

School of Nursing, Midwifery and Paramedicine

**The experience of receiving mental health care for people with
personality disorder**

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**This thesis is presented for the Degree of
Master of Philosophy (Nursing)
of
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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number #HR 50/2014 and Royal Perth Hospital Human Research Ethics Committee, Approval Number # REG 13-112

Signed..........

Date.....30 - 11 - 2016.....

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ABSTRACT

This thesis documents the experiences of people diagnosed with a personality disorder who accessed mental health care at one health service in Western Australia. The research focus is on people diagnosed with the subtype of emotionally unstable personality disorder. Historically, these people have not been treated well by health professionals when they have accessed care during times of crisis.

The study utilised a mixed methods research approach to collect data from participants to evaluate their current experiences of accessing services. Eighty-two people participated in the quantitative component of the study and eleven of these agreed to complete structured interviews for the second qualitative phase of the research.

Participants perceived some improvements in the attitudes of health professionals towards them, but the care provided remained uncoordinated and was dependent on the individual health professional at point of contact with the health care system. Management plans that allowed for readmission during times of crisis were not always honoured when the person presented to the emergency department and this made them feel unsupported and devalued. Quantitative data showed that participants felt they were treated differently due to health professionals' attitudes and communication styles.

Participants did describe in the qualitative interviews some positive changes in the approaches made by health professionals towards them which they found valuable in resolving the presenting crisis and in fostering their mental health recovery. However, overall they reported that their care was still fragmented. The links between the emergency department which is now the gateway to care for mental health consumers and mental health specialist staff was viewed as being ad hoc and this further impacted on their overall level of mental health and wellbeing. Some of the structured programs, such as the Changes Program (Changing Habitual Attitudes by Nurturing Growth, Education and Self Responsibility Program) which was previously located on the hospital campus and provided a specialist outpatient treatment program for twenty eight years was helpful but no longer existed. Many participants stated that this program had been helpful to them in the past and its closure was viewed as a step backward in service delivery.

While they were aware of their need to engage and participate in their mental health recovery, they needed guidance and support from health professionals to enable this to happen and to prevent relapses occurring. The findings demonstrate the important role that health professionals play in maintaining the wellbeing of people diagnosed with emotionally unstable personality disorder and how their interactions and communication can influence consumer outcomes dramatically particularly during times of crisis. Improved communication for crisis management between emergency department and mental health specialists is critical to providing positive support during times of crisis and to foster the consumer's engagement in mental health recovery.

TABLE OF CONTENTS

DECLARATION	i
ACKNOWLEDGEMENTS	ii
ABSTRACT	iii
TABLE OF CONTENTS	v
CHAPTER 1	1
INTRODUCTION, BACKGROUND AND CONTEXT OF THE STUDY	1
1.1. INTRODUCTION	1
1.2. WHAT IS PERSONALITY?	2
1.3. DEFINITION OF PERSONALITY DISORDER	2
1.4. PREVALENCE OF PERSONALITY DISORDER	3
1.5. DIAGNOSIS OF PERSONALITY DISORDER	5
1.5.1. Diagnostic and Statistical Manual of Mental Disorder Version 5 (DSM V).	6
1.5.2. International Classification of Disease 10th Edition (ICD 10).	10
1.6. CLINICAL PRESENTATION OF PERSONALITY DISORDER	12
1.7. HISTORICAL CONTEXT OF DIAGNOSING OF THE SUB TYPE EUPD	14
1.8. ATTITUDES OF HEALTH PROFESSIONALS TOWARDS PEOPLE WITH EUPD	15
1.9. HELP SEEKING BEHAVIOURS AND ACCESS TO SERVICES	16
1.10. CLINICAL PATHWAY FOR THE ACUTE INPATIENT CARE OF PEOPLE WITH EUPD	17
1.11. ACCESS TO SERVICES FOR PEOPLE WITH EUPD PARTICIPATING IN THIS RESEARCH	18
1.12. IMPACT OF NATIONAL POLICIES AND STRATEGIES ON PEOPLE DIAGNOSED WITH EUPD	19
1.13. WHAT IS MENTAL HEALTH RECOVERY?	21
1.14. AIM AND OBJECTIVES OF THE STUDY	22
1.15. NEED FOR THE STUDY	22
1.16. SIGNIFICANCE OF THE STUDY	23
1.17. SETTING FOR THE STUDY	23
1.18. OVERVIEW OF FINDINGS	23
1.19. LIMITATIONS OF THE STUDY	24
1.20. ORGANISATION OF THESIS	24

CHAPTER 2	
METHODOLOGY	26
2.1. INTRODUCTION	26
2.2. RESEARCH DESIGN	28
2.3. ETHICS	29
2.4. RECRUITMENT OF PARTICIPANTS	29
2.4.1 Inclusion Criteria for People with a Personality Disorder.	29
2.4.2 Inclusion Criteria for People who were the Control Group for the Quantitative Component of the Study.	29
2.4.3. Informed Consent.	30
2.4.4. Confidentiality and managing distress.	30
2.5. PHASE ONE: QUANTITATIVE DATA COLLECTION	30
2.5.1. Research aim.	30
2.5.2. Analysis of the data.	32
2.6. PHASE TWO: QUALITATIVE RESEARCH	32
2.6.1. Steps Undertaken by the Researcher Prior to Commencing and During the Study to Ensure Trustworthiness of Data and Credibility of Findings.	32
2.6.1.1. <i>Researcher assumptions documented before commencing the study.</i>	32
2.6.1.2. <i>Bracketing researcher bias.</i>	33
2.6.1.3. <i>Theoretical sensitivity.</i>	33
2.6.1.4. <i>Trustworthiness and credibility of findings.</i>	35
2.6.2. Data collection.	35
2.6.3. Data analysis.	36
2.7 DATA STORAGE, MANAGEMENT, ACCESS AND DISPOSAL	36
2.8 SUMMARY	37
CHAPTER 3	
RESULTS	38
3.1. INTRODUCTION	38
3.2. RESULTS OF PHASE ONE STUDY – QUANTITATIVE STUDY	38
3.2.1 Characteristics of Participants.	38
3.2.2. Survey Results.	40
3.2.2.1 <i>General answers to questions by both groups</i>	42
3.2.2.2 <i>Medications</i>	48
3.3 RESULTS OF PHASE TWO STUDY: QUALITATIVE STUDY	50
3.3.1 Introduction.	50

3.3.2 Results.	50
3.3.2.1 <i>Question 1: What are the positive aspects of the care you have received when treated for your personality disorder?</i>	51
<i>Consistency and commitment of the staff</i>	
a) Sub category: Skill development	52
b) Sub category: Validation of feelings	53
3.3.2.2 <i>Question 2: What are the negative aspects of the care you received when treated for your personality disorder?</i>	54
a) Sub category: Lack of interest	55
b) Sub category: Judgement	56
3.3.2.3 <i>Question three: What aspects of care have aided your recovery when treated for your personality disorder?</i>	57
3.4 OVERALL SUMMARY OF FINDINGS	58
CHAPTER 4	
DISCUSSION	59
4.1 INTRODUCTION	59
4.2 DEMOGRAPHIC FINDINGS	59
4.3 GENDER RATIO DIFFERENCES	60
4.4 LEVEL OF SUPPORT	61
4.5 ACCESSING PROFESSIONAL SUPPORT	62
4.6 CLINICAL RELEVANCE OF FINDINGS	63
4.7 SUMMARY	68
CHAPTER 5	
IMPLICATIONS FOR PRACTICE, RECOMMENDATIONS AND CONCLUSION	69
5.1 INTRODUCTION	69
5.2 CLINICAL IMPLICATIONS AND RECOMMENDATIONS	69
5.2.1 Need for longer treatment programs for people with EUPD	69
5.2.2 Improved access to care	70
5.2.3 Supporting health professionals to work more effectively with people with EUPD	72
5.2.4 Educational implications and recommendations	73
5.2.5 Recovery focussed person centred care	74

5.3 RECOMMENDATIONS		75
5.4 CONCLUDING STATEMENTS		76
REFERENCES		78
APPENDICES		94
Appendix 1a and b	Ethics approvals	95
Appendix 2a and b	Patient information sheet and consent form	97
Appendix 3	Standardised questionnaire	101
Appendix 4	Permission letter to adapt survey	104
Appendix 5	Structured interview guide	105
Appendix 6	Demographic data sheet	106
TABLES AND FIGURES		
Table 1	DSM V diagnostic sub-categories types for personality disorders	7
Table 2	Sub-types of Personality Disorders (ICD 10) F60.0-F60.9	10
Table 3	Demographic characteristics of participants	39
Table 4	Results of Patient Satisfaction Questionnaire	42
Table 5	Number of medications taken by participants	48
Table 6	Medications prescribed by name and class for participants	48
Figure 1	Differences between control and personality disorder group results on sub-scales of survey	47

CHAPTER 1

INTRODUCTION, BACKGROUND AND CONTEXT OF THE STUDY

1.1 INTRODUCTION

Living with a personality disorder can be a stigmatising and challenging experience for the affected individual. This thesis describes the findings of an exploratory study using a mixed methods research design to document the experience of receiving mental health care for people living with a personality disorder in the Western Australian community. The research focus is on people diagnosed with a personality disorder with the subtype of emotionally unstable personality disorder (EUPD) and their experiences of accessing care from one public mental health service. Historically, this group of health consumers have not been treated well by the health care system during times of crisis and they have often been labelled and stigmatised by care providers rather than given support and care (Veysey, 2014). Australian national mental health policy is now focused on the delivery of mental health care in the community setting and people are now only admitted to hospital when they are acutely unwell (Australian Health Ministers, 2009). This ensures that treatment takes place within the least restrictive environment and the consumer is able to maintain their established social supports.

During times of crisis, the emergency department (ED) is a gateway to mental health care and when seeking help this consumer group is often confronted by health professionals displaying negative attitudes and behaviours towards them (Veysey, 2014). Many health professionals believe that the ED is not the place to provide care to people with a personality disorder and that the ED environment impacts negatively on their help seeking behaviours (Olson, Marcus, & Bridge, 2013). This research explores the treatment experiences of this group of consumers from their presentation to the ED, referral to specialist hospital based mental health services and follow up care.

Chapter 1 explores factors shaping the experience of living with a personality disorder. It outlines how personality disorders evolve, how they are classified and the subtypes of personality disorders. The chapter also describes the study objectives, the need for the study, the significance of the findings and the study limitations as identified by the researcher. The findings provide valuable information to guide the content of educational programs for health professionals. This will allow them to work more effectively with these people in a manner that

supports their recovery, decreases stigmatising experiences and fosters hope for improvement to their level of health and wellbeing (Fanaian, Lewis, & Grenyer, 2013). The findings also inform health policy and service planning to promote recovery focused services for these consumers.

1.2 WHAT IS PERSONALITY?

The word “personality” comes from the Latin word “*persona*” (Merriam-Webster Online Dictionary, 2016, no pagination) which referred to a mask worn by performers to disguise their identity in the different roles they played in the theatre. A person’s personality makes them unique. It is the representation of habits, traits, attitudes and ideas that are displayed externally through the roles they embody as they relate internally to motivation, goals and various aspects of selfhood. Genetic and environmental factors interact to influence the way in which we view our life experiences and how we manage and adapt to the challenges we face as we move through the stages of the life cycle. According to Feist and Feist (2012), personality gives both consistency and individuality to a person's behaviour and is demonstrated through a pattern of relatively permanent traits and unique characteristics. Many of the characteristic traits found in people with a personality disorder are found to a lesser degree in the general population. However, when these traits cause significant functional impairment and subjective distress the person may be diagnosed with a personality disorder (Feist & Feist, 2012).

1.3 DEFINITION OF PERSONALITY DISORDER

The definition of personality disorder put forward by the American Psychiatric Association (2013) in the Diagnostic and Statistical Manual of Mental Disorders (DSM V) includes longstanding patterns of maladaptive experiences and behaviours emerging during adolescence or early adulthood (American Psychiatric Association, 2013). These are more pronounced than acceptable cultural norms and not associated with any medical diseases, head trauma, substances or drug abuse or medication. The enduring pattern is not better explained as a manifestation or consequence of another mental disorder (American Psychiatric Association, 2013).

People with a personality disorder display characteristic inappropriate patterns of thoughts, perceptions, feelings and behaviours that begin in early adolescence and are frequently lifelong (Skodol et al., 2011). Social and occupational functioning may be impaired without major distress or loss of contact with reality (Clark, 2007).

People with personality disorder are often reluctant to accept professional help and tend to blame others for the problems they are experiencing.

Personality disorders manifest across areas of functioning affecting the person's way of perceiving and interpreting other people and events, the range and intensity of their expressed emotions, the extent to which their emotional responses fluctuate, the appropriateness of their emotional response and the level of interpersonal functioning and impulse control (Löffler-Stastka, Ponocny-Seliger, Fischer-Kern, & Leithner, 2005). These patterns of behaviour are inflexible and pervasive and affect the person's social and personal interactions with others. They also cause significant distress and impairment in their level of occupational, social and personal functioning (Davison, 2002).

People with personality disorders often find their environment to be a difficult, confronting and an unfriendly place (Krawitz & Watson, 2000). They report that other people do not seem to have the time, sensitivity or acceptance of them that is needed to understand their anguish and level of social disconnection (Gunderson & Lyons, 2008b). The lack of connection to others in their environment is often interpreted as rejection of what they are going through and of them personally (Fagin, 2004). The rejection becomes overwhelming for them and this leads to their withdrawal from interactions with others. In the health care environment their perceived rejection leads to poor communication with health professionals and treatment difficulties.

1.4 PREVALENCE OF PERSONALITY DISORDER

Personality disorders are now accepted as an important disorder in psychiatry worldwide and are estimated to affect around 4% - 15% of the world population (Lenzenweger, Lane, Loranger, & Kessler, 2007; Bateman & Tyrer, 2004). In an international study conducted by Huang et al., (2006) across seven countries it was estimated the prevalence of personality disorder in the general population of those countries was 14.8%. Coid, Yang, Tyrer, Roberts, & Ullrich (2006) reported the prevalence of personality disorder in the United Kingdom was 4.4% and a Norwegian study the prevalence of personality disorder was estimated at 13.4% based on a large sample of 2053 individuals aged between 18 and 65 years. They reported individual subcategories ranged from 0.3% (sadistic) to 5% (avoidant) (Torgersen, Kringlen, & Cramer, 2001), with higher prevalence recorded in urban areas compared to rural ones (Tyrer & Bateman, 2004). Approximately 6.5% of

Australians have a life time prevalence of personality disorder (Jackson & Burgess, 2000). It is also estimated that 31.4% of all people who are diagnosed with other mental disorders such as schizophrenia, bi-polar disorder or depression have a co-existing personality disorder (Zimmerman, Rothschild, & Chelminski, 2005).

The DSM-V describes that some personality disorders such as antisocial personality disorder are more frequently diagnosed in males, where as other personality disorders (such as borderline, dependent or histrionic personality disorder) are more likely to be diagnosed in females (American Psychiatric Association, 2013). In this diagnostic group approximately 10% will suicide which is 50 times greater than the suicide rate in the general population (Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004). Krawitz and Watson (2000) reported in their paper that 70% of the women were diagnosed with a borderline personality disorder and had reported that they had been victims of sexual abuse (Krawitz & Watson, 2000). While personality disorder accounts for less than 5% of all hospital admissions (Bateman & Tyrer, 2004), people with personality disorders are more likely to be in contact with mental health and primary health care services. It is estimated that 50% of consumers in community mental health services and 25% in primary care have a diagnosed personality disorder (Beckwith, Moran, & Reilly, 2014). Of those diagnosed with a personality disorder it is estimated that 1-2% will be diagnosed with the borderline personality disorder and represent 10% of mental health patients receiving community mental health services and 20% of acute inpatient mental health units (Lieb et al., 2004).

Women rather than men are more likely to be diagnosed with a borderline personality disorder which suggests there is a gender bias (Sansone & Sansone, 2011). Women are generally diagnosed at a rate of two to three times more frequently than men, with a 70% to 30 % ratio suggesting that diagnostic difference also exists based on gender (Lieb et al., 2004). For example, in 1990 Swartz, Blazer, George, and Winfield, (1990) reported that the borderline personality disorder is significantly higher among women (up to 77%). However, in more recent studies, Sansone and Sansone, (2011) found that it was the frequency of presentation that accounts for the gender bias. Woman present to the ED more frequently than men because they are more ready to ask for help to address their mental health needs (Coid et al., 2006). In contrast, men with personality disorders present to substance-abuse treatment programs or are more likely to be incarcerated (Sansone & Sansone, 2011) with prisoners observed to be 10 times more likely to have an antisocial

personality disorder than the general population (Fazel & Danesh, 2002). Moreover, women with personality disorders are more likely to be clients of outpatient mental health services due to higher rates of help seeking behaviour for repeated self-harming behaviour (Beckwith et al., 2014).

In this current study nearly 70% of the respondents were female and again the gender difference may be due to the fact females generally present to the ED and attract a DSM V diagnosis of Borderline Personality Disorder (Swartz et al., 1990). This is speculation as ICD10 diagnostic classification of EUPD (F60.3) includes aggressive, borderline and explosive types which may be attributed to both genders (World Health Organization, 2010).

Another explanation regarding the gender difference in DSM V diagnoses of personality disorder is that it is due to difficulty processing human emotions (Snowden, Craig, & Gray, 2013), with those diagnosed with borderline personality disorder (more commonly in females) having difficulty processing facial emotion (Robin et al., 2012) which makes them hypersensitive to emotional expression (Martin & Thomas, 2015). Males on the other hand are more likely to have difficulty recognising and detecting fear so tend to attract diagnoses such as antisocial personality disorder (Snowden et al., 2013). It has also been suggested that males will seek more destructive methods of self-harm to address their distress (Harrison & Henley, 2014). Thus females' self-harming behaviour is less lethal than males so they are more able to present and re-present to the ED to seek help.

1.5 DIAGNOSIS OF PERSONALITY DISORDER

A person is clinically diagnosed with a personality disorder by health professionals using either the DSM V (American Psychiatric Association, 2013) or the International Classification of Diseases Version 10 (ICD 10) published by the World Health Organisation (World Health Organization, 1996). In Australia, both classification systems are utilised to assist health professionals to accurately diagnose the disorder and to formulate an appropriate treatment program.

The DSM V provides clinicians with a comprehensive list of symptoms associated with personality disorders and associated sub-types that are used to provide an accurate diagnosis. However, Australian hospitals are allocated funding based on the use of ICD 10 diagnoses and therefore, all consumer admissions are classified using this classification system (The National Centre for Classification in Health, 2016). As a result, both the DSM V and ICD 10 are used by clinicians; one

to assist with consumer diagnosis and the other to record the consumer's health activity in hospital and government databases. Each one of these classification systems presents a clear and objective account of criteria to enable health professionals to assess and diagnose personality disorders. A summary of each classification system will now be presented.

1.5.1 Diagnostic and Statistical Manual of Mental Disorder Version 5 (DSM V).

The DSM V released in 2013, has removed the multi-axial classification system that was present in the previous version of the DSM (DSM IV-TR) (American Psychiatric Association, 2013). In the DSM IV-TR, on the multi-axial classification system, Axis 1 was viewed as the top level and identified the main presenting clinical mental disorders identified in the consumer (American Psychiatric Association, 2000). In this classification system mental retardation and personality disorders were excluded from Axis 1 and were placed on Axis 2. As such, personality disorders were viewed as different to mental disorders and this diagnostic difference subsequently impacted on consumer access to services and care.

Prior to the release of the DSM V, the advisory panel concluded that the arbitrary boundaries between Axis 1 and Axis 2 should be removed. Consequently, the DSM V has a single axis system and therefore, personality disorders are classified as one type of mental disorder (Stetka & Correll, 2013).

This single system removes artificial distinctions between conditions, benefitting consumer diagnosis and outcome, clinical practice and research use (Black, 2014). The decision has potentially reduced the stigma consumers with personality disorder experience when accessing health services and the DSM V has created more equality in assessment and diagnostic outcomes for this consumer group (Black, 2014). The DSM V makes the diagnostic process easier and provides greater clarity in using the classification to formulate the consumer's treatment and management plan (Stetka & Correll, 2013).

The DSM V clusters personality disorders in cluster A, B, C and other. Cluster A personality disorders (paranoid, schizoid and schizotypal personality disorder) are now grouped within the "Schizophrenia spectrum and other psychotic disorders" in a separate chapter of the DSM V. Cluster B includes (antisocial, borderline, histrionic and narcissistic personality disorders) and Cluster C, (avoidant, dependent and obsessive-compulsive personality disorders). The other personality disorder cluster

covers personality change due to other medical conditions, other specified personalities disorders and unspecified personality disorders. Personality disorders are divided into 10 sub-categories as part of the DSM V diagnostic process. A summary of the key characteristics of each sub-category type is outlined in Table 1.

Table 1: DSM V diagnostic sub-categories types for personality disorders

Sub-category type	Characteristic patterns related to disorder
Paranoid personality disorder	A characteristic pattern of distrust and suspicion that is so intense it can be mistaken for persecutory delusions. These beliefs adversely impact on all the relationships the person has as any perceived rejection is misinterpreted. These people avoid engaging in groups, seem to be self-sufficient and are perceived as being secretive even devious. Friends, spouse and colleagues, in fact everyone, find them difficult to get on with.
Schizoid personality disorder	A characteristic pattern where the person is generally described as being socially isolated by choice. These people display limited emotions and prefer solitary intellectual matters, often with a fantasy world that is complex but emotionless. They have little interest in or any apparent need for family, intimate or sexual relationships and are content with their situation, and are seldom seen in a social context. For these reasons they are rarely present to access help for their problem.
Schizotypal personality disorder	Characteristically they do not seek to associate with people by choice because such meetings cause considerable personal distress. These people consider themselves to be different and do not conform to social norms leading to unusual choices in clothing, odd mannerisms and other eccentricities of behaviour. They tend to isolate themselves and are uncomfortable in social situations.
Antisocial personality disorder	Characteristically superficially charming but this is often short lived, giving way to a disregard for others and social norms. These people show little regard for their

Sub-category type	Characteristic patterns related to disorder
	own safety or the safety of others and do not abide by the rule of law. They display impulsiveness and aggressive behaviour and a lack of self-responsibility or remorse. This abnormal behaviour may be exacerbated by drugs and alcohol.
Borderline personality disorder	A characteristic pattern of overwhelming emotional highs and lows experienced by the person. Their interpersonal relationships and self-image are frequently unstable. These people have marked need for affection and intimacy. When they give or receive affection or intimacy they often find it constricting and disappointing. The depths of their pain is often expressed in extreme self-harming which may include drug and alcohol abuse.
Histrionic personality disorder	A characteristic pattern where everything in life seems to be a “drama”. There is excessive attention seeking, excitement seeking and needing to be the centre of attention. These people seek intimacy and see intimacy where others do not. To gain “centre stage” there may be great attention to physical appearance, emotional blackmail and anger that others find exhausting.
Narcissistic personality disorder	A characteristic pattern of exaggerated expectations of affirmation and acknowledgement of social and vocational achievement. A sense of self-importance that is unrealistic and out of step with actual achievements. These people consider themselves as special, and expect others to admire them and offer them special services and favours. They have a lack of empathy toward others which makes them generally dislikeable.
Avoidant personality disorder	A characteristic pattern of negative self-worth, low self-esteem and inadequacy which results in the person persistently believing that they will be rejected, they will fail and that they will not achieve personal goals and

Sub-category type	Characteristic patterns related to disorder
	objectives. These people avoid social activity but crave the social relationships with others.
Dependent personality disorder	A characteristic pattern of submissive behaviour related to the desire or need to be “taken care of”. These people are not able to take self-responsibility and have a general lack of self-reliance. They need excessive help from others to make decisions.
Obsessive-compulsive personality disorder	Characterised by preoccupation with structure, orderliness and control. The person continually strives for perfection which they never achieve due to their preoccupation with detail. These people are rigid, controlling and lack flexibility. They often observe social norms to the point where social situations become intolerable as they prefer familiar patterns and avoid changes.
Personality change due to another medical condition	A persistent personality disturbance that is judged by others to be the result of a physiological disorder or a medical condition (for example a brain lesion).
Other specified personality disorder and unspecified of personality disorder	When the individual's personality pattern meets the general criteria for a personality disorder, having traits of several different personality disorders, but the criteria for a specific type of personality disorder are not met.

(Cowen, Harrison, & Burns, 2012; American Psychiatric Association, 2013)

1.5.2 International Classification of Disease 10th Edition (ICD 10).

In Australia, the International Classification of Disease 10th Edition (World Health Organization, 1996) is used to classify presenting disease of all people admitted to health services. The ICD 10 classifies “Mental and behavioural disorders” under Chapter 5 and coded numerically into blocks ranging from F00-F99. Disorders of adult personality and behaviour are classified numerically in the block F60-F69 (World Health Organization, 1996). The disorders that are related to this thesis are those in the block F60.0-F60.9 and hence the remaining disorders in this block classification are outside the scope of this study.

The ICD 10 describes personality disorders as a variety of long standing conditions and behaviour patterns that emerge in early life that define the person's individual characteristics and ways of relating to themselves and others. As these patterns of behaviour are well established, the person is often resistant and unwilling to make changes in their social situations. They perceive, think, feel and relate and respond to social and personal situations differently from what is considered normal in their culture. The ICD 10 suggests that these disorders are usually but not always associated with emotional distress and problems with social functioning (World Health Organization, 1996). The nine sub-types of personality disorders F60.0-F60.9 as outlined in the ICD 10 relevant to this thesis are described below in Table 2.

Table 2: Sub-types of Personality Disorders (ICD10) F60.0 -F60.9

Sub-type of personality disorder	Characteristics
F60.0 Paranoid personality disorder	Characterised by hypersensitivity to anything that is perceived to be negative and not supportive. Excessive self-importance and self-reference and recurrent suspicions without justification. Relationships and the personal integrity of partner are frequently questioned. .
F60.1 Schizoid personality disorder	Characterised by the person withdrawing and disconnecting from intimate and social relationships with people; instead there is a preference for fantasy, imaginary, solitude and introspection.
F60.2 Dissocial personality disorder	Characterised by an indifference to usual social obligations and a disregard for the feelings of others. Low tolerance to frustration and a low threshold to aggression. Blame others for problems.
F60.3 Emotionally unstable personality disorder	People with emotionally unstable personality disorder (EUPD) have an emotional state that is labile, unpredictable and given to sudden and unaccountable changes of mood or behaviour. This emotional state makes the person prone to

Sub-type of personality disorder	Characteristics
	<p>outbursts of emotion with the incapacity to control the behavioural explosions. This disorder is characterised by a tendency to act impulsively and without consideration of the consequences. There are two types of EUPD included in this diagnosis: 1) the impulsive type, characterised predominantly by emotional instability and lack of impulse control, and 2) the borderline type, characterised by additional features of disturbances in self-image, internal preferences, chronic feelings of emptiness, intense and unstable interpersonal relationships, and self-destructive behaviours that include suicide gestures and attempts.</p>
F60.4 Histrionic personality disorder	<p>Characterised by overwhelming theatrical expressions of emotions, lack of consideration for others, continual attention seeking behaviour. These people are egocentric and self-indulgent.</p>
F60.5 Anankastic personality disorder	<p>Person displays perfectionism, and checking and preoccupation with details. They are rigid and inflexible. Feelings of doubt.</p>
F60.6 Anxious [avoidant] personality disorder	<p>Characterised by overwhelming emotions of agitation and restlessness. The person is concerned with not being accepted by people or rejection. Hypersensitive to feedback, expects and believes all feedback is negative and personal. Views the world as a potentially risky and dangerous place.</p>
F60.7 Dependent personality disorder	<p>Characterised by an over whelming dependence and expectation that other people will be involved in making almost all decisions in their life. Has a tendency to be influenced by other people. Lacks personal drive or motivation to</p>

Sub-type of personality disorder	Characteristics
	achieve personal goals and direction. The person remains fearful of being abandoned by others. Passive compliance.
F60.8 Other specific personality disorders	This classification includes narcissistic, passive-aggressive and immature personality disorders.
F60.9 Personality disorder unspecified	Pathological personality (NOS) and character neurosis (NOS).

(World Health Organization, 1996)

1.6 CLINICAL PRESENTATION OF PERSONALITY DISORDERS

Personality disorders were first described in the DSM II in 1968 (American Psychiatric Association, 1968) but the definitions given at this time do not reflect those outlined in the DSM V (American Psychiatric Association, 2013). The clinical presentation of people with personality disorders is determined by the key characteristics of the sub-types identified in the DSM V and outlined in Table 1 or ICD 10 outlined in Table 2. Generally, people with a personality disorder present as highly vulnerable and demonstrate cognitive styles and behaviours that contribute to their distress and alienate them from other people (Appleby & Joseph, 1991; Bodner et al., 2015). This is exacerbated by the fact that many health professionals hold the belief that this group of consumers do not have an authentic illness (Tyrer & Bateman, 2004), and display aberrant or attention seeking behaviour that is challenging to manage and treat (Hayward, Tilley, Derbyshire, Kuipers, & Grey, 2005). Historically, there has been debate about the validity of a personality disorder diagnosis and hence the value of hospitalisation and treatment for this group (Aiyegbusi & Kelly, 2015; Bateman, Gunderson, & Mulder, 2015; Davison, 2002).

People diagnosed with a personality disorder who present clinically to health services are often described by health professionals as impulsive, demanding, manipulative, disruptive (Hayward et al., 2005), pessimistic, destructive, prone to self-harming behaviour (Kaplan, 1986) and have poor coping skills (Hayward et al., 2005). They also have higher rates of somatic complaints, alcohol abuse or dependence and a more negative perception of their health status (Iza et al., 2007). Their strength and positive attributes are seldom identified when they present in crisis as their challenging behaviours may overshadow these strengths and have the

capacity to negatively influence their interactions (Kaplan, 1986). For example, people with personality disorders are known to 'split' health professional into groups of good and bad. This induces a sense of powerlessness in staff because they no longer feel unable to protect the person, they are alienated from their colleagues and they experience blurring of professional boundaries (Hayward et al., 2005).

When seeking help, people with personality disorders characteristically display poor communication skills and are unable to clearly articulate the difficulties they are experiencing. Instead, they may verbalise that they are feeling unsafe or that they want to self-harm or are actively suicidal (Fanaian et al., 2013). Similarly, when the consumer presents in times of crisis to the ED as a part of their self-management plan that has been negotiated with their treating team, their presentation may be misconstrued as a new crisis and the strengths that the person used to seek help are lost (Hayward et al., 2005). For the consumer, this reinforces that health professionals cannot be trusted to support them in self-managing their illness and they feel alienated from a system that had contracted to help them. Furthermore, the stigma directed towards them impacts on the effectiveness and comprehensiveness of health care provided to them and their significant others (Aiyegbusi & Kelly, 2015). This is especially evident for people diagnosed with EUPD (Knaak, Szeto, Fitch, Modgill, & Patten, 2015). The very nature of personality disorder can imply separation of the consumer from the rest of the community on the basis that they are somehow different to everybody else around them (Cowen, Harrison, & Burns, 2012). The sub-type of personality disorder that is most problematic to health services providing mental health services is the ICD 10 diagnosis EUPD. EUPD occurs in approximately 2% of the general population, it is present in 10% of consumers accessing mental health community care and 20% of mental health inpatients (Koehne & Sands, 2008).

1.7 HISTORICAL CONTEXT OF DIAGNOSING OF THE SUB TYPE EUPD

The sub-type EUPD owes its diagnostic roots to older classifications that used the term Borderline Personality Disorder (BPD) from DSM II (Association Psychiatric Association, 1968) to DSM IV-TR (American Psychiatric Association, 2000). Historically, the term BPD was first proposed in the United States of America in 1938 to describe behaviours in a group of people who did not fit into either the psychotic or psychoneurotic diagnostic category at that time (National Collaborating Centre for Mental Health, 2009). Kaplan (1986) used the term BPD to describe a

group of people who had a set of unique character problems that made them extremely difficult to treat. These people were described as being pessimistic, demanding, destructive and prone to self-harming behaviours and at the time they were viewed as having the capacity to negatively influence staff and other patients (Kaplan, 1986). The 'revolving door phenomenon' is a term coined to describe people with BPD who presented to the ED each time they experienced a crisis (Flewett, Bradley, & Redvers, 2003). They typically arrived to the ED clutching a transitional object, for example, a favourite teddy bear or blanket (Hooley & Wilson-Murphy, 2012). The transitional object was viewed by them as a source of comfort and support in times of stress and crisis, but was not perceived as such by health professionals. This behaviour reinforced the labelling and stigmatising of this group and influenced the way that health professionals may interact with people diagnosed with EUPD.

1.8 ATTITUDES OF HEALTH PROFESSIONALS TOWARDS PEOPLE WITH EUPD

Health professionals' attitudes play an integral part in the delivery of care to people diagnosed with EUPD. However, many clinicians only see the EUPD diagnosis and not the person and make judgements about the causes of their presenting behaviours. For improved treatment for this group there is a need for staff to understand their vulnerability, fear and the difficulty they experience in trusting people when they seek help (Bateman & Tyrer, 2004; Siefert, 2012). Some health professionals consider the diagnosis of a EUPD to be an untreatable mental disorder with a poor prognosis (Aldridge, 2015; Swift, 2009) and believe that recovery is not possible with only remission of symptoms achievable. Regardless of these attitudes, people with EUPD do improve and progress in their life, learn new skills and ways of coping and address challenging life issues. As a result they no longer need to seek assistance from health professionals as often. Many are able to retain important personal survival skills and make informed decisions about their own mental health (Western Australian Mental Health Commission, 2010).

Historically, people with a personality disorder have not received quality care and treatment when they seek mental health services and the term, personality disorder generally has been consistently misused and misunderstood by health professionals and the general population since it was first identified as a distinct disorder (Kim & Tyrer, 2010). For example, they may be perceived to be a very challenging and

difficult group to manage in the acute care environment (Newton-Howes, Weaver, & Tyrer, 2008), and health professionals may use negative terminology such as ‘attention seeking, passive aggressive and maladaptive’ to describe the person’s behaviour (Aldridge, 2015, p1). Health professionals are reluctant to engage with them on an emotional level, minimise the person’s presenting symptoms and often fail to assess the strengths the person brings to their illness management (Aviram, Brodsky, & Stanley, 2006). As a result, this group of consumers are stigmatised, treated differently and labelled as having ‘behavioural problems’ rather than as people in crisis with a serious mental disorder (Bodner et al., 2015).

Clinical judgments made about the consumer have also been reinforced in documentation by health professionals in medical records and management plans. This documentation often trivialises the person’s distress, their need to be helped when in crisis, and their ability to access appropriate services (Aviram, et al., 2006). This negative stance increases and validates the stigma that health professionals and the community direct towards them (Swift, 2009). The negative attitudes held by health professionals have remained unchanged over time and are not influenced by interactions with consumers (Aviram et al., 2006; Friedel, 2004). The adverse approach which is dismissive and not recovery focused is reported to be prevalent in many health care settings even if the management practices are different (Bhebhe & Fuller, 2009). When working with this consumer group, health professionals often experience counter transference, which makes it easier for them to express their negative attitudes towards the person (Gunderson & Links, 2008a). Additionally, health professions assume that people with EUPD are responsible for their behaviours and should be respectful to others when in acute environments such as the ED (Vijay & Links, 2007). They treat them without concern for their individual needs and ignore their high levels of personal distress which affect their ability to communicate and function (Aiyegbusi & Kelly, 2015). They fail to perceive that this group has specific individual characteristics that in a crisis situation reduces their level of tolerance and increases their level of impatience and impulsivity (Davison, 2002).

1.9 HELP SEEKING BEHAVIOURS AND ACCESS TO SERVICES

People diagnosed with EUPD have divergent views of the health care system and the health services they receive (Bender et al., 2001). The literature highlights that they have more visits to their general practitioner (GP) than the general population

(Beckwith et al., 2014). However, GPs may not effectively intervene due to lack of knowledge and skills, time deficits or interest in working with mental health consumers. They may not be able to provide the level of crisis management the person requires and so refer them to the ED (Bender et al., 2001) or if they assess that the person is a risk to themselves refer them for specialist hospital based mental health care (Hoff, 2010).

As a group, people with EUPD frequently self-present to mental health services and EDs when in crisis (Fanaian et al., 2013; Hayward & Moran, 2007). For some, the ED is viewed as a safe haven that they can directly access in times of crisis (Byrne, Henagulph, McIvor, Ramsey, & Carson, 2014). They often choose the ED that has previously provided them with a sympathetic treatment approach where staff have been helpful to them in resolving their crisis. However, the nature of their presentation, along with their previous documented health history can impact on the care they receive on arrival at the ED (Aldridge, 2015). This leads to the consumer receiving a suboptimal level of care (Bodner et al., 2015; McGrath & Dowling, 2012). In many situations, health professionals' responses may limit the consumer's access to treatment and result in them going unnoticed and untreated (Koekkoek, van Meijel, & Hutschemaekers, 2010). This occurs even though the literature highlights this groups' higher degree of need and intervention from mental health professionals (Hayward, Slade, & Moran, 2006). At a local level the need for a well-developed discharge plan for mental health consumers who have passed through the ED was highlighted in the Stokes Review of public mental health facilities/services in Western Australia (Stokes, 2012).

The police are often involved in transporting people with a EUPD to the ED for assessment in circumstances when the person is assessed to be a risk, for example, self-harming in a public place (O'Brien & Flote, 1997). Working within the 2014 Western Australian Mental Health Act, police are also involved in returning people who leave the ED following admission without a health clearance who are deemed to be a risk to themselves, others, or due to their involuntary status under the Act (Government of Western Australia, 2014). Community mental health services who are case managing the consumer can also facilitate a planned admission to a mental health unit through the ED. This admission is coordinated in a manner to reduce the number of 'crisis' ED presentations by the consumer (National Institute for Health and Care Excellence, 2009). Planned admissions may be part of their management plan developed in collaboration with their community mental health professional to

facilitate access to mental health care in times of crisis. It is an integral part of follow-up care as recommended in Stokes (2012).

A crisis admission plan may include a stay in a mental health specialist unit for a period of 1-5 nights admission (Helleman, Goossen, Kaasenbrood, & van Achterberg, 2014) followed by another period of community care from specialist mental health professionals (Department of Psychiatry; Royal Perth Hospital, 2013).

1.10 CLINICAL PATHWAY FOR THE ACUTE INPATIENT CARE OF PEOPLE WITH EUPD

As previously stated, people with EUPD are seen to be some of the highest users of health services and represent up to 30% of mental health admissions. Their length of hospital stay is usually short and to prevent recidivism a clinical pathway to support care is identified as best practice. The two stage clinical pathway developed at the hospital where this study was conducted aimed to balance the recommendation of brief admissions with the need to validate the person's experience and deliver high quality care. This pathway allows people to be admitted for a first or review admission from 7-12 days or a consumer controlled crisis admission of 1-3 days. Both admission programs aim to work with the consumer to acknowledge their experience and to empower them to self-manage their treatment program, thus promoting hope of recovery and optimism about their future progress. Both admission programs ensure consumer safety, through assessment of their presenting issues and learning new skills to manage the symptoms they are experiencing such as dialectical behaviour therapy or cognitive behavioural therapy. The program included post discharge transition support pathways for people to readjust back into community life. The pathway also facilitates ease of access back to the service in times of crisis and a presentation to ED is viewed as part of this pathway. Therefore, it is important that all health professionals support consumers when they present in crisis using this pathway to care. The pathway has been evaluated to be cost effective for people with EUPD presenting to the hospital in times of crisis. It also supports the normalisation of ED presentations for people with EUPD (Department of Psychiatry; Royal Perth Hospital, 2013).

1.11 ACCESS TO SERVICES FOR PEOPLE WITH EUPD PARTICIPATING IN THIS RESEARCH

The current admission procedure for people with EUPD presenting to the hospital is a single point of entry through the ED according to the EUPD clinical pathway

(Department of Psychiatry; Royal Perth Hospital, 2013). Following presentation to the ED, it is assessed whether the person requires a referral to the specialist hospital based mental health service. The Stokes Review (2012) recommended an improved level of care for mental health consumers discharged from the ED that includes discharge accommodation, GP follow-up, community support and follow-up telephone calls (Stokes, 2012). The clinical pathway developed by the service to care for people diagnosed with EUPD is in line with this recommendation (Department of Psychiatry; Royal Perth Hospital, 2013).

Re-admission within a 28 day period is considered a failed discharge at the hospital where this study was conducted. This is supported by the Australian health standards policy that outlines specific guidelines for management of patients after discharge (Department of Psychiatry; Royal Perth Hospital, 2013). Included in these guidelines are specific time-frames under which a person following discharge is considered to have made a successful transition back into their community. Since 2006, the Australian Federal Government has adopted a policy of national benchmarking and the 28 day policy indicator is an important demonstration of the effectiveness of community care and the organization's ability. A re-admission within 28 days often results from inadequate discharge planning or lack of preparation for discharge (Australian Government, 2014).

The three-day crisis plan hospital admission as part of the clinical pathway for people with EUPD developed by the service aims to encourage consumers to present to the ED for admission prior to a self-harm episode in order to support the self-management of their crisis. The three-day crisis plan hospital admission requires cooperation of clinicians to agree on the formulated management plan and to take the time to develop a relationship with the person when they present for help. A therapeutic alliance is needed between ED health professionals and the person as it is not always possible to meet the consumer's expectations of an immediate admission to the mental health unit.

On discharge from the three-day crisis plan hospital admission, the person is eligible to attend a semi-structured group therapy program; 3 sessions per week for six weeks outpatient program. Community mental health professionals work to engage the consumer with their regular GP to develop a good relationship to implement their mental health plan. This level of collaboration and engagement aims to prevent the 'revolving door syndrome' by providing the person with stable support in the primary care setting. The aim of treatment is to foster mental health

recovery that allows the person to live effectively in the community (Department of Psychiatry; Royal Perth Hospital, 2013).

1.12 IMPACT OF NATIONAL POLICIES AND STRATEGIES ON PEOPLE DIAGNOSED WITH EUPD

Over the past two decades, there have been a number of national strategies implemented in Australia aimed to improve mental health services for people diagnosed with a mental disorder and promote mental health recovery. These strategies have been developed through the National Mental Health Strategy and operationalised in National Mental Health Plans (Australian Health Ministers, 2009). The National Practice Standards for the Mental Health Workforce 2013 (Victorian Government, 2013), and the National Standards for Mental Health Services 2010 (Commonwealth of Australia, 2010) call for mental health services and clinicians to improve mental outcomes for Australians and adopt a recovery focused model of care (Australian Government; Department of Health, 2013). Nationally it is required that health professionals include consumers and their families in all aspects of decision making regarding their management plan.

Recovery focused care challenges the traditional model that professionals hold all the power and expertise to know how to help the person (Slade, 2013). Recovery paradigms emphasise that all people must be respected for their lived experience, expertise and strengths they contribute and bring to their care (Chester et al., 2016). However, in reality, when people with EUPD present for help, care is directed towards resolving the immediate crisis situation. There is a need to build recovery focused principles into care for this group of consumers through all aspects of their treatment trajectory, particularly during follow up by specialist community mental health teams (Australian Government, 2010).

The vision for Western Australia mental health care as described in “Mental health 2020, Making it personal and everybody’s business: Reforming Western Australia’s mental health system” (Western Australian Mental Health Commission, 2010) and “Better choices, better lives: The Western Australian mental health, alcohol and other drug services plan 2015-2025” (Western Australian Mental Health Commission, 2015) is the active engagement of consumers in their care and the availability of services to assist them to engage in mental health recovery. These strategic documents promote key principles that include: 1) de-stigmatisation of mental disorders, 2) integration of culturally appropriate health care to improve

quality of life and 3) promote mental health recovery (Western Australian Mental Health Commission, 2010, 2015)

The three day hospital admission program described in the clinical pathway for people with EUPD at the service where this study was completed commenced in 2013 and is consistent with identified best practice for the treatment of people with EUPD (Department of Psychiatry; Royal Perth Hospital, 2013). The hospital admission aims to empower consumers to continue to live productively in the community with the ability to access professional support during times of crisis. While some authors suggest that people with EUPD remain poorly managed by specialist mental health services (Fanaian et al., 2013), others see the benefits of short admissions where the person has access to specialist care without the fear of rejection and stigmatisation (Department of Psychiatry; Royal Perth Hospital, 2013).

1.13 WHAT IS MENTAL HEALTH RECOVERY?

Mental health recovery is now a possibility for many people living with a mental disorder and the importance of health professionals practising from a recovery focused framework is now embedded in Australian mental health policy (Commonwealth of Australia, 2010). Personal recovery is only achievable by the consumer. It is where the person feels empowered and has the self determination and hope for the future to live a productive life. When consumers are on the road to personal recovery they have good self-management strategies for their illness and more effective coping skills. They are able to work effectively with health professionals to have input into their ongoing care that enhances their level of mental health and wellbeing (Slade, 2013). Clinical recovery is a measure mainly used by health professionals and is where there is seen to be improvement in the consumer's clinical symptoms (Corrigan, et al., 2012a). While clinical recovery allows the consumer to engage in their own personal recovery journey, this process is enhanced when health professionals practice from a recovery focus. This focus is a shift away from the traditional medical model of care to an active collaborative partnership between health professionals and the consumer (Whitley & Drake, 2010).

When practising recovery focused care with people diagnosed with EUPD, health professionals will acknowledge the uniqueness of their experience and the need to develop specific personalised care that meets their needs (Happell, 2008). They will be treated with respect and dignity and the health professional will understand that the person's presentation when in crisis is an accumulation of their life experiences,

for example, previous abuse or trauma, and not just based on their presenting psychiatric symptoms (Vandecasteele, Debyser, Van Hecke, De Backer, Beecknam and Verhaeghe, 2015). The research described in this thesis was designed to evaluate from the consumer perspective the provision of mental health services provided to people with EUPD.

1.14 AIM AND OBJECTIVES OF THE STUDY

The research described in this thesis used a mixed method approach to explore the experience of receiving mental health care for people primarily living with EUPD in Western Australia. Specifically, the objectives were to:

1. Evaluate consumers' level of satisfaction with the hospital treatment received
2. Document the experiences of receiving mental health treatment at one hospital in Western Australia for consumers diagnosed with EUPD
3. Identify policy and practice changes that can facilitate recovery focused treatment for people with EUPD accessing public mental health services.

1.15 NEED FOR THE STUDY

People diagnosed with a EUPD present challenges to health professionals when they access care. Diagnostic difficulties over the years have resulted in many health professionals not recognising this disorder as an authentic illness and therefore, underestimated the impact of the person's symptoms on their level of wellbeing. Health professionals who display positive attitudes towards this group of consumers can assist them to resolve their presenting crisis and continue to strive for personal recovery while living successfully in the community (Chester et al., 2016; Martensson, Jacobsson, & Engstrom, 2014). In practising from a recovery framework, health professionals need to move beyond diagnostic labelling and incorporate the principles of recovery into their interactions and care with consumers (Chester et al., 2016). An improved understanding of the benefits to the consumer may help health professionals to enable help seeking behaviours during times of crisis without blame, judgement or stigma. The findings of this study will provide insight into the needs of people diagnosed with EUPD when they access care during periods of crisis. The findings will identify education needs of health professionals, families and carers to more effectively assist the mental health recovery for this group of consumers.

There is a need to document the lived experience of people diagnosed with EUPD to enable improvement in future services to reflect the specific needs of this group. An increased understanding of the lived experience will add to existing knowledge and assist in the formulation of future practice initiatives. These will provide greater levels of support for this group of consumers when they access mental health care.

1.16 SIGNIFICANCE OF THE STUDY

The findings of this study provide a voice for consumers primarily diagnosed with EUPD that outlines their perceptions of current models of care and their expectations of care as a consumer in 2016 and beyond. The findings provide information to the service where this study was completed regarding the perceived effectiveness of care provided. As Australian national mental health policy now requires health professionals to involve consumers in the planning of care, this research will provide them with an understanding of the lived experience of consumers.

Providing health professionals with a greater understanding of what it is like to live with EUPD may facilitate more positive attitudes, collaboration and engagement. This increased level of understanding has the potential to enhance health professionals' levels of satisfaction, and decrease their levels of stress associated with working with this consumer group.

1.17 SETTING FOR THE STUDY

Data were collected for this study from consumers accessing services at one public health service in Western Australia that has an acute mental health unit. A single point of entry for all mental health admissions at the service is via the ED. In the ED, specialist psychiatric liaison health professionals conduct the initial mental health assessment of the person. They may then refer the person to other support services or arrange an admission to the onsite mental health unit or other mental health services in Western Australia.

The hospital where this study was conducted services a diverse inner city population that include geographical areas with people who have high rates of homelessness, unemployment and drug and alcohol issues. People who present with EUPD often have multiple social issues complicated by drug and alcohol and physical health co-morbidities which add to the complexity and challenge of care for health professionals.

1.18 OVERVIEW OF FINDINGS

The findings of this current research support existing current literature in the area of consumers living with EUPD. While consumers who participated in both phases of the research talked about improvements in care, they also described care as being ad hoc and inconsistent and dependent on individual staff they had contact with when they contacted the service in crisis. The findings also highlight that while current pathways for treatment are in line with identified best practice, participants found longer support programs fostered the greatest positive changes in their mental health outcomes.

The findings clearly demonstrate the importance of health professionals having positive attitudes to work with this group of consumers and being willing to engage and support consumers with EUPD in all health care settings. The first contact with a health professional during times of crisis had a large impact on consumers' mental health and wellbeing. Health professionals who engaged positively with this group of consumers could intervene therapeutically to deescalate the presenting crisis and assist the consumer to more effectively self-manage their presenting symptoms. It is therefore, a key recommendation of this study that health professionals require improved knowledge and understanding of the lived experience of people living with EUPD and strive to work therapeutically with this group in all settings. Finally, de-stigmatising mental illness within the community remains a critical issue to ensure consumers reach their full potential for mental health recovery and are able to live productive lives.

1.19 LIMITATIONS OF THE STUDY

This research was conducted at one health service in Western Australia and this may be seen as a limitation to be able to generalise finding of this study. However, the findings are consistent with those outlined in the literature which report similar outcomes in a variety of settings and countries. As most participants in this study were diagnosed as F60.3 EUPD subtype of personality disorder, this may also be seen as a limitation of this research as the ability to generalise the finding to people diagnosed with other sub-types of personality disorder may be limited.

1.20 ORGANISATION OF THESIS

This thesis consists of five chapters. Chapter 1 provides a review of the literature on personality disorders, diagnostic processes and factors that impact on the consumer help seeking experience. The chapter presents the aim and objectives, need and significance of the study along with the limitations. Chapter 2 outlines the methodology used; the study design, ethics approvals, and method of sampling, data collection, and data storage and data analysis. Chapter 3 presents the finding of the self-report questionnaire and structured interviews conducted with participants. Chapter 4 provides the discussion related to the results. Chapter 5 provides implications of the findings to clinical practice, recommendations and concluding statements.

CHAPTER 2

METHODOLOGY

2.1 INTRODUCTION

The aim of the research was to obtain insights and an improved understanding of the phenomena under investigation using the most appropriate methodology to answer the research question (Casebeer & Verhoef, 1997). The chapter outlines the methodology used to analyse and write up the findings of this mixed methods research study along with descriptions of participants, recruitment process and how data were collected. The process of obtaining ethics is outlined along with providing participants with information to make informed decisions to participate in this study. Data storage and trustworthiness and credibility of findings are presented.

The use of mixed methods research originated from a systematic integration of qualitative and quantitative data within a single investigation (Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012). Mixed methods research originated from the social science discipline and has now gained popularity and recognition in the wider research arena (Wisdom & Creswell, 2013). The use of mixed methods research has expanded to answer a wide variety of research questions across many disciplines including nursing (Wisdom et al., 2012; Wisdom & Creswell, 2013).

The central premise of using mixed methods research is to obtain an improved understanding of the phenomena under study through merging quantitative and qualitative findings to answer the posed research question (Palinkas et al., 2011). This enables the respective strengths of qualitative and quantitative research methods to be harnessed and to generate more complete data with different perspectives of findings (Curry, Nembhard, & Bradley, 2009).

Complex organisational processes that occur in health care systems support the use of mixed methods research (Verhoef & Casebeer, 1997) and enable researchers to obtain an improved understanding of the research problem (Curry et al., 2009), for example, how service delivery impacts health seeking behaviour. The approach provides flexibility and adaptability to study designs (Moffatt, White, Mackintosh, & Howel, 2006). Mixed methods research has several advantages: 1) it allows the participants' point of view to be presented; 2) it increases multidisciplinary research opportunities; and 3) it provides flexibility in the use of the application of the methodology. It also mirrors the way in which people naturally collect information, for example, in health you have diagnostic coding and qualitative descriptions of the

lived experience of the illness accompanying that diagnosis (Wisdom & Creswell, 2013).

Researchers using mixed methods research utilise one of the following approaches: 1) a *convergent parallel design* where two independent strands of qualitative and quantitative data are collected simultaneously with independent data analysis and the researchers then look for convergence, divergence, contradictions and/or relationships between the two data sources; 2) *exploratory sequential design* where the findings of a stage one qualitative study are used to design the second phase of quantitative data collection; 3) *explanatory sequential design* where first phase quantitative data is analysed to guide second phase qualitative data collection; or 4) *embedded design* where the researcher has a qualitative or quantitative data collection with a qualitative or quantitative procedure or intervention occurring at the same time. Hence, two types of data are collected to answer different aspects of the research question (Creswell & Plano-Clark, 2011; Tashakkori & Teddlie, 2016).

The strength of mixed methods research has been demonstrated in recent studies in the health area. For example, Aiyegbusi and Kelly (2015) used a sequential mixed methods study to examine the nurse patient relationship in forensic and therapeutic community settings for people diagnosed with personality disorder. The researchers incorporated quantitative Delphi study data with qualitative insights gleaned from participants. The use of mixed methods allowed the researchers to incorporate information obtained from a large number of expert informants from a Delphi study with qualitative data collected from a forensic unit and therapeutic community setting to improve the quality of care. Similarly, Brotto, Knudson, Inskip, Rhodes, & Erskine (2010), used mixed methods research to examine the lived experiences of people who self-reported as being asexual. In the first phase of their study they administered a validated online survey to determine participants' sexual preferences. They then randomly selected 15 individuals who identified as being asexual to participate in structured interviews. The qualitative phenomenological approach allowed them to explore the experience of asexuality that was highlighted in the quantitative data. The strength of mixed methods research enabled the researchers to appropriately select participants and customise the qualitative interviews.

While the strength of a mixed methods approach is well recognised, many researchers have reported limitations using this methodology that have consequences for the overall study. The allocation of resources and time management becomes

more demanding with mixed methods (Wisdom & Creswell, 2013). Researchers also need to have experience in both methodologies and this may increase the workload associated with the study and number of people involved (Marshall & Hays, 1994). Therefore studies utilising a mixed methods approach may be more complicated to plan and implement than a single method research (Wisdom & Creswell, 2013).

2.2. RESEARCH DESIGN

Mixed methods research was chosen for this study because it allowed the researcher to examine from quantitative and qualitative perspectives the lived experience of consumers accessing mental health services. A *sequential explanatory design* was employed. The first step of the research process was to determine whether “people with EUPD who accessed mental health services have the same satisfaction of mental health services as those who have other mental disorders”. Therefore, in phase 1 of the study (quantitative) a control group of participants was used so the quantitative data being collected on consumers with EUPD could be compared with consumers diagnosed with other types of mental disorders. This was important to evaluate the impact the level of stigma, negative attitudes and poor interactions towards people with EUPD by determining any between groups difference during analysis.

A quantitative survey (the 18 item Patient Satisfaction Questionnaire, PSQ-18) was administered to the sample, data were collected and analysed using descriptive and inferential statistics to answer the research questions posed. The data from both phases of the research were then interpreted as connected results. That is the qualitative findings were used to expand and explain the quantitative results.

In this study, quantitative data relating to participants’ satisfaction with the care they received when they were admitted to the mental health unit was collected using an amended version of the short form “Patient Satisfaction Questionnaire” (PSQ-18). Qualitative data were then collected from a subset of these participants through the use of structured interviews (Chwalek & McKinney, 2015) which is a recommended research method when little is known about the subject under examination.

In phase II of the research (qualitative) participants from phase I with EUPD were invited to participate in interviews to further expand on their experiences within the health care system.

2.3. ETHICS

Permission to conduct the study was obtained from one public health service in Western Australia and reciprocal approval was obtained from the Curtin University Human Research Ethics Committee (See Appendix 1 a & b). No incentives or inducements were made to attract any participants to the study.

2.4 RECRUITMENT OF PARTICIPANTS

Participants were recruited through the hospital mental health unit during the non-acute phase of their illness. At the time of recruitment to the study they were able to make an informed decision about the risks and benefits of participating in the study. Their ability to provide informed consent was assessed by the treatment team before they were asked to participate in the study.

2.4.1 Inclusion criteria for people with a personality disorder.

Consumers were invited to participate in the study if they were:

1. Aged 18 years or older and provided written informed consent.
2. Diagnosed with EUPD (ICD10 F60.3).
3. Had at least one admission to the mental health unit at the hospital for treatment of EUPD.
4. Able to read, understand and speak English to complete the survey and to be interviewed (if the person agrees to participate in the second stage of the study).

2.4.2 Inclusion criteria for people who were the control group for the quantitative component of the study.

Consumers were invited to participate in the study if they were:

1. Aged 18 years or older and provided written informed consent.
2. Currently treated at the hospital and diagnosed with a mental disorder other than personality disorder.
3. Had at least one admission to service for treatment of a mental health disorder.
4. Able to read, understand and speak English to complete the survey.

2.4.3 Informed consent

Consumers who met the inclusion criteria were provided with an information sheet that outlined the purpose of the study, what would be involved and the risks and benefits of participation (See Appendix 2a). Each person was given the

opportunity to ask questions related to the study before deciding if they wanted to participate. They signed a consent form (See Appendix 2b) and were given a copy (the researcher retained the original). By signing the consent form participants gave permission for the researcher to: 1) contact them to clarify any issues or to conduct a further interview if necessary and 2) to publish the findings of the study in reports and journal publications. Participants were assured that their confidentiality would be maintained and they would not be able to be identified in any of the publications.

Consumers were informed that participation in the study was voluntary and that withdrawal or refusal to participate had no adverse effect on any treatment they may receive from the service or that they would receive in the future.

2.4.4 Confidentiality and managing distress

Participants' confidentiality was ensured by de-identifying all data contained in all transcripts, reports and thesis. All participants were allocated a unique number that was used to de-identify them. Only the researcher and the supervisors have access to the data.

Prior to the research being undertaken it was identified that some participants may experience some level of distress as a result of being interviewed. This risk was reduced by the researcher's increased understanding of working with people with a EUPD. Professional counselling at the hospital where the research was conducted was arranged to offer to any participants in the event that they did experience a level of distress as a result of the interview. After each interview, a debriefing opportunity was given to each participant and if any distress was identified, the person was offered supportive professional follow-up. No patients required referral or follow up as a result of participating in this research.

2.5. PHASE ONE: QUANTITATIVE DATA COLLECTION

2.5.1 Research aim

The aim of the study was to evaluate consumer's level of satisfaction with hospital treatment that they received. Two groups of participants were recruited according to the inclusion criteria outlined in sections 2.4.1 and 2.4.2. One group had an ICD10 diagnosis of EUPD and the other group had an ICD10 diagnosis of a mental disorder other than personality disorder. Demographic data (date of birth, gender, social situation, employment status and psychological supports) and medical

history (diagnosis, number of admission and medication type dose and frequency) were collected from all participants.

All participants completed the modified Patient Satisfaction Questionnaire (18) – PSQ18 (See Appendix 3). The PSQ18 was originally designed to evaluate the views psychiatric inpatients had of their doctors and to measure their satisfaction with services in general. Permission to change the wording to reflect the mental health context was obtained from the authors of the scale (See Appendix 4). The term ‘Doctor[s]’ was changed to ‘mental health professional[s]’ and the term ‘medical care’ was changed to ‘mental health care’. The PSQ18 is a standardised self-report questionnaire that asked consumers to rate “How they felt about the mental health care that they had received”. The questionnaire utilised a 5 item Likert scale that ranged from 1 “strongly agree” to 5 “strongly disagree” (Barker & Orrell, 1999; Marshall & Hays, 1994). The PSQ18 is relatively short (18 questions) and takes approximately 10 minutes to complete (Marshall & Hays, 1994) and is unlikely to cause any distress or anxiety (Barker & Orrell, 1999). The PSQ-18 is a useful patient satisfaction questionnaire and has previously been used to assess the quality of mental health care (Barker & Orrell, 1999; Holikatti, Kar, Mishra, Shukla, Swain & Kar, 2012). The PSQ-18 has demonstrated validity and reliability since its introduction in 1994. It has good psychometric properties and effectively measures patient’s satisfaction (Barker & Orrell, 1999).

Data reported in Holikatti et al. (2012), where the composite PSQ-18 scores in individuals with mood disorders (major depressive disorders; depression (n=18) and anxiety disorders (n=22) were compared with psychotic disorders (Schizophrenia (n=10) and bipolar disorder (n=10) were used to determine the sample size. Reported mean composite PSQ-18 scores for mood disorders (n=40) and psychotic disorders (n=20) were M=17.6, SD 3.4 and M=20.7, SD1.0 respectively. The sample size estimate (d) for testing differences between two means, was calculated according to Cohen’s calculation $d = \mu_1 - \mu_2 / \sigma$ (Cohen, 1988); where $\mu_1 - \mu_2$ is the difference between the two population means and σ is the population standard deviation. Thus the effect size for the PSQ-18 was $d = 20.7 - 17.6 / 2.2 = 1.41$. Using Cohen’s ‘Power Tables for Effect Size d’ (Cohen, J., 1988, p55) it was estimated that an effect size of 1.4 at a significance level 0.05 and a power of 0.80 would require that at least 9 participants were needed in each group. In order to reject the null

hypothesis that “people with EPUD who accessed mental health services have the same level of satisfaction of mental health services as those who do other mental disorders” it was determined that a sample size of at least 18 participants was needed.

2.5.2 Analysis of the data

Data obtained from the PSQ-18 was entered into an excel database then exported in to SPSS Statistical Package Version 19.0 (IBM Corporation, 2010). Demographic data were analysed using descriptive statistics. Planned t-tests were used for continuous data and Chi Square analysis was used for categorical data. A p value of <0.05 was considered statistically significant.

2.6 PHASE TWO: QUALITATIVE RESEARCH

2.6.1 Steps undertaken by the researcher prior to commencing and during the study to ensure trustworthiness of data and credibility of findings

2.6.1.1 Researcher assumptions documented before commencing the study

The researcher made several assumptions before commencing the study that needed to be documented to prevent bias in data analysis. These were:

1. People with personality disorders do not always receive quality care when they present to public health services;
2. Health professionals often display negative attitudes towards people with personality disorders;
3. People with personality disorders’ perceptions and constructions of the social reality of accessing care during times of crisis influence how they experience the phenomenon;
4. A better understanding of the experience of help seeking of people with personality disorder will enhance mental health practice;
5. An enhanced understanding of the “lived experience” will facilitate better collaboration between health professionals, service providers, and people with personality disorders.

2.6.1.2 Bracketing researcher bias

It is important for qualitative researchers to have open mindedness and curiosity while they are investigating a subject area. It is also important to acknowledge what the researcher brings to the research situation and to reflect on how these influence

the research process (Tufford & Newman, 2012). Throughout this study, the researcher reflected on how his personality and knowledge of the subject area may bias, impact or compound the research outcomes. Prior to commencing data collection, he outlined his interest in the area and his personal assumptions about people who have a EUPD. He identified factors that could influence or impact on data collection when conducting interviews and the need for him to keep his professional and researcher roles separate. He reflected on feelings that may compromise his neutrality during data collection, analysis and write up of findings. He also reflected on his ability to deal with any bias, for example, if bias was identified the transcript may need recoding and further analysis. The above framework was adhered to during all aspects of this qualitative part of the research and was useful in assisting the researcher to achieve theoretical sensitivity and as a framework to solve problems that were encountered during the study.

2.6.1.3 Theoretical sensitivity

Corbin and Strauss (2015) describe theoretical sensitivity as the researcher being able to understand and give meaning to the data they have collected and through analysis of that data to be able to identify what is important and what is not (Corbin & Strauss, 2015). Theoretical sensitivity allows the researcher to challenge their assumptions, identify bias and to look beyond their current knowledge to find new ways of looking at the area under investigation. Identifying assumptions at the beginning of the research highlights for the researcher their view of the world and increases their self-awareness to eliminate bias that may be caused by these assumptions.

In noting these assumptions the researcher also identified that the multi-dimensional experience from the living with a EUPD had not been fully explored and by using mixed methods research the qualitative component would provide a more expansive view than that currently portrayed in the literature. This view built on the quantitative findings from the first phase of the study. The final literature search was not undertaken until after data collection and analysis was completed to find data relevant to emerging findings. Prior to commencing the first interview with a participant the researcher made the following memo in a journal:

While I have had over 30 years of experience as a mental health nurse and have worked most of this time with people who have a diagnosis of EUPD, conducting the interviews will be a new

experience for me as I am primarily a clinician. While I have my interview questions I am conscious that I must focus on being a researcher and not drop into the familiar role of being a clinician as this might compromise data collection and bias the findings. Hence, it is my first experience of having to consciously be aware of the need to separate my clinical skills from my role as a researcher. Documenting my assumptions prior to commencing the research which are outlined in 2.1.6.1 of this chapter was good as it allowed me to gain an awareness of the preconceived ideas I hold to this group of consumers and my need to not let these ideas impact on my interview or analysis of data in order to remain objective.

I will also need to draw a line between being a clinician and a researcher if the consumer becomes distressed during the interview as I would normally manage this distress in my role as a nurse. I will have to make sure as a researcher that the team is informed and allow them to respond to the person as clinicians. I will however, acknowledge the distress and the humaneness of the experience. While I am very experienced as a clinician I am very nervous as a new researcher and I hope this does not impact on my ability to obtain rich and authentic data.

Finally, during the course of this study, the researcher's assumptions and preconceived ideas were challenged and debated with colleagues at university in presentations prior to candidacy. His assumptions, data analysis and write up were reviewed by supervisors adding to his theoretical sensitivity. Their feedback assisted in clarification of the research process and opened new insights into the data being analysed.

2.6.1. 4 Trustworthiness and credibility of findings

Trustworthiness and credibility of findings were ensured by adhering closely to all stages of data collection, analysis and write up outlined in mixed methods research explanatory sequential study design and inductive content analysis as described by Elo and Kyngas (2008). Researcher team checks by supervisors of randomly selected interviews also enhanced the trustworthiness of findings

(Goldblatt, Karnieli-Miller, & Neumann, 2011). The trustworthiness, credibility and transferability of the data in this study were further ensured by selecting adult participants with a diagnosis of EUPD and comparisons made to the control group. Lastly, trustworthiness, credibility and transferability were demonstrated by setting the findings of this study within the context of current scientific literature.

2.6.2 Data collection

Qualitative data were collected using structured interviews conducted at a mutually agreed place and time for the participant. Thirteen consumers who participated in the first phase of the study agreed to be interviewed. An interview guide was used (See Appendix 5) for the session and to ensure consistency in allowing participants to describe their experiences (both positive and negative). The interviews were digitally recorded with the permission of the participant and the researcher completed field notes after each interview. Interviews were conducted in a quiet familiar room at the hospital. Participants were provided with water and a copy of the interview guide. They were informed that they could terminate the interview at any stage without penalty. Prior to each interview commencing, the researcher established rapport with the participant and described both their professional and researcher roles. The researcher also asked participants some general questions about their background, their social situation and current emotional state to ensure that the participants felt comfortable and able to participate in the structured interview.

The digital recorder was then turned on once the person had signed the consent form. The interviewer opened with the first question and allowed participants to respond and describe their experiences. The interview proceeded until the participant had no more information to share.

2.6.3 Data analysis

Digital recordings of each interview were transcribed verbatim into written data and field notes were compared to the transcribed interviews to ensure that all information was captured. Inductive content analysis as described by Elo and Kyngas (2008) was used to analyse data obtained from structured interviews. This method of analysis has been widely used in both nursing and psychological related research (West, Rudge, & Mapedzahama, 2016). Inductive content analysis includes a method of open coding, creating categories and abstraction (Elo & Kyngas, 2008). Open coding involves highlighting key words or phrases in the transcribed text to

identify headings or codes. Thus important parts of text are reduced to a single word or phrase that represents the meaning of each section of interview data (Alexander et al., 2016).

Data were read multiple times to ensure the trustworthiness of coding technique and to ensure that all data were coded. Coding sheets were then used to generate categories (Elo & Kyngas, 2008). Categories were formed by grouping together headings that had similar meaning or commonality, or deemed to belong together (West et al., 2016). The purpose of creating categories was to identify critical categories and their links to sub categories in the data (Elo & Kyngas, 2008). The coding process was checked by other members of the research team and any discrepancies were debated until consensus was reached. The final step of content analysis is to construct an abstracted meaning that brings categories into a framework that provides an overview of the interpretation of data (Curry, et al., 2009). The final stage of analysis (abstraction of data and the researcher's interpretation) is presented as findings in the results chapter of this thesis.

2.7 DATA STORAGE, MANAGEMENT, ACCESS AND DISPOSAL

Quantitative data were stored on the researcher's password protected computer in a locked office for analysis using SPSS Statistical Package Version 19.0 (IBM, 2010). The researcher and the supervisors were the only people with access to data related to this research study. Electronic data were maintained on a database that was password protected and could only be accessed by the researcher using a password protected login. Hard copies of surveys were stored in a locked cupboard in the researcher's office.

All interviews were transcribed verbatim and de-identified using a code. The code book was kept in a separate locked cupboard from the analysed transcripts in the researcher's office. Consent forms were stored separately to data collected using questionnaires and other research documents. Qualitative data management was completed manually as the researcher believed that this method best suited his analysis style and post it notes and palm cards were used during the analysis process to move data around and into finalised categories. At the completion of the study all data will be handed to supervisors and kept for seven years securely at the university and then destroyed in line with current university policy at that time.

2.8 SUMMARY

Mixed methods research was viewed as the most appropriate methodology to capture the total experience of people with EUPD accessing mental health care services. The research was conducted in two phases commencing with a quantitative questionnaire identifying consumer satisfaction and outcomes. This data informed the structured interview guide which was used in the second phase of the study to explore the lived experience of consumers.

CHAPTER 3

RESULTS

3.1 INTRODUCTION

Chapter 3 of this thesis details the results of Phase 1 (quantitative data) and Phase 2 (qualitative data) of this exploratory mixed methods research study. Data were collected between April 2014 and November 2015 at one metropolitan hospital in Western Australia. Eighty-two consumers participated in Phase 1 of the research and thirteen in Phase 2.

3.2 RESULTS OF PHASE ONE STUDY – QUANTITATIVE STUDY

3.2.1 Characteristics of Participants

All participants were recruited from the inpatient unit at the hospital and met the inclusion criteria and had at least one admission to the mental health unit at the service. Eighty-two people agreed to participate in the study. Of these 35 (42.7%) participants had an ICD 10 diagnosis of F60.3 EUPD and 47 (57.3%) who made up the control group were diagnosed with a mental disorder other than EUPD. The control included participants with substance use disorder (n=3), schizophrenia (n=1) bipolar disorder (n=3), unipolar depression (n=16), anorexia nervosa (n=1), anxiety disorder (n=2) and self-harm (overdose) (n=1). The EUPD group comprised 27 (77.1%) females and 8 males (22.9%) and the control group consisted of 27 males (57.5%) and 20 females (42.5%). The age range of the EUPD group was 19-62 years of age (mean 42) and the control group was 18-61 years of age (mean 33.5).

Of the total participants most were not in paid employment (n=50, 60.1%) and the majority had few social supports. Of the 82 participants 17 (20.7%) were followed up by a community mental health case manager, 7 (8.5%) got support from a peer support worker, 37 (45.1%) had regular contact with a counsellor and 14 (17.1%) received informal support from other people (friends and family). The majority of participants had an identified community based General Practitioner (n=76, 92.7%). See Table 3 for breakdown according to group.

Table 3: Demographic characteristics of participants with EUPD (n=35) and Controls (n=47)

		EUPD	Control	Total
Age (in years)	16-25	16	10	26
	26-35	6	7	13
	36-45	6	12	18
	46-55	5	11	16
	56-65	2	7	9
	Range	19-62	18-61	18-62
	Mean	42	33.47	37.11
Gender	Male	8	27	35
	Female	27	20	47
ICD 10 Diagnosis	EUPD	35		35
	Substance use		3	3
	Schizophrenia		1	1
	BPAD		3	3
	Depressive disorders		16	16
	Adjustment disorder		20	20
	Anorexia nervosa		1	1
	Anxiety disorder		2	2
	Self-harm (overdose)		1	1
Social situation	Living with Friends/Other	4	7	11
	Living Alone	15	16	31
	Living with Family	9	14	23
	Living in Relationship	4	6	10
	Homeless	3	4	7
Number of admissions	1	26	11	37
	2	8	2	10
	3	4	4	8
	4	2	3	5
	5	1	3	4
	>6	6	12	18
Employed	No	21	29	50
	Yes	14	18	32
MH Case Manager	No	26	39	65
	Yes	9	8	17
Peer support worker	No	32	43	75
	Yes	3	4	7
Counsellor	No	16	29	45
	Yes	19	18	37
General Practitioner	No	3	3	6
	Yes	32	44	76
Other	No	29	33	62
	Yes	4	10	14

To determine whether there were any within group differences Chi Square analyses were conducted with group entered as the dependent variable. Chi Square analyses revealed a group difference in gender (χ^2 (df 1) = 9.881, $p = 0.002$) but no other differences in participant characteristics (age (χ^2 (df 39) = 44.395, $p = 0.225$), number of admissions (χ^2 (df 5) = 21.125, $p = 0.174$), social situation (χ^2 (df 4) = 0.740, $p = 0.946$) employment status (χ^2 (df 1) = 0.024, $p = 0.528$), support from case manager (χ^2 (df 1) = 0.922, $p = 0.413$), support from peer support worker (χ^2 (df 1) = 0.00, $p = 1.00$), support from counsellor (χ^2 (df 1) = 2.071, $p = 0.182$), other supports (χ^2 (df 1) = 1.778, $p = 0.411$) and identified General Practitioner (χ^2 (df 1) = 0.142, $p = 0.513$).

3.2.2 Survey Results

The Short Form Patient Satisfaction Questionnaire (PSQ-18) requires that participants indicate their agreement or disagreement to eighteen statements according to a 5 point Likert Scale where 1 = strongly agree, 2= agree, 3 = uncertain, 4= disagree and 5= strongly disagree. The PSQ-18 is designed so that some items are worded so that agreement reflects satisfaction with the mental health care they received while others are worded so that agreement reflects dissatisfaction with mental health services received. For the analysis the raw data was rescored so that high scores reflected satisfaction with mental health services and low scores dissatisfaction according to the scoring provided by the authors. The items were thus scored from 5= satisfaction and 1 = dissatisfaction. Because for some items, the expected frequencies were less than 5 and they violated the assumptions of a Chi Square analysis, it was necessary to combine '1= strongly agree with 2= agree', and '4= disagree with 5 = strongly disagree' scores to form a 3 point Likert scale; where 3= satisfied with mental health services, 2 = uncertain and 1= dissatisfied with mental health services.

To obtain the subscale scores items 3 and 17 are combined to provide a 'general satisfaction' score, items 2, 4, 6 and 14 were combined to provide 'technical quality', items 10 and 11 'interpersonal manner'; 1 and 13 'communication'; 5 and 7 'financial aspects'; 12 and 15 'time spent with mental health professional'; and items 8, 9, 16 and 18 'accessibility and convenience'.

The results for the item scores are provided in Table 4. There were significant group differences relating to the time spent by mental health professionals with more

than a third of the EUPD group indicating that mental health professionals were in too much of a hurry when they treated them compared to two thirds of the control group who indicated that this was not the case for them (X^2 (df 2) = 6.501, $p=0.039$). There were also group differences in the response to the statement that the mental health professional's office had everything needed to provide complete mental health care with more than 25%, of the control group indicating agreement compared with less than 10% of the EUPD group (X^2 (df 2) = 5.155, $p=0.076$, trend). PSQ-18 scores were also analysed according to gender. When Chi square analyses were performed on iPSQ-18 item and subscale score with gender as the dependent variable there were no significant differences $p>0.05$ (Chi Square).

Table 4: Results of Patient Satisfaction Questionnaire (PSQ-18) by group EUPD (n=35) and Controls (n=47)

		Personality Disorder n=34 %	Control n=47 %	Total n=81 %	X2	df	p
1. Mental health professionals are good at explaining the reason for medical tests.	Agree	5	6	11	0.341	2	0.843
	Undecided	3	6	9			
	Disagree	26	35	61			
2. I think my mental health professional's office has everything needed to provide complete mental health care.	Agree	3	12	15	5.155	2	0.076 [#]
	Undecided	7	4	11			
	Disagree	24	31	55			
3. The mental health care I have been receiving is just about perfect.	Agree	5	6	11	1.934	2	0.38
	Undecided	9	7	16			
	Disagree	20	34	54			
4. Sometimes mental health professionals make me wonder if their diagnosis is correct.	Agree	15	19	34	0.112	2	0.946
	Undecided	6	9	15			
	Disagree	13	19	32			

5. I feel confident that I can get the mental health care I need without being set back financially.	Agree	8	23.5	10	21.3	18	22.2	1.122	2	0.571
	Undecided	7	20.6	6	12.8	13	16.0			
	Disagree	19	55.9	31	66.0	50	61.7			
6. When I go for mental health care, they are careful to check everything when treating and examining me.	Agree	5	14.7	7	14.9	12	14.8	0.012	2	0.994
	Undecided	6	17.6	9	19.1	15	18.5			
	Disagree	22	64.7	31	66.0	53	65.4			
7. I have to pay for more of my mental health care than I can afford.	Agree	8	23.5	12	25.5	20	24.7	0.826	2	0.662
	Undecided	6	17.6	5	10.6	11	13.6			
	Disagree	20	58.8	30	63.8	50	61.7			
8. I have easy access to the mental health specialists I need.	Agree	8	23.5	6	12.8	14	17.3	2.351	2	0.309
	Undecided	6	17.6	6	12.8	12	14.8			
	Disagree	20	58.8	35	74.5	55	67.9			
9. Where I get mental health care, people have to wait too long for emergency treatment.	Agree	14	41.2	15	31.9	29	35.8	1.307	2	0.52
	Undecided	9	26.5	11	23.4	20	24.7			
	Disagree	11	32.4	21	44.7	32	39.5			
10. Mental health professionals act too businesslike and impersonal toward me.	Agree	6	17.6	8	17.0	14	17.3	0.014	2	0.993
	Undecided	6	17.6	8	17.0	14	17.3			
	Disagree	22	64.7	31	66.0	53	65.4			

11. My mental health professionals treat me in a very friendly and courteous manner.	Agree	0	0.0	3	6.4	3	3.7	2.528	2	0.282
	Undecided	4	11.8	7	14.9	11	13.6			
	Disagree	30	88.2	37	78.7	67	82.7			
12. Those who provide my mental health care sometimes hurry too much when they treat me.	Agree	12	35.3	11	23.4	23	28.4	6.501	2	0.039*
	Undecided	8	23.5	4	8.5	12	14.8			
	Disagree	14	41.2	32	68.1	46	56.8			
13. Mental health professionals sometimes ignore what I tell them.	Agree	12	35.3	14	29.8	26	32.1	0.555	2	0.758
	Undecided	4	11.8	8	17.0	12	14.8			
	Disagree	18	52.9	25	53.2	43	53.1			
14. I have some doubts about the ability of the mental health professionals who treat me.	Agree	8	23.5	11	23.4	19	23.5	0.245	2	0.885
	Undecided	4	11.8	4	8.5	8	9.9			
	Disagree	22	64.7	32	68.1	54	66.7			
15. Mental health professionals usually spend plenty of time with me.	Agree	9	26.5	7	14.9	16	19.8	1.73	2	0.421
	Undecided	3	8.8	4	8.5	7	8.6			
	Disagree	22	64.7	36	76.6	58	71.6			
16. I find it hard to get an appointment for mental health care right away.	Agree	18	52.9	17	36.2	35	43.2	2.863	2	0.239
	Undecided	4	11.8	11	23.4	15	18.5			
	Disagree	12	35.3	19	40.4	31	38.3			

17. I am dissatisfied with some things about the mental health care I receive.	Agree	13	38.2	16	34.0	29	35.8	1.625	2	0.444
	Undecided	2	5.9	7	14.9	9	11.1			
	Disagree	19	55.9	24	51.1	43	53.1			
18. I am able to access mental health care whenever I need it.	Agree	9	26.5	10	21.3	19	23.5	2.397	2	0.302
	Undecided	8	23.5	6	12.8	14	17.3			
	Disagree	17	50.0	31	66.0	48	59.3			

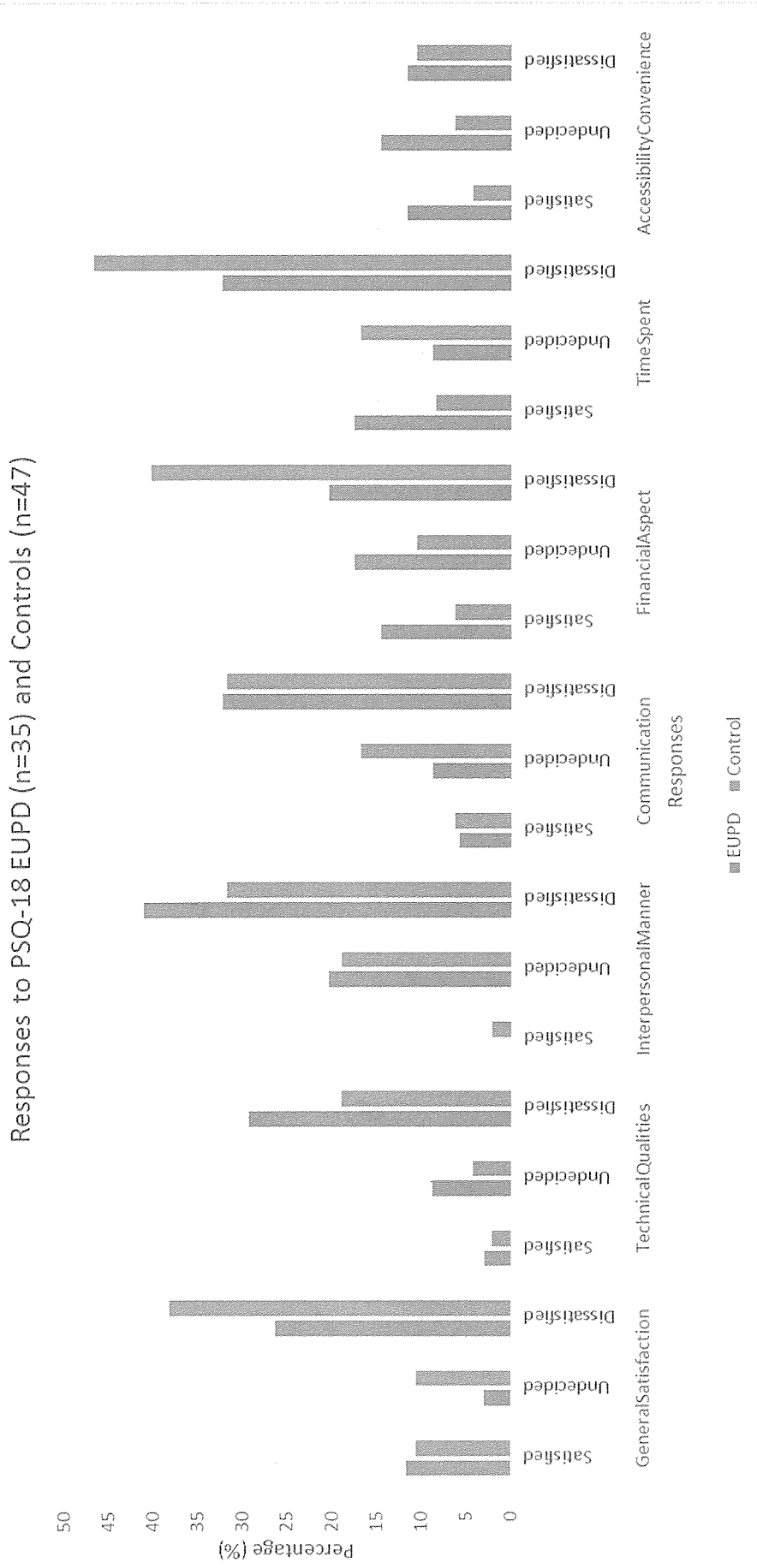
*Significant at $p < .05$, #significant at $p < .10$

3.2.2.1 General answers to questions by both groups

In general, most respondents, 60% of both EUPD and controls indicated dissatisfaction about mental health services provided, with controls indicating higher levels of dissatisfaction (EUPD 25% and controls 37%). The EUPD group reported the greatest dissatisfaction with technical qualities, communication and interpersonal manner of the mental health professionals that provided care. The control group reported their greatest dissatisfaction as being time spent by health professionals and the financial aspects of their care. This group also reported high levels of dissatisfaction with the communication and interpersonal manner of the health professionals. However, none of these group differences were statistically significant ($p>0.05$).

Specific between group differences on each of the subscales of the survey are outlined in Figure 1.

Figure 1: Results of Patient Satisfaction Questionnaire (PSQ-18) subscales by group EUPD (n=35) and Controls (n=47)



3.2.2.2 Medications

Of the 82 participants, 30 were not taking any medication. Of those who were taking medication 28 were taking a single medication with the remaining 24 taking two or more medications. See Table 5, for the frequency of medications taken according to group. There were no statistical group differences in the number of medications taken (Chi Square, $p>0.05$).

Table 5: Number of medications taken by participants with EUPD (n=35) and Controls (n=47).

Number of medications	Control	EUPD	Total
0	16	14	30
1	14	14	28
2	6	4	10
3	4	1	5
5	2	1	3
6	1	1	2
7	2	0	2
8	2	0	2

Medications were grouped according to the World Health Organisation's Anatomical Therapeutic Chemical (ATC) classification system (WHO Collaborating Centre for Drug Statistics Methodology, 2016). The most common type of medications taken were antipsychotics (n= 40) and antidepressants (n=25). There were no statistical differences between the number of medications taken in each group (Chi Square $p>0.05$). Medications taken according to group are outlined in Table 6.

Table 6: Medications prescribed by name and class for participants with EUPD (n=35) and Controls (n=47)

Class	Medication name	Control	EUPD	Totals
Analgesics	Paracetamol	4	1	5
	Aspirin	2	0	2
	<i>Total</i>	6	1	7
Antidepressants	Citalopram	3	1	4
	Desvenlafaxine	4	1	5
	Escitalopram	1	1	2
	Fluoxetine	1	1	2

Class	Medication name	Control	EUPD	Totals
	Fluvoxamine	0	1	1
	Mirtazapine	1	0	1
	Paroxetine	4	0	4
	Prothiaden	1	0	1
	Sertraline	3	0	3
	Venlafaxine	1	1	2
	<i>Total</i>	<i>19</i>	<i>6</i>	<i>25</i>
Antiepileptic's	Carbamazepine	1	0	1
	Clonazepam	1	0	1
	Lacosamide	1	0	1
	Lamotrigine	3	1	4
	Pregabalin	1	1	2
	Sodium Valporate	1	1	2
	Topiramate	2	0	2
	<i>Total</i>	<i>10</i>	<i>3</i>	<i>13</i>
Anti-glaucoma	Iboplope	0	1	1
Antihypertensive	Prazosin	1	0	1
Anti-inflammatory	Ibuprofen	2	0	2
	Naproxen	1	0	1
	Predonisolone	1	0	1
	<i>Total</i>	<i>4</i>	<i>0</i>	<i>4</i>
Antipsychotics	Lithium Carbonate	2	0	2
	Olanzapine	11	11	22
	Quetiapine	8	6	14
	Risperidone	2	0	2
	<i>Total</i>	<i>23</i>	<i>17</i>	<i>40</i>
Anxiolytics	Buspirone	1	0	1
	Diazepam	1	2	3
	Lorazepam	2	1	3
	<i>Total</i>	<i>4</i>	<i>3</i>	<i>7</i>
Blood Glucose lowering drug	Metformin	0	1	1
Corticosteroids	Fluticasone	0	1	1
Diuretics	Furosemide	1	0	1
Drugs for constipation	Docusate	1	0	1
Drugs for Peptic Ulcer (H2 agonist)	Ranitidine	1	0	1
	Omeprazole	1	0	1
	Pantoprazole	0	1	1
	<i>Total</i>	<i>2</i>	<i>1</i>	<i>3</i>
Drugs used in benign prostatic hypertrophy	Dutasteride	1	0	1
Drugs used in opioid dependence	Methadone	1	0	1

Class	Medication name	Control	EUPD	Totals
Hypnotic and sedatives	Nitrazepam	1	0	1
	Temazepam	3	0	3
	<i>Total</i>	<i>4</i>	<i>0</i>	<i>4</i>
Lipid modifying agent	Simvastatin	1	0	1
Opioids	Tramadol	1	0	1
	Oxycodine	2	0	2
	<i>Total</i>	<i>3</i>	<i>0</i>	<i>3</i>
Psychostimulant	Dexamphetamine	0	1	1
Thyroid hormone	Thyroxine	1	0	1
Vitamin B1	Thiamine	1	1	2
Vitamin K Antagonist	Warfarin	1	0	1

3.3 RESULTS OF PHASE TWO STUDY: QUALITATIVE STUDY

3.3.1 Introduction

An integral part of this mixed method research project has been the opportunity to combine both qualitative and quantitative data collection methods to more fully explore meanings of treatment and management for people living with EUPD. The qualitative data collection illustrated the individual personal journey of each person who was willing to be part of this research whilst the quantitative data expressed the prevalence of the opinions of the participants to their treatment options. It also compared the opinions of people diagnosed with a EUPD with those without EUPD who were treated in the hospital.

3.3.2 Results

Thirteen people originally agreed to participate in this research after reading the information sheet and speaking with the researcher. However, one person subsequently withdrew from the interview and their data was destroyed in line with the process outlined in the ethics application for this study. Another participant's interview was also found to be unusable for technical reasons as the recording was unable to be transcribed accurately and so was discarded so no misinterpretations of what was said would occur. This data was also destroyed. The data presented in this chapter is the analysis from interviews conducted with eleven people. Five participants were female (age range 20-60 years) and six were male (age range 20-

40 years). The transcribed data were coded and the major categories identified within the questions posed.

3.3.2.1 Question 1: What are the positive aspects of the care you have received when treated for your personality disorder?

A major category evolving from Question 1 of the interviews was identified as: Consistency and commitment of staff with the sub categories: (a) skill development (b) validation of feelings which emerged during analysis.

Consistency and commitment of the staff

The interview process gave the participants an opportunity to explain their need during times of crisis for a safe place. This was achieved by regular contact with the same staff that knew them and their history. One participant described the experience of being heard, validated and given a safety net because people knew them and understood what they wanted when they presented to hospital: *“I was angry and suicidal but she [the nurse] started talking to me about my art and how it made me feel and I started turning from that internal hate to just this bliss and joy [feeling happy about myself and in control] and I walked out [of the ED] happy”* (P5). Coming to somewhere like the hospital, where people provided support and emotional care was important to participants. Friends and a social network were not the same and participants identified the attributes of staff that they valued. These attributes made them feel safe and allowed them to talk through the issues they were experiencing: *“The nurses are sort of like that safety net, the shock absorbers”* (P3). Another participant explained their sense of comfort when admitted to the mental health unit as the staff understood what people with EUPD did when in crisis and were still accepting of them: *“everyone [staff] here understand and they have empathy and they know why we do the things we do and how you react to certain situations and they accept that”* (P4). Similarly, the next participant described how this understanding fostered positive attitudes towards the staff that were caring for them: *“I have got some really good workers [health professionals] around me at the moment [while in hospital] which has been really good”* (P10). Yet another described the ward environment and the staff response as very positive and therefore, effective for their wellbeing: *“There was a lot of good will and good intent [from staff]”* (P3).

Not all responses from participants towards staff were positive, particularly in the area of continuity of care. They spoke about the importance of staff knowing them as a person and what they had been through. This was often lacking due to staff turnover and this meant that they had to keep retelling their story to each new health professional: “*there is no continuity of care so every new person you see you have to rehash [retell your story of what has happened to you], rehash and it is not good to keep rehashing the negatives*” (P8). Those that had been consumers at the hospital for a period of time described a different experience when they were enrolled in the “Changes Program” (Changing Habitual Attitudes by Nurturing Growth, Education and Self Responsibility Program) that was run at the hospital in the 1990’s. They found the program very beneficial as: “*there was a safety in the continuity [of care provided]*” (P8) as the same health professionals were involved in the program and the care to the participant was consistent over a period of time. The Changes Program formally the DHP (Day Hospital Program) was located on the hospital campus and provided a specialist outpatient treatment program for 28 years. The Changes Program was a group therapy treatment and the change agents were a multidisciplinary team of practitioners and the program involved immersing the consumer in a full-time structured group psychotherapy program over a 12-month period. Nine groups were run each week, each focusing on areas of the consumer’s functioning that needed to be changed (Egan, Smith, Lumley, & Speldewinde, 2000). People worked together to help one another to overcome old, ineffective patterns of living and enable them to instead start to substitute new, healthy and effective ways of being in the world. The very supportive nature of the milieu of the Changes Program empowered the consumer to attempt initial change, then the positive support of the milieu served to re-enforce the change process by ongoing interactions with the group (Egan et al, 2000).

a) Sub category: Skill development

Skill development was the first subcategory of *consistency and commitment of the staff*. Participants valued the opportunity to develop new skills to manage their problems and to practice those skills. Consistency of staff also meant that participants were given the opportunity to actively participate and practice the skills they were acquiring when admitted to the unit: “*There was a high expectation on us*

to play our part and not waste people's time "(P8). Working with the person to enable them to look to the future with ways of addressing situations in the here and now rather than sliding back into old patterns of behaviour was useful to the next participant: *"There is a need to focus on how far I had come and what I can do as opposed to what I can't do"* (P8). Another participant explained how the skills they learnt enabled them to shift their focus *"It feels good afterwards [when they had learnt new skills] to not follow that patterning of shame, hurt and isolation and actually going in and looking at it in a different way [because of the new skills learnt]"* (P5).

b) Sub category: Validation of feelings

Validation of feelings was the second sub category of *consistency and commitment of the staff*. The attitudes displayed by staff impacted greatly on participants' level of wellbeing and the development of any therapeutic alliance when they sought help from health professionals. If staff displayed a positive and respectful attitude this was helpful and appreciated by participants as one person explained *"I was always treated as though I had a problem [by staff with poor attitudes], now I was actually being listened to I was being treated like a human being. I wasn't treated like I was an idiot; [like] I was a waste of time"* (P7). Being treated with respect and regard like a normal person should be the norm not the exception when people with personality disorders access health services during times of crisis. The personality of individual staff members was so important to the development of a good therapeutic alliance and participants were very open in their expressions of both the positive aspects: *"You called a spade a spade"* (P7) and their negative responses: *"for me already feeling unworthy to be shoved in and out the door and back again [not treated well] said I am not worth the effort"* (P7).

For participants being given a diagnosis of personality disorder by health professionals in a manner they could understand was considered *"a double edged sword, being confronted [by their illness]"* but *"bringing relief [that they knew what was wrong]"* (P3). Without an understanding of what was wrong they experienced a *"huge sense of fear and uncertainty in some respects, and burden"* (P3).

In summary, the attitudes displayed by health professionals along with consistency in staff when accessing treatment at the hospital were identified by participants as positive factors that enhanced their capacity to cope during times of

crisis. They also spoke of being involved in formal programs that allowed them to develop new skills to address the issues that they confronted on a daily basis as helpful in moving forward to live productively in the community. Being seen as a person and not just being labelled as having a personality disorder was important as they felt valued and part of the treatment team. This is consistent with recovery models of care and of the need to empower and involve the consumer in decisions about the management of their illness.

3.3.2.2 Question 2: What are the negative aspects of the care you received when treated for your personality disorder?

The category identified for question two revolved around participants *not getting needs met* when they presented for help from health professionals. Sub-categories for *not getting needs met* included (a) lack of interest and (b) judgement. The category was about while participants were the receivers of care they were often alienated by health professionals and were not included in a true consultative process when it came to individual treatment they required and received. This was mainly due to the prevailing negative attitudes displayed towards them by members of the treating team. One participant expressed their concern and anguish about the lack of knowledge and care and how they were dismissed and treated poorly by health professionals when they sought help: *“People don’t know: what is the best treatment for patients with borderline personality? They don’t have a XXXXXXXX clue (P1).* They continued to divulge how: *“two of [their] friends had died because they did not get proper treatment, in fact they killed themselves. People are not looked after enough [by health professionals when they present in crisis]” (P1).*

Participants talked about their sense of being different from most health consumers accessing services: *“a person with a personality disorder has different needs” (P2)* and how that impacted on their ability to access and engage with health professionals: *“Like how can someone be on the same page if you're not even reading from the same book?” (P3).* This type of response reinforced the negative view held towards them by many health professionals and other people in the community. This also made them believe that their treatment was not that important to others. It also confirmed that the management plans that had been developed for them to implement during times of crisis were not honoured when they accessed the health system. Therefore, their crisis management was subject to question and often

seen as not coping in the community as the following participant explained *“I felt like a test subject that people can work on. In the past I haven't benefitted from anti-depressants but still they put me on them [and do not ask if they are helpful]”* (P1). Similarly, using medication to try to fix the person's problem instead of other interventions was not viewed by participants as helpful or effective: *“throwing anti-psychotics and mood-stabilisers at me has really made absolutely no difference in terms of getting to the core of the issues at hand”* (P2).

Therapy in some form has always been considered by health professionals as essential elements for mental health recovery, and for people with personality disorder cognitive behaviour therapy (CBT) has often been the preferred choice of therapy for many clinicians. However, a participant disagreed: *“CBT for me was an absolute waste of time”* (P7). Likewise, finding the therapy of best fit eluded the next participant who stated: *“I need a very specific brand of behaviour therapy, it's not CBT, it's not DBT [dialectical behavioural therapy], it's schema therapy, behaviour can be learnt and [so] it can be unlearnt”* (P2).

a) Sub category: Lack of interest

The first sub category of *not getting needs met* identified in the data was *lack of interest*. Participants discussed at length their disappointment with the *lack of interest* staff showed towards them and the negative attitudes displayed that made them feel both inadequate and disconnected. *“[The] psychologist wasn't even invested and didn't talk the whole time”* (P1). Staff also demonstrated a *lack of interest* in finding out from participants what strengths they had to assist them to develop strategies to more effectively manage, as a participant explained: *“I have used coping strategies for the last 35 years and they [staff] were not willing to engage with me at that level; they treated me like a kid”* (P4). Participants described their frustration with their experience of accessing mental health services when in crisis, believing their management plan would be honoured: *“it is frustrating that you still have to try and explain to six different health professionals that a crisis care plan [as part of the person's management in the community was] is in place and should [be honoured to allow them to] get a guaranteed bed”* (P1). In regards to treatment and management of personality disorders there has to be a ready acceptance that it is a real illness in all its aspects. When people do not feel that they have this acceptance they experience rejection as the following participant explained:

“I think that some of the staff possibly don't believe in personality disorder [that it is not a real illness] and think that you are just being a drama queen [putting it on]” (P7).

b) Sub category: Judgement

The second sub category of *not getting needs met* was titled *judgement*. Participants talked about their understanding of the general consensus of people towards the diagnosis of personality disorder and the judgement that went with this consensus. As a result people with EUPD were described as: *“selfish, narcissistic, self-interested, mean, nasty, cold and psychopathic”* (P5). This was reiterated in judgements made about participants from staff they had encountered and the derogatory comments directed towards them like *“Stop acting like a spoilt child”* (P2). Another participant was told they were *“unpredictable”* (P4). *Judgement* towards them was also felt from family, friends and participants themselves around the diagnosis of personality disorder: *“I think the word validation is big, and invalidation has never entered my realm until I was [diagnosed with] borderline [personality disorder]. I am so invalidated in my life”* (P5). Participants talked about being alienated and stigmatised because of their diagnosis and because of the lack of understanding about personality disorder generally in the community. One participant described the anxiety they experienced and the insecurity associated with having to move out of their accommodation because of their illness: *“my housemates want me to move out because they don't think that they can deal with someone with a mental health problem”* (P4).

Being diagnosed with EUPD can mean that you are categorised and that makes you *“so alienated people don't know what to do with you”* (P1). This can lead to self-doubt and feelings of worthlessness as the next participant expressed: *“I presume that I'm not worthy of their time or friendship”* (P2). In summary, participants spoke of *not getting their needs met* when they accessed health services and being made to feel that they were not worthy of receiving care during times of crisis. The judgements made about them by health professionals, was also experienced from others in the community setting. This impacted on both their ability to live productively in the community setting and on their recovery journey.

3.3.2.3 *Question three: What aspects of care have aided your recovery when treated for your personality disorder?*

The category for question three was called: *having hope for recovery*. Participants spoke with hope for their future and acknowledged that it would require continued input from both themselves and mental health professionals: *“I definitely believe that I can recover from this but I need proper and longstanding and consistent follow up”* (P2). Idealistically, one participant wished for: *“a little village where you could have your own room.... you could still go to work... but if you needed nursing care it was still there and you could take a bit of time out from your domestic life and rest up a little bit”* (P3). Staff acceptance and understanding were appreciated and one participant explained how they had noticed a changing attitudes of some staff towards them which made the admission to the mental health unit more accessible: *“The last time I came in they [staff] encouraged me and I hadn't really realised that I was improving before they said that”* (P4). In the same way, some staff seen as taking time to engage and develop a therapeutic alliance was highlighted by the following participant who explained: *“having somebody sit down and say you do this and explain what that is was a bit of a light-bulb moment”* (P3). Another participant related how they had been provided with assistance and solutions of self-soothing patterns to reduce stress for ongoing issues to aid recovery: *“I am getting answers for the anxiety, for the anger”* (P6).

Other people who were diagnosed with EUPD were also viewed as important supports for some of the participants: *“Now I have got a really good set of mates that are all the same and we all really get each other because we have all got the same sort of crazy”* (P5). The same participant went on to say: *“Communicating and being able to be validated in myself, that's has been the best thing, the assertiveness”* (P5).

Participants who had a long standing relationship with the hospital where this study was conducted identified that the long term treatment Changes Program they participated in as outpatients during the 1990s was the most useful and effective treatment intervention as it enabled them to practice acquired skills from the variety of groups. This program no longer exists and many of the participants expressed their dismay that it had ceased. They were frustrated with the current variety of short lived programmes which they believed were inadequate and did not meet their needs: *“To get the same quality today [as provided by the Changes Program] you would*

have to go to five places, five different care units” (P9). Participants talked about “consistency of facilitatorseverybody had the opportunity to learn, opportunity to truly learn and practise the skills” (P8).

In summary, participants reported that they had noticed a change in the way they were treated when they presented for help during times of crisis and some of these approaches made them feel valued and well treated and were helpful to them. However, the programs needed to bring about long term change for them personally did not currently exist even though some participants has been involved with a program they found beneficial during the 1990s.

3.4 OVERALL SUMMARY OF FINDINGS (QUANTITATIVE AND QUALITATIVE)

The findings demonstrate that consumers’ experiences when presenting for care are dependent on the individual responses of clinicians that they encounter. When they presented in crisis negative encounters did little to improve their mental wellbeing and added additional stress and trauma to the illness experience. Much of the feedback from consumers in this mixed methods research was based on the quality of communication and on the willingness of the health profession to validate their illness as equal to any other person presenting to the ED or inpatient setting. Changes in health funding resulted in the cutting of programs judged by consumers who had a longer engagement with the health service as beneficial to their mental health outcomes. The results will now be discussed in detail in Chapter 4 of this thesis.

CHAPTER 4

DISCUSSION

4.1 INTRODUCTION

This chapter discusses the results of the mixed methods research study on the lived experience of people with EUPD. Similarities deduced across Phase I (quantitative) and Phase II (qualitative) findings affirm the use of a mixed methods approach in this research. The similarities of findings across both phases also enhanced the trustworthiness and credibility of findings and allowed for the consistency in the totality of results to be deliberated on in this discussion chapter.

4.2 DEMOGRAPHIC FINDINGS

As the age range of participants diagnosed with EUPD was 19 to 62 years with a mean of 42 years they had a range of experiences related to their exposure to the health care system. This age distribution was extremely valuable in Phase II (qualitative) as participants with multiple admissions over a number of years were able to reflect on changes that had occurred in treatment. They were also able to reflect on how these changes impacted on their current level of mental wellbeing. Moreover, their experiences were able to be compared to younger participants who were newer recipients of health care. For example, the older participants in Phase II spoke positively of the Changes Program that was established at the hospital for many years and how it had benefited their mental wellbeing. They viewed such programs as helpful to learn new coping mechanisms and assist their recovery. The program also provided them with support over a 12 month period to develop coping strategies that made them more confident to live in the community and practice their newly developed patterns of behaviour. As a result of economic cutbacks in health the Changes Program no longer exists and the current lack of similar programs for people with EUPD was highlighted by all participants. This was further compounded by the absence of a community mental health team at the service meaning that consumers' avenues to support following discharge were through private health care services or the ED when a crisis occurred as part of their agreed discharge crisis management plan (Department of Psychiatry; Royal Perth Hospital, 2013). While some community programs are run by non-government organisations to support

people with EUPD in the community setting, they are difficult to access and have a limited numbers of places. Due to the lack of community mental health teams at the service, many of the participants in this study were being case managed by community mental health team from other services in nearby locations. This added to the complexity of obtaining quality well-coordinated care for this group of consumers.

More females 27 (77.1%) than males 8 (22.9%) were recruited to phase I (quantitative) of the study. The PSQ-18 was analysed, with gender as a dependent variable; there were no statistically significant gender differences in any of the PSQ-18 results. In phase II (qualitative), to manage any potential gender bias in the qualitative results both males and females were actively recruited. While gender bias was not identified in the results, it is still important to discuss apparent gender ratio differences present in Phase I (quantitative) participants.

4.3 GENDER RATIO DIFFERENCES

As previously stated, it is well recognised that women with personality disorders present to the ED more often than men because they are more willing to ask for help to address their mental health needs (Coid et al., 2006). This also means that they are more likely to attract an ICD 10 diagnosis of EUPD (Swartz et al., 1990) at a rate that is two to three times higher than in men. The 70% to 30% ratio is suggestive that diagnostic differences exist based on gender (Lieb et al., 2004). Another explanation regarding the gender ratio difference in people with personality disorders is the difficulty this group has in processing human emotions (Snowden et al., 2013). For example, those diagnosed with EUPD, more commonly females, have difficulty processing facial emotions (Robin et al., 2012) and therefore more readily misinterpret the intentions of others. This leads to them becoming hypersensitive to emotional expression and precipitates impulsivity, such as, self-harming behaviours (Martin & Thomas, 2015). As a result, they frequently present to health care providers in crisis due to the distress they are experiencing.

On the other hand, males diagnosed with a personality disorder are more likely to experience difficulty in processing human emotions in the area of recognising and detecting fear, and respond aggressively. Consequently, they tend to more readily attract diagnoses such as antisocial personality disorder rather than EUPD (Snowden et al., 2013). Men also seek more destructive methods of self-harm to address the

level of personal distress they are experiencing (Harrison & Henley, 2014). For that reason, men with personality disorders, more commonly present to substance-abuse treatment programs, or are often imprisoned (Sansone & Sansone, 2011).

Consequently, prisoners are 10 times more likely to have an antisocial personality disorder than the general population (Fazel & Danesh, 2002).

Finally, in the discussion on gender ratio differences, recent descriptions by (Sansone & Sansone, 2011) suggested that it is the frequency of presentation that accounts for the gender bias ascribed to women. As females' self-harming behaviour is less lethal than males they are more likely to have multiple presentations to the ED. However, the gender ratio difference debate continues, as ICD 10 diagnostic classification of EUPD (F60.3) includes aggressive, borderline and explosive types which can be attributed to both genders (World Health Organization, 2010).

4.4 LEVEL OF SUPPORT

The difficulty that people diagnosed with EUPD have in processing human emotions (Snowden et al., 2013) may also impact on the support network available to them in their everyday lives. They readily misinterpret every day interactions with those around them (Martin & Thomas, 2015), and as a result, people who were once willing to provide support may withdraw that support. This lack of support is exacerbated during times of crisis when they experience high levels of personal distress. Mental health consumers also demonstrate self-stigmatising behaviours that increase their feelings of worthlessness (Livingston & Boyd, 2010) and this may further exclude them from potential support systems. Finally, Krawitz and Watson (2000) report that 70% of women with EUPD had reported being a victim of sexual abuse and this may make females less willing to interact with others as they have previously been let down by those they trusted.

The findings of Phase I (quantitative) show that a lack of support networks was common for EUPD participants with 50 (61%) not working and 17 (48.6%) not living with their families or significant others. The lack of family/significant other support networks reinforces the importance for this group to have formal crisis management plans or programs such as the Changes Program to provide structured gateways to professional support.

4.5 ACCESSING PROFESSIONAL SUPPORT

The lack of social support in the community also reinforced the importance of health professionals displaying positive attitudes towards people with EUPD when they present to ED in crisis. This group is extremely vulnerable to any negative responses directed towards them. The literature reports that health professionals hold negative attitudes towards people with EUPD (Veysey, 2014), and interactions with them do not alter these attitudes (Aviram et al., 2006; Friedel, 2004). This premise was also supported by the Phase I (quantitative) findings that report two statistically significant between groups difference where consumers with EUPD agreed that mental health professionals were “*more hurried when they provided treatment to them*” and disagreed that “*the mental health professional’s office had everything needed to provide complete mental health care*”. The statistically significant differences in responses between the EUPD and control group to both of the above statements may have occurred as a result of health professionals attitudes towards them. While all people with mental disorders are known to experience stigma (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012b; Wrigley, Jackson, Judd, & Komiti, 2005) it appears that having a diagnosis of EUPD adds a further dimension to the stigmatising experience (Commons Treloar & Lewis, 2008; Livingston & Boyd, 2010; Rao et al., 2009). This is of concern, as this finding related to interactions with mental health professionals who have specialist training and have chosen to work with this group of health consumers. These differences were also identified by Rao et al. (2009) who found that health professionals’ attitudes towards people diagnosed with mental disorders were influenced by the person’s specific psychiatric diagnosis.

Participant responses to these two statements may also have been due to participants’ self-stigmatising (Livingston & Boyd, 2010) or to the difficulty this group experience in processing human emotions (Snowden et al., 2013). Any misinterpretations of health professionals’ communication with them may have increased their hypersensitivity to the situation and accounted for between groups difference on these questions on the survey. Whatever the reasons for these differences, health professionals need to reflect on their communication styles when working with consumers with EUPD and be aware of the potential for counter transference of negative attitudes onto care delivery. They must also acknowledge that this group have a long history of being ostracised by society, have high levels of

impulsivity and are hypersensitive which leads to multiple opportunities for miscommunications to occur (Tyrer, Reed, & Crawford, 2015).

On a positive note, participants in Phase II (qualitative) provided evidence of experiencing a shift towards more positive attitudes by health professionals in the ED towards them when they presented in crisis, but this change remained at the individual health professional's level. Another positive aspect identified in Phase I (quantitative) findings was that 32 (91.4%) of participants with EUPD stated that they had an identified GP. They were also likely to make contact with the GP when a crisis occurs (Liotti, Farina, & Cortina, 2008). This rate of engagement with GPs is consistent with the findings in the literature with Liotti et al. (2008) suggesting this group are more likely to visit their GP and to report psychosocial impairment compared to the general population. However, not all GPs feel competent to manage their health care needs (Thornicroft, Rose, & Kassam, 2007) or believe they have the time to allocate to this group of health consumers. Their level of awareness of possible countertransference issues arising from any negative attitudes held towards people diagnosed with EUPD may also impact on their ability to work effectively with them during times of crisis (Lubman, Hall, Pennay, & Rao, 2011).

4.6 CLINICAL RELEVANCE OF FINDINGS

While there were no further statistically significant between groups differences on the PSQ-18 in Phase I (quantitative), it is also important to look at what the findings mean from a clinical perspective. It is of interest to note that the control group was as dissatisfied with some of the services provided to them as the EUPD group. This finding was very surprising and concerning as mental health services should have by now perfected the provision of care to people with mental disorders, such as, schizophrenia. Both the EUPD and control group were unhappy with some financial impacts of care on them [Q5- PSQ-18]; some technical qualities of health professionals [Q1-PSQ-18]; [Q3- PSQ-18]; [Q6- PSQ-18]; [Q8- PSQ-18] and health professionals' communication and interpersonal manner [Q11- PSQ-18].

Although Phase II (qualitative) findings did portray an improvement in health professional attitudes towards people with EUPD, as previously mentioned these improvements were at the individual practitioner level and were not viewed as an improved system wide approach to care for this group. Phase II (qualitative) findings also supported Phase I (quantitative) findings where participants recounted their

level of dissatisfaction with health professionals' communication and interpersonal manner. In Phase II (qualitative) findings negative examples of interactions with health professionals were provided in a category called: *consistency and commitment of staff*. In this category, participants spoke of high staff turnover impacting negatively on their ability to form relationships with any particular staff member over longer periods of time. Participants viewed this long term engagement as critical to support permanent changes in their level of mental wellbeing. The high staff turnover resulted in participants having to retell their lived experience on each presentation. This reduced opportunities to engage in more meaningful interactions to foster sustainable behavioural change and improved coping skills. Again, the Changes Program was mentioned as an example of the benefits of working in a planned structured manner with the same health professionals over a 12- month period.

In Phase II (qualitative) findings, participants spoke of how health professionals' negative attitudes towards them impacted directly on their level of wellbeing again reinforcing similar findings in Phase I data. They considered the diagnosis of EUPD to be devastating enough but to then be treated poorly and discriminated against by health professionals because of their illness was overwhelming. This also added considerably to their health care burden. They reported experiencing stigma and were self-stigmatising and were made to feel that their treatment was not as important as others. These feelings were also reinforced when their negotiated crisis management plan was not supported at the time of presentation to the ED (Department of Psychiatry; Royal Perth Hospital, 2013). These behaviours by health professionals were confronting to participants as the DSM V had affirmed for them that personality disorders were a distinct mental disorder and as such they should be afforded the same priority of care.

As mentioned earlier in the discussion chapter, up to 70% of women with EUPD have been victims of prior sexual abuse. Therefore, it is important that health professionals have the knowledge and skills to work with people who have experienced early traumatic life events or their feelings of helplessness and victimisation can be exacerbated leading to further traumatisation. The person with EUPD is sensitive to all interactions that provoke anxiety and overwhelm their mental capacities and this may result in their escalating emotions and inability to accurately understand other peoples' motives towards them. Suicide attempts may be

precipitated by poor emotional regulation and impulse control and by a lack of support and interpersonal communication problems. The suicide rate for people with EUPD is now a serious public health issue with an estimated rate of up to 10% (Bateman & Fonagy, 2010; Patel, Flisher, Hetrick, & McGorry, 2007). With the first presentations of people later diagnosed with EUPD occurring during late childhood/early adolescence, it is very important for health professionals to engage with this group of young people in all settings. This will facilitate accurate diagnosis and referral to early intervention services (Patel et al., 2007).

The clinical pathway developed at the hospital where this study was completed (Department of Psychiatry; Royal Perth Hospital, 2013) is viewed as best practice in providing support and a formulated crisis management plan for people living in the community with EUPD. While this plan from an organisational perspective is viewed to provide good clinical outcomes, in reality it is dependent on how the consumer is treated when they seek help. Negative attitudes towards people with EUPD still exist (Veysey, 2014), and while health services have tried to decrease the impact of stigma, for example, by using the term EUPD as opposed to BPD, participants in this study are testament that changing a label does little to change entrenched attitudes.

The use of a crisis management plan was also viewed as a way to facilitate cultural change in the ED as the plan brings with it the expectation that the person presenting in crisis will be afforded the appropriate level of emergency care (Department of Psychiatry; Royal Perth Hospital, 2013). However, hospital bed shortages and established ED triage procedures challenge the ability of the plan to deliver the consumer a priority to ED care on their arrival. This dilemma, portrayed by ED staff instils a sense of helplessness in the consumer as to where to turn if communication is broken and their lifeline to help is not honoured. If the crisis management plan is not honoured, the consumer is destined to long waits in the ED. Bright lights, noise and discrimination may replace the hope and sanctuary promised when the person presented to the ED in search of help and support. The four-hour rule, an efficiency measure, introduced by health services has become standard practice within EDs'. This means that people should be reviewed and treated within the four hour timeframe (South Metropolitan Area Health Service Business Performance Unit, 2010). In order to complete a comprehensive mental health assessment it is common for this consumer group to breach the four hour rule. Their

continued presence impacts on ED outcomes and further influences the negative attitudes displayed towards them by health professionals (Department of Psychiatry; Royal Perth Hospital, 2013). A further issue impacting on the care the person may receive, is whether there is a bed available for admission to the mental health specialist unit at the service for 1-3 nights hospital admission as part of the crisis plan (Department of Psychiatry; Royal Perth Hospital, 2013). If this bed is not available, alternative mental health beds will be sourced at other services (Moore, Hodge, & Menasse, 2011). However, the person may not be known to the referred service and there is no guarantee the crisis management plan will be honoured as policy differences exist between services. While medications are not viewed as first line treatment for this group (Tyrer & Bateman, 2004) with the lack of bed availability these people may be given a medication script and discharged from the department rather than be provided with the psychological support they sought on arrival.

When examining the medications prescribed to participants in this study it was found that generally, the control group were prescribed medications more frequently than the EUPD group. This is viewed by the researcher as consistent with evidence based psychotropic treatment for the mental disorders present in the control group. Drug frequencies only were reported in this study as participants were poor historians in regard to the medication they were prescribed. The medications taken by both groups were within the Western Australian Psychotropic Medication Guidelines (West Australian Psychotropic Drugs Committee, 2016). Medications were considered by Phase II (qualitative) participants as an adjunct treatment to psychological interventions such as cognitive behaviour therapy or dialectical behavioural therapy for people diagnosed with EUPD. They did not view medications as being able to “fix their problems” and this is supported by the literature that suggests that medications are most effective when used only for short periods of time (Tyrer & Bateman, 2004). In collaboration with the consumer, their use, identification of target symptoms and monitoring processes should be established and an end date for their use identified. The consumer’s level of impulsivity needs to be assessed and accounted for when making prescribing decisions. Due to the difficulties in distinguishing between mental state and components of personality it remains difficult to evaluate the exact benefits of medications prescribed. It may be uncertain if the improvement results from

addressing the core symptoms or other co-occurring mood disturbances, suicidal behaviour, paranoid ideation or abnormal thought processes (Tyrer & Bateman, 2004).

The education of health professionals, particularly nurses, to work with people who have mental disorders has long been the subject of debate (Happell & Cutcliffe, 2011; Wynaden, 2010). There is increasing pressure on universities to better prepare graduates to work with mental health consumers. Increased exposure to theory and practice in the mental health area may serve to both improve health professionals' attitudes towards mental health consumers as well as decreasing the stigma directed towards them. Postgraduate educational programs in the critical care area should have an advanced component of mental health content to better prepare ED nurses to work with people who have mental disorders. This is extremely important now that EDs are gateways to care and many people presenting in crisis have undiagnosed mental disorders and co-occurring alcohol and other drug problems. This is in line with current Western Australian policy direction supporting the readiness of health professionals in all settings to deliver high quality care to mental health consumers and people with alcohol and other drug problems (Wynaden, 2010).

Improved knowledge and skills of the importance of health professionals practising recovery focused mental health care (Spandler & Stickley, 2011) should be nurtured in the context of all health settings. This can be achieved through building relationships, challenging stigmatising cultures and promoting healing and safe environments for people with EUPD. Health professionals need to fully understand why recovery is an important mental health concept that should be practised in all settings where consumers present (Chronister, Chou, Kwan, Lawton, & Silver, 2015; Slade, 2013; Thielke, 2011; Williams, Almeida, & Knyahnytska, 2015). The Commonwealth of Australia, Department of Health (2010, no pagination) identified six underlying principles that guide the delivery of recovery orientated mental health practice: "1) uniqueness of the individual; 2) real choices; 3) attitudes and rights; 4) dignity and respect; 5) partnership and communication; and 6) evaluating recovery". These six principles emphasise the individuality and complexity of each person's lived experience. There is a need for health professionals to treat people with respect and incorporate these principles into their management plan (Australian Government, 2010).

Knowledge and understanding of how to provide trauma informed care to people with EUPD will also provide an improved platform for all health professionals to optimise care (Muskett, 2014). As many people with EUPD have a history of childhood sexual abuse, it is importance for health professionals to be aware of the impact of trauma on the person's presenting symptoms and their need to be cared for in a safe environment.

Finally, clinical supervision is professionally recommended for health professionals working with mental health consumers (Brunero & Stein-Parbury, 2008) with challenging behaviours, especially those displaying self-harming behaviours. Clinical supervision allows nurses to reflect on the care provided to the consumer. It ensures they evaluate their attitudes towards the person and develop new clinical knowledge and competence through mentorship with a person who is removed from their usual clinical setting (Cookson, Sloan, Dafters, & Jahoda, 2014). Nurses also require experienced clinical mentors that can support them to work with consumers with challenging behaviours. Further confidence will be obtained through experience and postgraduate education.

4.7 SUMMARY

There was consistency in findings between Phase I and Phase II participant experiences supporting the trustworthiness of the research findings in each phase. While participants reported experiencing more positive attitudes and improved care from some health professionals they had contact with, overall the system experience remained relatively unchanged. The implications and recommendations from this chapter will now be presented in Chapter 5.

CHAPTER 5

IMPLICATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This concluding chapter of the thesis presents the implications of the findings of this research; makes recommendations for changes at the clinical, service and educational level; and provides concluding statements and suggestions for future research in the area.

5.2 CLINICAL IMPLICATIONS

5.2.1 Need for longer treatment programs for people with EUPD

A major finding of this study was the “consumer voice” supporting the concept of a longer structured program such as the Changes Program that operated in the 1990s at the service where the research was completed. Current practice only provides consumers with access to a three day inpatient crisis admission and a three sessions per week for six weeks outpatient program which they described as being inadequate to meet their requirements. Longer programs such as the Changes Program afforded them with time to grasp the concepts of behavioural change and practice the skills learnt, such as cognitive behavioural strategies to better manage feelings of anxiety and stress. The new behaviours and ways of interacting learnt in the Changes Program were then practised within the person’s social environment and these new skills were successful in reducing conflict. For example, when the person’s coping skills were improved their self-harming behaviours and level of emotional distress was decreased. Therefore, the Changes Program showed people how to decrease stress and live more successfully and socially within their environment.

Consistency of staff in these programs was very important to develop a therapeutic alliance with the consumer and to foster trust and authenticity in the ongoing 12 month professional relationship. Peer support was also identified as useful and empowering. It decreased feelings of stigma and normalised and validated the person’s diagnosis of EUPD as an illness within the group. The person did not feel different to others around them and this support provided them with opportunities for further personal growth. While the Changes Program was ceased due to economic costs, many of the participants who completed the program were able to achieve

mental health recovery, gain employment and have successful sustained relationships (Egan, 2000). Programs such as the Changes Program also reduced crisis presentations to the ED or other health providers because people were having regular contact with health professionals and felt well supported. The program reduced serious self-harm and hospitalisations that incurred high inpatient care costs (Egan, 2000).

The concept of longer support programs for people with EUPD is supported by Smith, Ruiz-Sancho and Gunderson (2001) who found that such programs provided effective avenues for people to develop sustained behavioural changes to enable them to successfully manage their lives in the community. Likewise, Chiesa and Fonagy (2003) found consumers with EUPD maintained progress for 36 months after completing an 18-week program. Results from a systematic review on EUPD recovery conducted in Australia suggested that EUPD is a stable condition, where symptomatic remission is possible and the likelihood of recurrence following a period of remission is low (Ng, Bourke, & Grenyer, 2016).

A recommendation from this study would be that longer programs such as the Changes Program be developed and run for six months at a time accommodating up to 12 people with EUPD at all mental health services in Western Australia. The economic benefits of such programs should be re-evaluated against the groups' ongoing use of the ED and the rates of recidivism to inpatient units during times of crisis.

5.2.2 Improved access to care

A person's history of previous admissions and a diagnosis of EUPD is a strong predictor of their future presentations to the ED and early readmissions to inpatient mental health units. Early admission within 28 days of discharge suggests previous treatment provided has been unsuccessful (Callaly, Trauer, Hyland, Coombs, & Berk, 2011) and a service's treatment success is determined by reduced consumer recidivism levels. In this study, only 20% of participants with EUPD had access to specialist mental health care in the community and therefore, most participants had no formal support provided to reduce their potential for future presentations to ED and mental health services. While many of them had a GP, the GP's level of preparedness to work with them during times of crisis varied (Liotti et al., 2008). As a result, the ED became their gateway to care. If the consumer's crisis management plan was upheld on arrival to the ED, they could transition to the inpatient mental

health setting for the agreed one to three-day crisis plan hospital admission. However, if the plan was not upheld or they did not have a crisis management plan, the ED became an inappropriate environment to reduce their presenting crisis owing to staff attitudes, misunderstandings, the four-hour rule, a lack of mental health beds, the lack of treatment plan and the overall acuity of the ED (Commons Treloar & Lewis, 2008). For this group, the pattern of repeat presentations and early readmissions becomes a vicious cycle. This is supported by Commons Treloar and Lewis (2008), who identified a lack of resources in health to meet the needs of people with EUPD. This lack of resources leads to health professionals becoming very frustrated by repeat presentations and readmissions which further impacts on the level of mental well-being of the presenting consumer. There is an imperative for a consistent approach and commitment across services to honour crisis management plans. This will enable people with EUPD to more actively self-manage their health care needs. A well-documented crisis management plan focuses treatment. It provides structure and enables health professionals to provide consistent quality care. Developing the plan collaboratively validates the person's concerns and helps them to identify and prioritise their responsibilities and articulate their expectations for treatment. The three-day crisis plan hospital admission requires the cooperation of clinicians to agree on the formulated management plan and to take the time to develop a relationship with the person when they present for help.

For those consumers who do not have a crisis management plan or there are no resources available to honour the plan when they present to the ED, it is important that the person is treated with respect and health professionals take the time to develop a relationship with them as they discuss their current situation and the availability of resources to assist them. Participants explained how consistency and commitment of staff was so important to reduce the feelings of loss, despair and abandonment which are reinforced by inconsistent or non-caring attitudes displayed by health professionals.

It is therefore, a recommendation of this study that all health professionals receive updated education and training about personality disorders, particularly EUPD and the importance of demonstrating positive attitudes and therapeutic optimism when working with this consumer group. Stigma reduction programs towards people with EUPD are also essential both within the health sector and general community to eradicate the long held negative attitudes displayed towards these people. All service

providers should develop an agreed plan of action to provide therapeutic support to people with EUPD when in crisis. The use of specialist mental health practitioners in primary care, for example, nurse practitioners can support GPs to more effectively provide care to this group of health consumers. This would be a cost effective way to assist this group during times of crisis and reduce ED presentations and recidivism to specialist mental health units.

5.2.3 Supporting health professionals to work more effectively with people with EUPD

Health professionals working with people with EUPD should optimally work within a multidisciplinary team to allow them to have ongoing clinical support. It provides them with the opportunity to debrief after caring for consumers with EUPD who frequently present as suicidal or engaging in deliberate self-harming behaviours. Clinical supervision is vitally important to allow health professionals the opportunity to identify and work with their conflicting emotions that are raised in the context of this clinical work (National Collaborating Centre for Mental Health, 2009). Clinical supervision allows health professionals a vision of hope and recovery for the consumer and to support each other in that shared vision. Every health professional can contribute to the effective care for people with EUPD (National Health and Medical Research Council, 2012) by understanding the key principles of recovery focused care. Recommendations based on the findings of this research include mandatory clinical supervision for all staff engaged with mental health consumers in the ED, mental health units and in the community.

Opportunities to support GPs to maintain consumers with EUPD with a mental health care plan in the community can be supported. Mental health nurse practitioners can be positioned to work with GPs to improve the care in the primary care setting. They could also develop effective crisis care plans with consumers, GPs and ED departments, thus empowering consumers with skills to self-manage their disorder more effectively. Likewise, mental health nurse practitioners could run workshops in Dialectical Behaviour Therapy (DBT) that incorporated mindfulness skills and introduced updated and new applications of skills in the areas of emotion regulation, distress tolerance, and interpersonal effectiveness within the inpatient and primary care settings (Lynch, Trost, Salsman, & Linehan, 2007). DBT teaches behavioural skills designed to increase resilience, facilitate acceptance and change,

and ultimately allows the person to live successfully within their community (van Den Bosch, Verheul, Schippers, & van Den Brink, 2002).

5.2.4 Educational implications and recommendations

Long term suicidality is the most frequent presentation for people with EUPD to the ED and ED professionals require training and education to work with people with psychological distress (Hazelton, Rossiter, & Milner, 2006). Empathy, compassion and an understanding of the importance of maintaining personal boundaries when working with people with EUPD are skills that will enhance the therapeutic alliance and consumer mental health outcomes. For instance, invading the person's personal boundary creates (Bunclark & Hurn, 2015) problems with relationships, including relationships with health professionals. The majority of participants with EUPD have experienced a variety of abuse during their lives and struggled with maintaining their personal boundaries. As a result, their responses during interactions with ED staff may limit the compassion shown toward them and increase their feelings of being devalued and stigmatised. Miscommunication due to the consumer's problem to accurately interpret the emotions displayed by others may also add to problems with interactions with health professionals.

Stigma and discrimination from health professionals was identified by participants in this study and reinforced their sense of worthlessness and compromised their access to health services. Some evidence suggests educational interventions are effective in decreasing stigma especially for general health care professionals with limited mental health training (Henderson et al., 2014). Current comprehensive nurse education programs have been repeatedly criticised for not having a stronger mental health focus and graduates are not selecting mental health as a first preference (Happell, Wilson, & McNamara, 2015). Basic counselling skills needs to be included in courses for all mental health and emergency department staff, to gain the expertise needed to work with people presenting with personality disorders. Education is also important to understanding the importance of providing continuity of care to this group of health consumers as approximately one in five admissions to mental health services are people with a diagnosis of EUPD (Wingenfeld, Spitzer, Rullkötter, & Löwe, 2010). Understanding trauma and learning about trauma informed care is essential for frontline staff to meet the needs of these people. This training can be at the undergraduate level and integrated across

the disciplines of nursing, social work, psychology, occupational therapy and medicine as these students will encounter consumers with EUPD when they graduate and move into the workforce. Postgraduate courses across all areas of health should expand on this undergraduate skill set. All ED postgraduate programs should have specific mental health advanced content to prepare ED staff to work with mental health consumers including those with alcohol and other drug problems.

5.2.5 Recovery focussed person centred care

Many psychosocial treatments for people diagnosed with EUPD have been proven to be effective in randomized controlled trials in the past couple of decades, including DBT, mentalization-based therapy, transference-focused psychotherapy, and cognitive behavioural therapy (Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012). The Australian Government, Department of Health, identifies that the principles of recovery oriented mental health practice are relevant to all of the 10 national standards for the contemporary mental health workforce in Australia and apply to all mental health service systems, including the non-government community mental health service sector (Australian Health Ministers, 2009). Recovery refers to “both internal conditions experienced by persons who describe themselves as being in recovery – hope, healing, empowerment and connection – and external conditions that facilitate recovery – implementation of human rights, a positive culture of healing, and recovery-oriented services” (Jacobson & Greenley, 2001; p.482) . Katsakou, Marougka, Barnicot, Savill, White, Lockwood and Priebe (2012) interviewed 48 consumers diagnosed with EUPD and found recovery involved developing self-acceptance, self-confidence and self-esteem, gaining control over emotions, moods and thoughts, improving relationships, getting involved in activities and employment, and making progress in clinical symptoms, such as suicidality, self-harming, eating problems, drug and alcohol consumption. Consumers with EUPD struggle with shame and guilt, not as a result of having a mental disorder, but because their sense of self is not developed and they find it hard to come to terms with ‘who they are’ (Ajayi, Bowyer, Hicks, Larsen, ailey, Sayers & Smith, 2009). This may mirror their enduring problems in developing a sense of identity and self-compassion, which often reflects a lack of secure attachment relationships and a history of abuse or neglect among people with EUPD (Turner, Neffgen, & Gillard, 2011).

It is therefore recommended, that all people who have contact with mental health consumers must understand the importance of practising from a recovery orientated framework and this content should be common to all health professional education programs (Australian Government Department of Health, 2013). It must also be part of postgraduate educational program for health professionals (Commonwealth of Australia, 2010).

5.3 RECOMMENDATIONS

People with EUPD deserve equity and accessibility in health service delivery. The following recommendations arise from the findings:

1. That health professionals must incorporate recovery orientated mental health practice and trauma informed care into their everyday practice;
2. That clinical supervision already routine practice for all frontline health professionals throughout Western Australia be implemented after each interaction with an EUPD patient as a critical part of the management plan.
3. That crisis management plans for people with EUPD need to be collaboratively developed and honoured when they present to any ED in times of crisis;
4. That health services should have well developed plans of care so that people with EUPD are not turned away from services when in crisis;
5. New models of primary care can be developed that allow mental health professionals, for example, nurse practitioners to work with GPs to more appropriately support mental health consumers in the community setting;
6. That long term programs incorporating a variety of both psychosocial and psychotherapy conducted by consistent staff need to be implemented across mental health services and evaluated for their cost effectiveness;
7. That a greater emphasis on mental health, including EUPD specifically, should be introduced into the health curricula for all health disciplines at both undergraduate and professional levels; and,
8. That cultural change is needed in front line staff to interact in valuing ways with people with mental disorders as early intervention is critical to good mental health outcomes.

5.4 CONCLUDING STATEMENTS

The findings of this thesis have demonstrated that changing the name of a disorder does little to change how people respond to the person when they present in crisis for help. The findings show that people with EUPD remain stigmatised from society and that they experience stigma at a higher rate than people diagnosed with other mental disorders. While the ED is now the gateway to care for people with mental disorders, professionals at the entry to the health care system require more knowledge, skills and improved attitudes to work with this group. The long standing premise that people with EUPD are not worthy of health professionals' time and that other people presenting to the ED have more valid illnesses and therefore should receive priority care over people with EUPD needs to be eradicated at the service level.

Modern EDs and mental health services need to have health professionals that have the knowledge and skills to provide recovery orientated mental health care and trauma informed care. This will allow them to see the person and not just the presenting behaviours and understand that taking the time to care even in the ED environment can be very helpful to people who have EUPD. For example, appropriate gender mix when working with this group of health consumers as many females with EUPD have experienced sexual abuse and can be re-traumatised if this is not acknowledged in the care provided.

Health professionals need to challenge the notion that nothing can be done in acute care environments such as the ED for people with EUPD as the negative attitudes and behaviours displayed towards this group are self-fulfilling and continue to send the message to the person with EUPD that they are devalued and not worthy of care. Small changes by health professionals in their interactions with people with EUPD can do much to resolve the presenting crisis and to make the person able to self-manage their presenting symptoms more effectively. The long held stereotype that consumers with EUPD are challenging and difficult to work with needs to be eliminated from the health care environment and personality disorders need to be viewed as legitimate mental disorders which can be effectively treated with appropriate care and interventions.

Self-harming behaviours which are common behaviours in people with EUPD are becoming socialised in young people and therefore health professionals will increasingly be more exposed to these challenging behaviours. The provision of

effective early intervention is important in providing young people with more appropriate responses to living with stress. Health professionals in the ED are particularly important to this process as the attitudes displayed to young people on early presentations to the ED can influence the mental health outcomes and reduce their use of self-harming behaviours to deal with life stressors.

Finally, the researcher would like to acknowledge and thank the participants who gave of their time to tell their stories, some of which demonstrated a long history of engagement with the health care system. Sharing their lived experience has enabled this thesis to be completed and for their stories to be told. It is hoped that publications arising from this work will provide an avenue for their stories to be heard by health professionals, policy makers and service providers and to lead to improved care that is recovery focused, trauma informed and meets the needs of this consumer group.

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APPENDICES

Appendix 1a: Ethics approval from Royal Perth Hospital



Government of Western Australia
Department of Health
South Metropolitan Health Service

Royal Perth Hospital



24 March 2014

Mr Donald Speldewinde
Psychiatry Department
Royal Perth Hospital

Dear Donald

Project Title: **The Experience of Receiving Mental Health Care for people with Personality Disorder**
Protocol No: **N/A**
HREC Reference: **REG 13-112**

On behalf of the Royal Perth Hospital, I give authorisation for your research project to be conducted at the following site(s):

Royal Perth Hospital

This authorisation is based on the approval from RPH HREC and the review by the RPH Research Ethics and Governance (REG) Office. **This authorisation is valid subject to the ongoing approval from the HREC.**

This authorisation is based on the ethical approval from the HREC, and on the basis of compliance with the 'Conditions of Authorisation to Conduct a Research Project at Site' (attached) and with the compliance of all reports as required by the Research Governance Office and approving HREC. Non compliance with these requirements could result in the authorisation be withdrawn.

The responsibility for the conduct of this project remains with you as the Principal Investigator at the site.

Yours sincerely

PROF FRANK DALY
Executive Director
Royal Perth Hospital

Appendix 1b: Ethics approval from Curtin University



Memorandum

To	Professor Dianne Wynaden, Nursing and Midwifery
From	Professor Peter O'Leary, Chair Human Research Ethics Committee
Subject	Protocol Approval HR 50/2014
Date	7 April 2014
Copy	Mr Donald Speldewinde, Nursing and Midwifery Dr Karen Heslop, Nursing and Midwifery

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*The experience of receiving mental health care for people with personality disorder*". The Committee notes the prior approval by Royal Perth Hospital Human Research Ethics Committee (REG 13-112) and has reviewed your application consistent with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is HR 50/2014. *Please quote this number in any future correspondence.*
- Approval of this project is for a period of four years **07-04-2014 to 07-04-2018**.
- Annual progress reports on the project must be submitted to the Ethics Office.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:
This study has been approved by the Human Research Ethics Committee of (INSERT LEAD HREC NAME) and Curtin University 50/2014.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:

- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (If a serious or unexpected adverse event occurs)

Yours sincerely

Professor Peter O'Leary
Chair Human Research Ethics Committee

Appendix 2a



Royal Perth Hospital

PARTICIPANT INFORMATION SHEET

The Experience of Receiving Mental Health Care for people with Personality Disorder.

Investigator: Donald Speldewinde, Department of Psychiatry

You are being invited to participate in a research study because you have been diagnosed as having a personality disorder. This information sheet explains the study and describes what will be involved should you decide to participate. Please read the information carefully and ask any questions you might have. You may also wish to discuss the study with a relative or friend or your GP.

Background and aim

The Chief Investigator has been working with patients diagnosed with a personality disorder for more than twenty years and in that time has observed that hospitalisation often creates large amounts of stress and at times conflict between the patient and staff. From the findings of this study it is hoped we will be able to develop strategies that make hospitalisation less stressful for both patients and staff. We plan to develop treatment packages that are more effective in helping people with a personality disorder cope with their condition.

What participation in the study involves

If you agree to participate, you will be asked to **complete a patient satisfaction questionnaire**. This has 18 questions asking you to rate on a scale of one to five your experiences in hospital. You will also be asked to participate in an **interview** that will last about thirty minutes. This will involve a more detailed discussion about your experiences in hospital. This interview will be audio recorded and transcribed by the Chief Investigator. At the conclusion of the study these records will be destroyed.

Possible side effects and risks

Because there are no additional medical procedures involved in this study, there are no foreseeable major risks or side-effects associated with participation.

It is important to note that there are no right or wrong answers to the questionnaire or to questions during the interview. It is your individual experience that we are interested in. It is important to know that you do not have to answer any question that you do not want to.

At the conclusion of the interview, the Chief Investigator will ask if the interview caused disturbing issues to arise and if so will arrange additional counselling support and debriefing from RPH Department of Psychiatry staff not involved in the study.

Possible benefits

Participation in this study may have no direct benefit for you, but may help the development of treatment packages that are more effective in helping people with a personality disorder cope with their condition and hospitalisation where necessary.

Privacy and confidentiality

The information gathered about you by the investigator or obtained during this study will be held by the investigator in strict confidence and all the people who handle your information will comply with the Privacy Act 1988. If the results of the trial are published in a medical journal, as is intended, no reader will be able to identify individual patients.

What if something goes wrong?

In the event that you suffer an unexpected side effect during this study that arises from your participation, you will be offered all full and necessary treatment by Royal Perth Hospital. The Ethics Committee has approved this study on the basis (amongst others) that the reported risk of such an event is either small or acceptable in terms of the risk you face as a result of your current illness.

Costs to participation

There will be no costs incurred as a result of participation in this study. You will not be paid for participation.

Voluntary participation and withdrawal

Participation in this study is entirely voluntary. You do not have to participate if you do not want to and your decision to participate or not will in no way affect your current or future care at RPH. You are also free to withdraw from the study at any time without reason or justification.

Contact Information

If you have questions about this study, please contact Donald Speldewinde on 041 88 11 329.

This study has been approved by the Royal Perth Hospital Ethics Committee. If you have any concerns about the conduct of the study or your rights as a research participant, please contact Prof Frank van Bockxmeer, Chairman of the RPH Ethics Committee, via (08) 9224 2292 or rph.hrec@health.wa.gov.au and quote the ethics approval number (REG 13-112).

This study has also been approved by the Curtin University Human Research Ethics Committee (approval number). If needed, verification of approval can be obtained either in writing to the Curtin University Research Ethics Committee, c/- Office of Research and

Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9226 2784 or by emailing hrec@curtin.edu.au.

Appendix 2 B



Royal Perth Hospital

CONSENT FORM

The Experience of Receiving Mental Health Care for people with Personality Disorder

Investigator: Donald Speldewinde, Department of Psychiatry

I, agree to participate in the above study. I have been provided with a copy of the Participant Information Sheet explaining the study which I have read and understood. . I have been given the opportunity to ask questions about the study by the Investigator and any questions have been answered to my satisfaction. I understand that I may withdraw from the study at any time without affecting any future medical treatment, or the treatment of the condition which is the subject of the study. I am aware that all research data collected will only be used for the purpose of this study and will be kept confidential and that my participation will not be disclosed without my consent.

Signed **Date**

Signature of Investigator **Date**

Name of Investigator

Appendix 3

SHORT-FORM PATIENT SATISFACTION QUESTIONNAIRE (PSQ-18)

On the following pages are some things people say about their mental health care. Please read each one carefully, keeping in mind the mental health care you are receiving now.

(If you have not received care recently, think about what you would expect if you needed care today.)

We are interested in your feelings, good and bad, about the mental health care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

Circle one number on each line.

Questions	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
1. Mental health professionals are good at explaining the reason for medical tests.	1	2	3	4	5
2. I think my mental health professional's office has everything needed to provide complete mental health care.	1	2	3	4	5
3. The mental health care I have been receiving is just about perfect.	1	2	3	4	5
4. Sometimes mental health professionals make me wonder if their diagnosis is correct.	1	2	3	4	5

5. I feel confident that I can get the mental health care I need without being set back financially.	1	2	3	4	5
6. When I go for mental health care, they are careful to check everything when treating and examining me.	1	2	3	4	5
7. I have to pay for more of my mental health care than I can afford.	1	2	3	4	5
8. I have easy access to the mental health specialists I need.	1	2	3	4	5
9. Where I get mental health care, people have to wait too long for emergency treatment.	1	2	3	4	5
10. Mental health professionals act too businesslike and impersonal toward me.	1	2	3	4	5
11. My mental health professionals treat me in a very friendly and courteous manner.	1	2	3	4	5
12. Those who provide my mental health care sometimes hurry too much when they treat me.	1	2	3	4	5
13. Mental health professionals sometimes ignore what I tell them.	1	2	3	4	5
14. I have some doubts about the ability of the mental health professionals who treat me.	1	2	3	4	5
15. Mental health professionals usually spend plenty of time with me.	1	2	3	4	5

16. I find it hard to get an appointment for mental health care right away.

1 2 3 4 5

17. I am dissatisfied with some things about the mental health care I receive.

1 2 3 4 5

18. I am able to access mental health care whenever I need it.

1 2 3 4 5

Appendix 4

Permission to adapt survey

Dear D.C. Speldewinde

Thank you for contacting the RAND Corporation.

You can find the information about permissions for RAND Health surveys at http://www.rand.org/health/surveys_tools.html#questions-or-comments.

As noted on this page, "All of the surveys and tools from RAND Health are public documents, available without charge. Please provide an appropriate citation when using these products. No further permissions are necessary. In some cases, the materials themselves include specific instructions for citation. Some of the surveys and tools listed on this website are not available from RAND Health. However, we provide links to these materials hosted elsewhere, where you may find instructions for use."

If you have any additional questions about RAND Health surveys or tools, you may email them at RAND_Health@rand.org.

Information regarding the PSQ-18 survey can be found at http://www.rand.org/health/surveys_tools/psq.html.

Best regards,

Michelle Colbert
Customer Service Specialist
RAND Corporation

Appendix 5

Structured Interview Guide

Before each interview the researcher established rapport by introducing himself, describing his professional role within RPH and their interest in the treatment and management of personality disorders. The researcher asked participants some general questions about their background, their social situation and current emotional state to ensure that they felt comfortable and able to participate in the structured interview.

Structured Interview Questions

1. Can you tell me about the care that you have received at RPH?
2. Can you tell me about any aspects of care that you think have aided your recovery?
3. Can you tell me what you think RPH can provide to help you recover?

Appendix 6

Demographic data

Participant Number:

Date

DOB Gender Male Female

Date consent signed

DSM IV diagnosis

Number admissions

Admission date

Social situation

- Living alone
- Living in relationship
- Living with family
- Living with friends/others
- Homeless

Employed Yes No

Psychological supports

- General Practitioner
- Counsellor
- Peer Support Worker
- Case Manager
- Other

Medications

Medication name	Dose	Frequency	Route	CPZE