain engagement of patients with BPD. Guidelines included teaching the patient to balance their perceptions and retrain negative schema to help them feel more comfortable to enter into and maintain treatment. Guidelines also referred to the clinical practice of clinicians which could improve relationships with patients and thereby foster engagement.

Guidelines also incorporated the instillation hope for the patient by helping patients to develop a comprehensive, realistic sense of self and others (including clinician), and to be able to integrate with others with their positive attributes, strengths and the skills they have developed to successfully manage life, e.g. relationships, frustrations and anger. This in turn aims to foster continued engagement in treatment.

The writer also recognises that the guidelines to improve compliance run close to and are intertwined with treatment as such, e.g. tolerating frustrations, managing emotional lability (see key concepts), impulse control and managing sensitivity in relationships.

The guidelines were developed and set out to fulfil the purpose of the study, namely to explore and describe the lived world of the patient with BPD in order to develop guidelines for facilitating compliance in patients with BPD. This was achieved by acknowledging the factors impeding engagement and setting out clear paths to address them, accompanied by stating who should be called to carry out the guidelines.

CHAPTER 7

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

This chapter concludes the study, highlights the main points revealed from the study, acknowledges the contributions and limitations of the study and puts forward some recommendations for further studies in the field of understanding the lived experience of patients with BPD.

This was accomplished by using a qualitative explorative and interpretative contextual research design within the hermeneutic phenomenology guided by the following broad research question:

“What are the experiences of a patient living with Borderline Personality Disorder?”

7.2 PURPOSE AND OBJECTIVES

The purpose of the study was to explore and describe the lived world of patients with Borderline Personality Disorder in order to develop guidelines to improve engagement for treatment compliance. To fulfil this purpose and aim, the specific objectives formulated were to

- explore the lived world of the patient with BPD
- describe the factors contributing to treatment non-compliance of patients with BPD
- interpret the meaning of their lived world with regard to treatment non-compliance
- develop guidelines for facilitating compliance in patients with Borderline Personality Disorder

The researcher contends that these objectives were reached, in that extensive data regarding the lived world of the patient with BOD was offered and interpreted (see

Chapter 5), several factors contributing to non-compliance were raised (see Chapter 5) and guidelines for promoting compliance were formulated (see Chapter 6).

7.3 CONTRIBUTIONS

The researcher is of the opinion that there has been a contribution to the scholarly knowledge of the experiences of patients with BP through this research. These reflections and the guidelines were put to a number of peers and managers who confirmed this. Further confirmation was found in that literature had not revealed some of the findings put forward in this research.

The main contribution was the extent to which the patient pretends to be better than they are. This contributes significantly to the way they engage in treatment. A further contribution was the manner in which engagement was studied in a qualitative approach. Many studies were found using a quantitative approach. Engagement as such was highlighted, as opposed to treatment *per se*, giving a different perspective and wider understanding of the lived experience of a patient with BPD. A further contribution is the guidelines proposed to facilitate engagement among patients with BPD.

The need to instil hope was evident from the findings and the guidelines to effect this were considered a key improvement to treatment by the peers who reviewed the guidelines.

The guidelines to support clinicians so they could improve their clinical practice were acknowledged as valuable by peers and management.

In an economic atmosphere calling for fiscal austerity, the guidelines were welcomed by management as means to improve compliance, as it was seen to decrease expensive re-hospitalisation, especially of dis-engaged patients, and less work hours wasted through no-shows.

7.4 CONCLUSIONS

The conclusions of the study were drawn from the study findings.

7.4.1 Conclusions from the research findings

The study findings highlighted the fact that the most important factors affecting engagement for a patient with BPD are the relationship with the clinician, the overwhelming feelings the patient experiences and the futility they feel regarding the treatment process.

The relationship with the clinician was revealed as important both to encourage the patient to engage as well as to remain engaged for the recommended/negotiated treatment. The emotional dysregulation of the patient made initial and sustained engagement difficult as the patient had extreme emotions relating to the clinician, which impaired the already fragile ability of the patient to develop trust and hope.

The overwhelming feelings of poor self-worth, anger and lack of hope all influenced the respondents' motivation and ability to enter and remain in treatment. The lack of hope they have in the treatment having a positive impact for them was a further significantly deterring influence on compliance. Methods of fostering engagement often overlapped on therapy as such, i.e. needing to teach frustration tolerance was advocated in the guidelines, but is also a recognised therapeutic exercise in itself.

The findings revealed that hope had a significant impact on compliance. The guidelines included methods to improve instillation of hope. Revisiting a patients' experience of having nothing to look forward to, eventually reveals possibilities that were previously "unknown" to the patient and the clinician, and thus reveals possibilities to find hope. The understanding of the patients' being-in-the world is fundamental in both engaging the patient and being able to instil hope.

7.4.2 Evaluating the objectives of the study

In concluding this study the researcher is of the opinion that the objectives of the study were actualised. The first and second objective was addressed when the researcher explored and described the lived world of patients living with BPD .This was derived through data collection using in-depth interviews (see findings in Chapter 5). As envisaged in the third objective, the meaning of the experiences was analysed and interpreted using hermeneutic interpretative process as discuss in Chapter 4 (see

Chapter 4.3). And so were the development guidelines which addressed the last objective of the study (see Chapter 6). Although the research purpose and objectives were met, there were limitations which were realised in the study.

7.5 LIMITATIONS

In this study there were limitations generated by the phenomenological methodology used, researcher based limitations and the study's own unique limitations. The researcher made concerted attempts to identify and also address the limitations in an effort to uphold research credibility and trustworthiness.

7.5.1 Sampling limitations

This research used a purposive sample as the protocol for hermeneutic study directs, therefore the results cannot be generalised to other situations as the scope of the research is narrow (Watson *et al.*, 2008:224). Limitations of purposive sampling are that the sample is handpicked by the researcher, and some inappropriate respondents may be selected. To facilitate appropriate sampling in this study, the researcher carefully studied the patient notes to see if they did indeed fit the criteria for potential respondents, e.g. had a clear diagnosis of BPD.

The limitation of the small sample was addressed by eliciting rich and true data from each respondent by ensuring good clinician/patient rapport, a sensitively compiled interview schedule and also by taking memos during the interview (so maximum data was captured). To make the sample as representative as possible (and thus increase transferability), a diversity of the respondents was selected, e.g. varying socioeconomic groups, ages, genders, length of contact with mental health services as well as compliant and non-compliant patients.

The respondents were given the opportunity to partake or decline, thus essentially they volunteered; this is known to have an impact on the findings (Nieswiadomy, 2008:204). To overcome this, a representative sample was chosen to ensure most of the participant variables were addressed, e.g. age, gender. To ensure true and robust data were revealed from a volunteer group who could readily assert their own agenda,

attention was given to building a rapport and norm of openness and truth, instigated by the researcher through example and ensuring they felt acknowledged.

7.5.2 Data collection limitations

The researcher was also the data collection instrument and had a potential of power differential. Most of the patients knew the researcher and this might have had the potential to affect their responses, both in truthfulness and detail, to try to please the researcher, to try to further their ends or to protect themselves. The researcher was attentive to this by ensuring clear boundaries and building rapport. The researcher knew most of them and had preconceived ideas about them too, and this also had the potential to affect the study. This was overcome by listening carefully to their responses, checking the interpretations with the respondents and only using data from the respondents, i.e. using quotes from the respondents.

The use of self-reporting was another limitation in data collection. Self-reporting is notoriously inaccurate due to participants wanting to please the researcher, poor memory, and with BPD, the added factor of their inability to accurately assess reality due to their intense emotional lability and black and white thinking.

Other variables, such as negative life events and problem solving abilities, were not considered, thus limiting the robustness of the data collection in the study and narrowing the scope of the research. The narrative from interviews was long, difficult to tabulate as it was contextual and often abstract. The researcher relied on body language for some interpretation, and this could have easily been misinterpreted, affecting the accuracy of the data collected. These limitations were overcome by constant checking of the meaning of any communication. The researcher also tried to compensate for these limitations by using actual quotes to substantiate inferences.

7.5.3 Researcher based limitations

The research had limitations relating to the researcher.

The first limitation is that the researcher is a novice researcher. This was overcome by being under the guidance from the researchers' supervisor and following the guidelines

and scrutiny from the Health and Disability Research Council. The researcher conducted literature reviews on the process of using hermeneutic research, and sought examples from other hermeneutic research to enhance the robust application of the methodology in the research process, e.g. conceptual skills of the researcher were enhanced by checking conceptualizations made in other research (as well as with the respondents and peers). The researcher's clinical interview skills did also help in keeping the research process (i.e. the data collection stage) safe and robust.

For hermeneutic research to be valuable and trustworthy, the researcher and participants needed to be open and honest regarding their views and accepting of the others' points of view (Pascoe, 2009:1312). This was difficult for the patients (because of the nature of their illness), and thus the findings could be slanted. The researcher tried to overcome this by ensuring that there was a comfortable atmosphere built on trust, and by setting the norm and example of openness by listening, acceptance and being non-judgmental. The researcher role was identified, i.e. information finder, not judge. Confidentiality by the researcher was also contracted.

Interpretation belongs to the participant and the researcher, but each has different pre-understandings and perspectives. This made the interpretation prone to bias. This was overcome by the researcher checking and acknowledging her own biases. Her known biases were presented in the report for the reader (see Chapter 4.2.2), e.g. her belief that the patient has a right to appropriate treatment, but that they also have responsibilities related to the treatment.

The researcher was quite overwhelmed by hearing each story and seeing the pain in their faces. She had to try hard not to focus on helping/therapizing, and sometimes this made her not go too deep and thus potentially missing some relevant data.

7.5.4 Studies' unique limitations

The study brings with it its' own set of unique limitations especially relating to the patients insight and ability to form an attachment with the researcher.

To enhance transferability, the constraints in which the research was done was described, e.g. a rural town, with a high representation of a particular ethnic group, and

at a time where there was economic hardship. Inclusion of these details was to enable the reader to understand the dynamics of the situation in which the research had been done, and this could then assist them to judge the trustworthiness, transferability and the scope and limitations of the research.

The particular subject under study had the potential to cause a lot of distress. Respondents were initially hesitant to answer questions they felt are private or might cause them to feel exposed or uncomfortable. This was overcome by taking time to develop rapport with the participants and structuring the questions so that the less overwhelming questions were asked first.

Due to the potential harm and stress to patients, some patients (e.g. acutely unwell) were excluded from the research and this could have an impact on the findings. The researcher anticipated that the patients who had chosen not to engage in treatment would also be reluctant to be participants in the study or participate fully, thus limiting the scope of the research because their views were not incorporated in the study. This was addressed by ensuring that there was indeed representation of non-compliant patients in the sample, and through building rapport gleaned the most complete data from them.

A further limitation of the study was that patients with other psychiatric (and medical/surgical) conditions were not included. They may or may not have similar experiences regarding compliance.

The major limitation of this study is that generalizations of this research are limited to experiences of patients with BPD in the setting of this research; therefore the data must only be used to study or compare patients in a similar circumstance, and as a guide to further research.

7.6 RECOMMENDATIONS

Recommendations stem from the findings, consulting literature and asking peers for opinions on the guidelines developed.

7.6.1 Recommendations for nursing practice

Recommendations for clinical nursing practice were covered in the guidelines. The main recommendations relating to compliance was to give realistic information to patients so they can engage in informed compliance and thus avoid unrealistic expectations (which lead to termination of engagement). This can be done by teaching the patient their rights and how to successfully assert them, and by addressing therapy interfering issues as identified by both parties. The main recommendations regarding building a rapport was to show understanding and caring, instil hope and to address the confusing emotional lability and attachment issues. The correct clinician needs to be linked up with each patient for a good rapport to be built, so an appropriate referral process and support for clinicians needs to be structured.

The ingrained negative self-schema the patient needs to be adapted to a more realistic and functional schema, starting with helping them believe they do deserve treatment and that there are good elements about them.

Distress tolerance and management of emotional lability both have an impact on compliance and needs to be addressed, however this can be a Catch 22 scenario as it is difficult to teach patients distress tolerance when not engaged, but they need a certain amount of tolerance toward distress (namely of therapy) to be able to engage in the first place (and similarly with emotional lability). To overcome this, the instillation of hope and feeling of safety is advocated.

The instillation of hope in treatment is imperative to foster compliance and can be achieved by staying in the moment, teaching the patient to acknowledge accomplishments, to tolerate disappointments and frustrations and to redefine success.

Many of these recommendations are used once the patient is in treatment, but my recommendations are to use the guidelines as a means to engage the patient with BPD.

The most significant recommendations to improve engagement with patients with BPD, is to build solid relationships, help patients weather their turbulent emotions and include the patient in treatment planning, all with the constant underpinning of instillation of hope.

7.6.2 Recommendations for future study

A few recommendations for future studies are raised as these issues were not addressed in the guidelines. These recommendations are potentially important if clinicians are to continue to portray themselves as the sanctuary/place to come to for help in the very turbulent world of a patient with BPD.

A study on family interventions/family therapy may be helpful in assisting the patient with BPD to process and manage anger and rebuild fractured family connections. This recommendation stems from the repeated reflection of the respondents that family do not understand nor support them, or even the cause of their illness.

A study to find better methods to support the clinician as they treat patients with BPD may be useful in light of the significant amount of stress and burn out experienced by clinicians, which ultimately affects relationships and engagement with patients. This recommendation stems from the researcher's clinical observation and experience of how demanding working with a patient with BPD is.

A study of engagement of patients with other chronic illnesses may be beneficial as it may reveal issues that could also be relevant to patients with BPD. This recommendation stems from the researcher's observation while working in general nursing and psychiatry in three countries, as well as the literature study done in preparation for this research.

A further valuable study following premised on findings from this study may be to research how therapists from different cultures with different philosophical outlooks, theoretical underpinnings and experiences understand and engage with patients with BPD. This follows the experience that patients are offered treatment programs that have been shown to be "effective with other people who have similar problems", but they also struggle to engage the patient, so in fact are not effective. This deterministic epistemology, that phenomena are misinterpreted, is due to the fact that they are based in the clinicians' narrow understandings and abilities. This recommendation stems from observing clinicians in different countries trying to use the same techniques to engage patients.

There is a need to continue researching compliance in patients with BPD as compliance despite knowing and addressing some issues relating to compliance is low, and has significant implications.

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ANNEXURE 1

REQUEST TO CONDUCT RESEARCH

8b Appleby Rise

Whakatane

3120

12 11 2012

Dear Committee

REQUEST TO CONDUCT RESEARCH

Please could you consider my request for permission to conduct a research project.

I am registered with the University of South Africa for a PhD in Health Studies and would like to request permission to do my research in the Whakatane Mental Health Service. My topic is "*A study of the lived world of the patient with Borderline Personality Disorder*". As part of my research I would be interviewing patients who have a diagnosis of Borderline Personality Disorder.

I will conduct the research in my own time and will strictly abide by research ethics and will be closely guided by my supervisors. Please find attached the Ethical clearance application form for more details. A copy of my full research proposal can be forwarded on request.

I appreciate your consideration, and would value the opportunity to discuss the possibility of doing the research in your service.

Yours Sincerely



Marlene Dor

ANNEXURE 2

APPROVAL TO CONDUCT RESEARCH

(UNISA, REGIONAL AND LOCAL)



UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

HSHDC/189/2013

Date: 3 July 2013 Student No: 552-438-5
Project Title: A study of the lived world of the patient with Borderline Personality Disorder.
Researcher: Marlene Dor
Degree: D Litt et Phil Code: DPCHS04
Supervisor: Prof MM Moleki
Qualification: D Litt et Phil
Joint Supervisor: Prof SH van Deventer

DECISION OF COMMITTEE

Approved

Conditionally Approved

Prof L Roets
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE



Prof MM Moleki
ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRIES



Health and Disability Ethics Committees
Ministry of Health
C/- MEDSAFE, Level 6, Deloitte House
10 Brandon Street
PO Box 5013
Wellington
6011

hdecs@moh.govt.nz

06 March 2014

Ms Marlene Dor
8B Appleby Rise
Whakatane
3120
Whakatane 3120

Dear Ms Dor

| | | |
|--------------|--|-------------------|
| Re: | Ethics ref: | 13/NTB/200 |
| Study title: | A study of the lived world of the patient with Borderline Personality Disorder | |

I am pleased to advise that this application has been approved by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at any locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a given locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 6 March 2015.

Participant access to ACC

New Zealand
Online Forms
to research

HOME MY PROJECTS MY CONTACTS HELP CONTACT US

A Study of the lived world of the patient with Borderline Personality Disorder

| | | | |
|--------------|--|------------------|---|
| Form Type | HDEC | Status | Submitted (submission code N2/15194011) |
| Reference | 13/NTB/200 | Owner | <i>Ms Marlene Dor</i> |
| Form Section | N/A | Created On | 02/10/2013 11:51:38 |
| Signatures | <i>This form is attached with electronic signatures. Any changes to the form will invalidate the signatures.</i> | Last Modified On | 01/12/2013 21:17:41 |

<https://www.ethicsform.org/Nz/Forms/FormIndex.aspx?Id=9028&SifFormId=0&Edit...> 16/03/2015

ANNEXURE 3

INFORMATION SHEET

INFORMATION SHEET

You are invited to participate in a study examining the “Lived world of the patient with Borderline Personality Disorder”. The results will enable clinicians in general to gain a better understanding of the impact of BPD and the treatment on the lives of patients. This could then enable them to give you more contemporary/updated care.

Your decision to participate is completely voluntary; please take your time to make your choice. Should you decide to participate, you will be asked to be interviewed approximately three times, and the interviews will explore your experiences of living with Borderline Personality Disorder. The questions will focus on what it was and still is like for you to have to engage in treatment. The interviews will be held in private and at a time and place negotiated to suit you. The interviews will also be recorded and transcribed in order to accurately capture the information you give. You do not have to answer any question, and you may stop the interview at any time without any need for explanation or fear of consequences. Should you need a translator, one will be provided for you.

Your details will remain confidential in that your participation will be kept private and no identifying information will be included in the report. However, if there are concerns that I am obligated to report, I will discuss this with you prior to reporting as required.

This research does not affect or substitute for your current treatment. I encourage you to continue your normal treatment as advised by your current clinician. You will not be asked to alter your treatment at all, so you will not be asked to change or take additional medication. I encourage you to discuss with your clinician that you are involved in the study, and seek support as necessary from them or other support person. You also have access to the Health and Disability Commissioner Advocate at any time at 0800 423 638 if you need advice or lodge a complaint.

The risk of participating in the research is that it may become distressing re-living some experiences. The research will be stopped, completely or temporarily if this should occur. At any time you may without prejudice withdraw from the research. Any medical costs that may arise related to participating in the research will however be met by you. I would like to offer re-

imbursement for any non-medical costs incurred by you through participating in the research e.g. travel costs.

This study has received ethical approval from the BOP Ethics Committee as well the UNISA Ethics Committee. If you wish, you will be given a copy of the final research report at the end of the study. The research report will also be available on the university website (available to staff and registered students at the UNISA University), and published in some professional journals.

I am always happy to answer any questions as they arise throughout the research process.

I thank you for considering participating in the research.

Yours Sincerely



Marlene Dor

Psychiatric District Nurse

Principal Investigator

ANNEXURE 4

CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH STUDY.

I understand that I have been asked to participate in a research study at Whakatane Mental Health Service. The purpose of the study is to evaluate "The lived world of the patient with Borderline Personality Disorder", ie what it is like to live with BPD.

I have been told I will be interviewed approximately three times. The interviews will focus on my experiences of living with Borderline Personality Disorder. The interviews will be held in private and be recorded and transcribed. The details will remain confidential in that my participation will be kept private and no identifying information will be included in the report. I will receive a copy of the final report, and it may also be distributed in nursing publications.

I understand the benefit will be that clinicians could gain a better insight into people living with Borderline Personality disorder. The risks are that I may become distressed while reliving/relating my experiences. I may bring a support person to the interview. I understand that I can contact support people e.g. my clinician at any time during the study for support. I understand my participation will be stopped if it should appear to be harmful to me. I accept that any costs due to the unlikely event that I may need medical treatment arising from my participation in the study will be met by me.

The study has been clearly explained to me and I have no further questions, and I do not require an interpreter. I believe that my participation will not affect my normal treatment or access to care. I have been invited to ask questions and discuss any issue relating to the study with the researcher, Marlene Dor. The complaints procedure has been explained to me and I understand that I have access to the Health and Disability Services Consumer Advocate at 0800 423 638. I have been offered compensation for travel and any other costs related to the participation in the study.

I declare I am over 18 and that I have had time to consider whether to take part. I voluntarily agree to participate in this study and realize I may withdraw at any time without prejudice. I have read and I understand the information given to me. The project was explained to me by Marlene Dor.

I hereby consent to partake in this study.

Signature of participant Date

Signature of witness Date

I, Marlene Dor, have explained the research project to

Signature Date

Researcher: Marlene Dor 07 3060154

ANNEXURE 5

INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

Demographics : Age,
: Marital status,
: Living situation,
: Gender,
: Education,
: Occupational status,
: First contact with mental health,

Please describe a typical day for you.

Tell me how you experience everyday living?

What do you understand by compliance/non-compliance?

What does BPD mean for you?

How do you experience BPD?

How has having BPD impacted your life?

What does your illness mean to you?

How do you experience living with BPD?

Describe what you consider as non-compliant/compliant

How do you feel about being on treatment?

How has being on treatment/not being on treatment affected your life?

What is it like for you when you have therapy?

What within you makes you comply/not comply?

What message do you give yourself to be compliant/not be compliant

What general principles guide your decisions to comply/not comply?

What is the decision to comply/not comply like for you?

How do you rationalize being compliant/ non-compliant?

What associations are there for you with being compliant, non-compliant?

Please describe what you see as effective compliance?

How do you recognize when compliance is effective/not effective

When can you first recall being compliant? What can you remember about that time?
What were the circumstances?

When can you first recall being non-compliant? What can you remember about that time? What were the circumstances?

What coping skills do you use to be compliant?

Tell me about the experience of a particular time when you were non-compliant

Tell me about the reactions you received from family, fellow patients and staff when you were compliant/non-compliant?

Tell me about your thoughts and feelings when non-compliant

What was the critical factor/s that made you decide to discontinue/alter recommended treatment?

What for you are the major issues relating to compliance/non-compliance?

Please describe the best and worst things about non-compliance

Tell me how you deal with non-compliance?

Have your feelings regarding non-compliance changed?

What has been the most difficult regarding non-compliance?

What has been the most helpful to encourage you to comply?

What have you learnt about yourself, looking back at your decision regarding compliance/non-compliance?

What have the consequences been for you when you've been compliant, non-compliant?

Has talking about BPD in these interviews changed anything about how you view BPD and compliance/non-compliance?

MEMOS

MY IMPRESSIONS

POSSIBLE THEMES NOTED

EXTRA QUESTIONS

ANNEXURE 6

CODE OF RIGHTS



Health and Disability Commissioner

Te Toihau Hauora, Hauātanga

CODE OF HEALTH AND DISABILITY SERVICES CONSUMER'S RIGHTS

The Code of Health and Disability Services Consumers' Rights sets out ten rights that you have as a health consumer which must be followed by anyone providing any sort of health or disability service. The Code applies to all health services and disability support services in New Zealand, whether you have paid for them or they are free of charge and include hospitals, doctors, nurses, homeopaths, diagnostic services, special needs assessors etc.

The purpose of the Code is to protect your rights as a health consumer and to help resolve any complaints you may have if you feel those rights have not been protected.

The main points of the ten rights are:

Right 1

You should always be treated with respect, including respect for your culture, values, beliefs and personal privacy.

Right 2

No-one should discriminate against you or push you into doing something or making a decision that you are not comfortable with.

Right 3

Your care and treatment let you live a dignified, independent life.

Right 4

Everyone looking after you should work together to make sure that you are treated with care and skill and that you receive the right services for your needs.

Right 5

You have the right to be listened to, understood and receive information in whatever way you need. Where possible, an interpreter should be provided if you need one.

Right 6

Your condition should be fully explained to you, to allow you to make choices for possible treatments. You should be given information on the benefits and side effects of treatments and told how long you may have to wait, who will be treating you and any costs involved. You can ask any questions about the services and expect an honest and accurate answer.

Right 7

It is your decision whether to go ahead with treatments or not and you are able to change your mind at any time.

Right 8

In most situations, you can have a support person of your choice with you if you wish.

Right 9

All these rights also apply when you are taking part in teaching or research.

Right 10

You can make a complaint about any aspect of your care or treatment. You should be given information on the process involved in making a complaint so it is easy for you to do so. Your treatment should not suffer if you do make a complaint.

If you have any concerns about the care you are receiving or you think that any of your rights have not been respected, you should discuss this with the person or organisation providing the services. If you are going to meet with the service provider(s) you are allowed to take a friend or relative with you. You are also able to ask for help from an independent Health and Disability Advocate.

Advocates are trained to help people in your situation and will advise and support you free of charge. You can contact your local advocacy service by ringing:

Free phone: 0800 11 22 33.

For more information on the Health and Disability Advocacy service, [click here](#)

If you are not happy with the provider's response to your complaint, you can contact the office of the Health and Disability Commissioner. The Disability Commissioner will decide if there has been a breach of your rights as described in the Code.

CONTACT DETAILS

[Click here](#) for contact details for the Nationwide Advocacy Service

The Health and Disability Commissioner's Office:

Auckland Office

Level 10 Tower Centre

45 Queen Street

PO Box 1791

Auckland

New Zealand

Ph: (09) 373 1060

Fax: (09) 373 1061

Wellington Office

Level 13 Vogel Building

Aitken Street

PO Box 12 299

Wellington

New Zealand

Ph: (04) 494 7900

Fax: (04) 494 7901

Free phone: 0800 11 22 33

E-mail: hdc@hdc.org.nz

ANNEXURE 7

PATIENTS' CODE OF RESPONSIBILITIES

Patients' Code of Responsibilities

Bay of Plenty District Health Board staff are committed to working in partnership with you to achieve the best possible outcomes. Help us to help you by:

- Being completely frank and honest about your health, family history of illness, current medications and treatments
- Cooperating and being involved in your care and treatment
- Asking questions about anything you do not understand
- Informing us if you are unable to keep an appointment
- Understanding your rights and telling us if you feel they are not being met
- Showing consideration to other patients by respecting their comfort, privacy and confidentiality
- Respecting the staff and property of the Bay of Plenty District Health Board



ZERO tolerance to violence

If you need more information:

- Ask a staff member or the manager of the ward / department
- Contact Quality and Patient Safety Team, Mon-Fri, 8am-4pm on 07 579 8176 or the After Hours Manager on Tga 07 579 8000 or Whk 07 306 0999