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Out of Sight, Out of Mind:

An Exploration of the Sexuality Experiences of Women with Enduring Mental Illness

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Abstract

This thesis explores the sexuality experiences of women with enduring mental illness. Sexuality is a complex and important aspect of a person's health and well-being. Yet, health professionals seem generally reluctant to discuss sexuality related issues, and few research studies have explored the sexuality of women with enduring mental illness. The aim of this research was to gain a deeper understanding about these women's sexuality experiences, including how they would like health professionals to address this aspect of their lives. Eight women were interviewed individually, and then together as a focus group. Working from a feminist theoretical perspective, the interview transcripts were analysed thematically. All the women considered their sexuality an essential component of their identity. However, powerful interlocking systems controlled and influenced how the women expressed their sexuality, often marginalising, and positioning them as 'Other'. The women's experiences highlight the need for mental health professionals to recognise that sexuality is an important aspect of a person's care and recovery. Mental health professionals need to offer services that enable women with enduring mental illness to openly discuss their sexuality.

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Chapter One: Introduction

*Sexuality is part of your very being, it's part of who you are
(Jandy, Int, p.7).*

This study has arisen from my experience as a primary mental health nurse. From 1995-2004 I worked at Newtown Union Health Service (NUHS), and was the first mental health nurse in New Zealand to work in a primary mental health programme (James, 2007). When working within a primary health care setting, the challenge for a nurse is to be both a specialist and generalist. Therefore my focus when working with a person with an enduring mental illness was to address not only their mental health needs but also their general health needs, including wider socio-economic issues.

My nursing approach and scope of practice was extended to include sexuality related issues such as sexual health checks, contraceptive use, pregnancy testing, and cervical smear taking. When practising in this extended way, I was often struck by the openness of people to discuss their sexuality. For example, at one mental health consumer-run service, where I was known as the 'condom queen' for my work around safe sex and contraception (James, 2007), there was always a high degree of interest from people to discuss their sexual relationships and other aspects of their sexual lives.

Prior to working at Newtown Union Health Service I worked in acute adult and adolescent mental health services. During those times I never really discussed a person's sexuality, and any discussions I did have were generally around contraception and avoiding pregnancy. Yet when working at NUHS, the positive response from people with enduring mental illness towards discussing their sexuality revealed to me that sexuality was important component of a person's life and well-being, and much more complex than simply contraception.

At the same time, I wondered if the keenness and willingness to discuss sexuality was because there were few other avenues for people to raise this aspect of their lives with health professionals, in particular with mental health staff. This hunch was supported by the findings of other studies (Cort, Attenborough & Watson, 2001; McCandless & Sladen, 2003) who found that mental health staff were reluctant to discuss sexuality related issues. Though I am now working as a nurse educator, my eight-plus years of working as a primary mental health care nurse highlighted to me the importance of addressing the sexuality experiences of people with enduring mental illness. This interest, coupled with my perception that sexuality was not an area of health that mental health providers addressed led me to embark upon this study.

My original aim when developing this study was to focus on how the women would like staff to address their sexuality experiences. However, it was very clear once the study was underway that sexuality was a whole area for discussion, and as a result, a much broader approach was taken.

The overall aim of this study is to explore the sexuality experiences of women with enduring mental illness. The specific objectives are:

1. To explore with the women how their sexuality experiences are currently being addressed by health professionals.
2. To explore how the women would like health professionals to address their sexuality experiences.

Women with Enduring Mental Illness

For the purposes of this research I chose to focus on the sexuality experiences of women with enduring mental illness. My reason for choosing a women-only group of participants arose from my clinical experience, as it appeared that there were some significant differences between men's and women's sexuality.

Both men and women spoke of the impact of medication on their sexual functioning; for the men this tended to be around erectile difficulties, and for women concerns about a lower libido. However, in medication reviews with their psychiatrist, if a man reported erectile difficulties, his psychiatric medication would be changed, but not so for women with decreased libido. Instead it was suggested that this was just one of those side effects that needed to be tolerated.

With the increased use of atypical antipsychotic medication resulting in an improvement in the negative features of schizophrenia, women reported a return of sexual feelings that they had not felt for years. For some women this aroused mixed emotions, with an excitement about experiencing feelings of attraction, but equally some concern and apprehension about being sexually intimate. Some women, concerned about the stress of being in a sexual relationship and the effect on their mental health, chose not to engage in sexual relationships.

The issue of contraception for women with enduring mental illness seemed to be viewed by secondary mental health services as predominantly a primary health care responsibility, even when they had more contact with the woman. If the woman did become pregnant, concerns would arise about the teratogenic risks of certain psychiatric medications, as well as the effect on her mental health if her medication were stopped. Some women chose or were encouraged to have a termination, and while some women seemed accepting of that decision, a few women spoke of their distress and anguish at feeling coerced into this decision.

Women also spoke about feeling very lonely, isolated and wanting to have a child. On a few occasions some women were prepared to engage in risky sexual behaviour in the hope of becoming pregnant. The rearing of a child they saw as giving them a degree of status and purpose to their lives that they felt was lacking. Other women who had children and did not want to become pregnant again, spoke of finding it difficult to negotiate condom use with their

partners who wanted more children. Finally, for those women whose children were being brought up by other people, the sadness and grief associated with not being able to bring up their own children would often become intensified when the woman was unwell.

Whilst feeling depressed and hopeless, a few women spoke of engaging in unsafe sexual behaviours, with casual sexual partners and no condoms, as a way of reinforcing their feelings of worthlessness. The women would then feel an immense sense of shame and embarrassment, which seemed to exacerbate their mental state. Concern would also arise about their risk of contracting a sexually transmitted infection (STI's). While STI's in men are generally symptomatic, in women they tend to be asymptomatic. The consequences for women from untreated STI's are serious, sometimes life threatening, and include cervical cancer, ectopic pregnancies, HIV, stillbirths and blindness in babies (World Health Organisation, 2000). Other consequences of unprotected sexual activity also include unplanned pregnancy and terminations.

When talking about their sexuality, the women's stories were often about their intimate sexual relationships, their self-esteem and identity, while the men tended to focus on sexual activities and sexual functioning. Few (1997) argues that women in general have specific needs given the cultural and socio-economic position of women in society; therefore when considering female sexuality it is essential to examine the economic, political and social aspects of gender relations. Taking all these factors into account I felt it was important to recognise the differences between men and women, as to bring them together in some generic approach would have overlooked those issues that specifically seemed related to women.

In early stages of this research I was aware there appeared little agreement over a suitable term that best described the women's experiences of mental illness. Some terms, for example, included a person with chronic or severe mental illness, a consumer, or a service user (Peterson, 2004). I was interested in hearing about the experiences of women with ongoing significant

experiences of mental illness, such as schizophrenia, bipolar, depression, and personality disorder, rather than those with more intermittent and short-term mental health experiences. It was the persistent nature of these experiences and the impact on the women's sexuality that I wanted to know more about. Unsure of what was the best phrase to use, I asked the women how they would like to be described. The women chose the term 'enduring mental illness' and so in acknowledgement of their feedback, when talking about the women in the study, or others with similar mental health experiences, I use this phrase. However, when referring to other studies, I use the terminology that appeared in the author's writings and publications, and as such will use terms like 'severe mental illness' or 'psychiatric patient'.

Sexuality

'Sexuality' as a theoretical term rather than 'sexual health' was chosen for this investigation due to the breadth it gave in exploring the women's experiences. The concept of human sexuality is often considered complex and difficult to define (Cort et al., 2001). Few (1997) suggests there is not one single definition of sexuality, but rather diverse sexualities. Sexuality is more than simply engaging in sexual activity and reproduction, but also encompasses common mental health issues such as self identity, social functioning, and the ability to form trusting relationships with others in social and intimate ways (Park Dorsay & Forchuk, 1994). I was particularly interested in how these issues were affected when overlaid with the experience of an enduring mental illness.

Stuart and Laraia (2001) identify four aspects of a person's sexuality. These include a person's genetic identity or their chromosomal gender; their gender identity – maleness or femaleness; their gender role – the cultural roles identified with their gender; and their sexual orientation – the gender to whom they are sexually attracted. Given that sexuality is a broad and diverse concept, I found in the early stages of the study that this division of sexuality into four relatively straightforward areas was a useful framework upon which

to begin examining the women's experiences of sexuality. However, I soon realised that this slightly reductionist approach did not take into account those wider influences, such as sexual experiences, gender expectations, ethical and moral concerns, that can also shape a person's sexuality (Pyke, Rabin, Phillips, Moffis & Balbirnie, 2002; Weeks, 1985).

The World Health Organisation (WHO) defines sexuality as:

A central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes values, behaviour, practices, roles and relationships ... Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors (World Health Organization, 2004).

This definition acknowledges the expression of sexuality on a personal level and also those wider social, cultural, historical and political structures that shape and influence its expression. Rather than focusing solely on behaviours and reproductive health, the WHO recommends that sexuality research investigate the underlying social, cultural and economic factors that influence a person's sexuality (WHO, 2004). This broader approach seemed pertinent to this study as it echoed my own clinical experience of working in primary health care where those wider socio-economic issues were recognised as impacting on a person's health.

I was also aware that the sexuality of people with enduring mental illness was often seen as problematic and pathologised (Deegan, 1999). The media representations of people with enduring mental illnesses as dangerous and violent (Cook, 2000) and eugenic ideologies (Deegan, 1999), have been identified as contributing to these attitudes. Cook (2000) argues that media stereotypes create stigma and fear, which act to control the sexual expression of people with experiences of mental illness. These attitudes both influence

and are then maintained by health professionals who tend to view sexual activity by people with mental illness as inappropriate, likely to slow recovery and therefore to be discouraged; or else as asexual (Dobal & Torkelson, 2004; Buckley & Wiechers, 1999). For people who experience mental illness, these beliefs can then become internalised, resulting in the person repressing their sexuality or over-worrying about their “normalcy” (Cook, 2000, p.199).

Historical factors also have tended to pathologise the sexual expression of people with enduring mental illness. Eugenic ideologies underpinned many of these beliefs and practices (Deegan, 1999). Given the influence of eugenic thinking ideologies within psychiatry, the following section outlines the eugenic movement, both internationally and in New Zealand, and its impact on the sexuality of people with enduring mental illness.

Eugenics

Between 1900 and 1940, eugenic theories developed as a worldwide movement, and were based on the belief that emotional, mental and social traits were genetically inherited (Allen, 1997). Society could therefore be protected from the types of people defined as socially ‘unfit’ by ensuring that their hereditary defects were not passed on (Taylor, 2005). Eugenics appealed as it sought to improve the human race by ensuring only the fittest reproduced and discouraged the ‘unfit’ or worthless members of society from having children.

Psychiatrists especially embraced eugenic theories, as eugenics positioned the aetiology of psychiatric illness within a genetically inherited framework. (Schulze, Fangerau & Propping, 2004). Therefore, psychiatry became established within a biological context like other areas of general medicine. This organic explanation for mental illness, provided psychiatry the legitimate body of knowledge it needed to raise its standing within the medical profession (Schulze et al., 2004).

With the support of psychiatrists and other scientists, the eugenic movement was able to enact its ideologies through legislation. Such legislation saw the implementation of worldwide eugenic programmes, which resulted in the forced sterilization of thousands of people, including psychiatric patients (Schulze et al., 2004; Sharav, 2005). In Nazi Germany, such programmes were readily enforced and eventually led to the murder of nearly 100,000 psychiatric patients in concentration camps (Ion & Beer, 2003).

New Zealand similarly embraced the eugenics movement. In 1904, Dr William Chapple proposed that in order to protect the future of New Zealand's society, all 'defective women' and the wives of 'defective men' should be compulsorily sterilised (Taylor, 2005). A 'defective' person was a broad term applied to someone considered of unsound mind who required supervision to ensure their and the public's safety, and was seen to have stronger than normal sexual instincts, be a prolific breeder, and therefore a drain upon the community (Smythe, 2000). Eugenic advocates, including Sir Frederick Truby King and the Medical Association, called for the sterilisation of such people as a way of controlling their reproduction. It was also seen as a way of curbing the behaviour of 'defective' women, as sterilisation was thought to make the women more compliant and manageable (Taylor, 2005). In 1928, the Mental Defectives Amendment Act was passed, and with that the establishment of the Eugenics Board which oversaw the voluntary sterilization of 'mentally defective' men and women (Taylor, 2005).

After World War II, and the horror of Hitler's eugenic practices, support for eugenic ideologies waned (Smythe, 2000). However, it could be argued that some aspects of eugenic thought remained, but in a more subtle and less explicit form, and this time focused specifically on women. For example, under Section 8 of the Mental Health Act 1969, unless the relationship was husband and wife, it was illegal to have sexual intercourse with a 'mental disordered female' (Mental Health Act, 1969). It is interesting to note that this law did not apply to 'mentally disordered' unmarried men. Sexual intercourse with a mentally disordered female remained an offence until 1992, when it

was removed with the passing of the Mental Health (Compulsory Assessment and Treatment) Act (1992).

Paternalistic motives may have underpinned such legislation, in that it may have been thought necessary to protect women considered vulnerable and not capable of effective decision-making. However, the legislation does suggest the influence of eugenic thinking in making it illegal for a woman to engage in consensual sexual intercourse, as it implies an underlying concern about this group of women producing children.

While eugenics may no longer be evident in mental health legislation, eugenic ideology is still seen as influential within psychiatry. Psychiatric genetics, which emerged at the beginning of the 20th century to explain the aetiology of psychiatric disorders, continues within the concept of genetic susceptibility (Schulze et al., 2004). Thus, a prominent cause of mental illness today is seen as the interaction of a person's genes with their environment.

The above discussion regarding eugenics highlights the past and current concerns about genetic susceptibility of people with enduring mental illnesses and the inheritable nature of genes. These concerns are seen to have influenced the sexuality of people with enduring mental illness to be constructed as problematic (Deegan, 1999), and my awareness of the influence of eugenics within psychiatry was something that developed throughout this research. The following section outlines other relevant concepts that have informed my study.

Conceptual Frameworks

In 1998, The 'Blueprint for Mental Health Services in New Zealand' outlined a plan for mental health services to work intersectorally with the wider community to improve services for those who experience mental illness (Mental Health Commission, 1998). A key feature of the 'Blueprint' was the adoption of a recovery approach to service delivery. The guiding principles

that underpin the concept of recovery are respect, equality, social inclusion, participation, and empowerment, and recovery is seen to happen when a person is able to “regain personal power and a valued place” in their community (p.15). Recovery involves supporting a person with enduring mental illness to reclaim their lives, and overcome some of the limitations that may have arisen from their mental health experiences. For health professionals this means tailoring a person’s care to their whole life, not just their illness, and utilising a wide range of services, treatments and life skills to enable that person to live a meaningful life (Mental Health Commission, 1998). As the recovery approach remains central to service provision within mental health services, I drew upon this concept, and my aim is that the knowledge gained from this study will further enhance the ability of health professionals to implement the recovery approach.

Whilst undertaking the analysis of the women’s stories, I encountered the phrase, ‘out of sight, out of mind’, which I have used to provide an overarching framework on which to examine and present the women’s experiences. In July 2007, Judge Mahoney released his report, ‘Te Aiotanga’ about the experiences of former in-patients of various psychiatric units during the 1940s to 1992 (Department of Internal Affairs, 2007). The report findings detailed conditions and treatments described by former in-patients as degrading, humiliating and cruel. Former staff members who participated in the forum, whilst not wanting to minimise the reported experiences, conceded that psychiatric hospitals were simply in tune with the “out of sight, out of mind” attitudes that prevailed towards mental illness and psychiatric patients (p.31).

This phrase, ‘out of sight, out of mind’ highlighted several relevant issues. Firstly, the experience of one’s sexuality is generally very personal and private, thus ‘out of sight’. Secondly, for the women participants their ‘out of sight’ sexuality experiences were also overlaid by being constructed as mentally ill, or ‘out of mind’. Finally, in regard to explaining staff approaches, the phrase ‘out of sight, out of mind’ illustrated the power of societal attitudes to shape and influence the delivery of health care, and similarly the role of

institutions in maintaining and upholding those beliefs. The phrase 'out of sight, out of mind' provided a suitable overarching framework to examine the women's sexuality experiences, as well as how staff had responded to these experiences.

As I was interested in gaining understanding of the women's experiences, I was drawn to a theoretical framework that positioned gender as central to its analysis. Feminist theory provided that framework. I was particularly drawn to the writings of bell hooks (1994 / 2000a / 2000b) and her notions of interlocking systems of domination. Other relevant feminist perspectives that have informed this study include postmodern feminist notions of identity, the concepts of 'Other' and 'politics of the personal'. I was also attracted to the political aims of feminist research to bring about social change (Fonow & Cook, 2005), and my aim for this study, is that the knowledge produced will bring about a change in clinical practice.

Conclusion

This study has arisen from my clinical experience as a primary mental health nurse. Working alongside women with enduring mental illness revealed to me the importance of sexuality related health issues. As there is currently very little research evidence on the sexuality experiences of women with enduring mental illness, this study will contribute to this small body of knowledge by providing an in-depth understanding into the sexuality experiences of this group of women (Crabtree, 2004; Randolph et al., 2006). Finally, the thesis findings have the potential to enable health professionals to better address the sexuality experiences of women with enduring mental illness, and promote recovery.

Chapter One has introduced the background, aim and key concepts that inform this study. Chapter Two reviews the literature related to the sexual behaviours of women with enduring mental illness, including the contextual factors that impact on these behaviours, reproductive health and sexual dysfunction.

Chapter Three outlines the feminist theoretical frameworks that underpin this study, followed by discussion of the chosen methodology and methods that were employed. This chapter concludes with discussion of the key ethical issues and reflexivity. Chapter Four, 'Out of Sight' and Chapter Five, 'Out of Mind' present the main themes that emerged from the women's stories. In Chapter Four I outline those 'Out of Sight' experiences that rendered the women's sexuality to become hidden and invisible, while Chapter Five refers to the women's experiences of how health professionals responded to their sexuality experiences, as women positioned as mentally ill or 'Out of Mind'. In Chapter Six I use the term 'Insight' upon which to base my discussion of the main issues that emerged from the data. Here I outline my own insights from interviewing the women and in Chapter Seven, I present my final conclusions and recommendations for health professionals and further research.

Chapter Two: Literature Review

Introduction

There is limited research literature related specifically to the sexuality experiences of women with enduring mental illness. Even within this literature women's experiences are generally invisible and hidden. Some studies did draw upon women's experiences (Cogan, 1998; Crabtree, 2004; Lyon & Parker, 2003; Miller & Finnerty, 1996; Randolph et al., 2006), but very few studies have considered sexuality in the broader context of relationships and intimacy (McCann, 2000; Volman & Landeen, 2007).

The studies that have been done about the sexuality of women with enduring mental illness were primarily focused on behavioural aspects, such as high-risk sexual behaviours, and sexuality was viewed within a problematic framework. This focus may reflect the author's disciplines and fields of work, as most were health professionals, either mental health nurses or doctors. These studies may also reflect commonly held assumptions of health professionals, who either tend to view people with enduring mental illness as asexual, or engagement in sexual activity as inappropriate and likely to inhibit recovery (Buckley & Wiechers, 1999; Dobal & Torkelson, 2004).

This chapter outlines the main themes that emerged from the literature review: the sexual behaviours of women with enduring mental illness; the contextual factors that influence these risk behaviours; reproductive health and sexual dysfunction. A summary of the key findings from this literature review is presented, followed by a discussion of where my proposed research fits within the current body of knowledge, and how my study adds to this knowledge. The next section details how the literature review was undertaken.

Literature Search

An extensive computer search of databases through Massey University library was undertaken for this review. Four main databases were accessed: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsychINFO, Medline and Web of Science. New Zealand databases were also searched including Index New Zealand. Searches focused around key words: sexuality and sexual health, mental illness/health, psychiatric, and women. To ensure the focus was women with enduring mental illness, material was excluded that primarily discussed mental health experiences that were of a more minor, episodic nature.

Initially, key words 'women's sexuality' and 'mental illness' revealed only five studies (Cogan, 1998; Crabtree, 2004; Lyon & Parker, 2003; Miller & Finnerty, 1996; Randolph et al., 2006). When the search was broadened to include 'women's sexual health' and 'mental illness/health', studies related to family planning, contraception, sexually transmitted infections, HIV, and general health care were identified (Coverdale & Aruffo, 1989; Coverdale, Turbott & Roberts, 1997; Howard, Kumar, Leese & Thornicroft, 2002; McCandless & Sladen, 2003; Ritsher, Coursey & Farrell, 1997; Steiner et al., 1998; Viguera, Cohen, Bouffard, Whitfield & Baldessarini, 2002).

Given the lack of research literature focused specifically on women, mixed gender studies were then considered and this yielded a larger but limited review. However, from a feminist research perspective this lack of differentiation between the genders of the participants, and the formation of a generic description of men and women's experiences, raises concerns. This suggests that the gender of participants makes no difference to the data being collected. It overlooks the powerful influence of social and cultural based gender differences that impact on a person's experience of mental illness (Ritsher et al., 1997). One feminist critique of traditional research studies is that women's experiences can become excluded when measured against masculine norms (Westkott, 1990). In other words, women's lives are defined

through men's lives. The lack of research literature related specifically to the experiences of women with enduring mental illness reinforces their invisibility, and was another reason for my decision to focus my study solely on women.

What is interesting to note is that this wider yield of studies largely examined sexual behaviours, especially high-risk sexual behaviours, and iatrogenic sexual dysfunction. A considerable number of studies focus on disease prevention especially in regard to HIV/AIDS (Carey, Carey & Maistro, 2004; Grassi, Pavanti, Cardelli, Ferri & Peron, 1999; Otto-Salaj, Kelly, Stevenson, Hofman & Kalichman, 2001; Woolf & Jackson, 1996). The majority of studies were quantitative and few studies explored the person's perspective. In most studies the sexuality and sexual behaviours of people with enduring mental illness largely appeared to be constructed as problematic and pathological. McCann (2003) argues that this negative construction contributes to the stigma and sense of marginalisation that people with enduring mental illness experience. The next section outlines in more detail the key research findings.

Sexual Behaviours

As noted some mental health providers consider people with enduring mental illness as asexual and thus not engaging in sexual activity (Buckley & Wiechers, 1999). However, contrary to this view, sexual activity over a 12-month period ranged from 54-74% (Carey, Carey, Weinhardt & Gordon, 1997; Meade & Sikkema, 2007). Studies examining sexual activity rates did so in the context of risk behaviours for HIV/AIDS (Buckley, Robben, Friedman & Hyde, 1999), and the following section discusses these studies.

Internationally, HIV prevalence rates among people with enduring mental illness are considerably higher than the general population. For example, in America, United Kingdom, Western Europe, and Australia, people with enduring mental illness have prevalence rates around 1% - 23%, compared to

0.1 - 0.6% for the general population (Carey, Weinhardt & Carey, 1995; Davidson, Judd, Jolley, Hocking, Thompson & Hyalnd, 2001; Gray, Brewin, Noak, Wyke-Joseph & Sonik, 2002; Meade & Sikkema, 2005).

Of greater concern are the male and female prevalence rates among this population. Within the general population, rates of HIV infection are greater for men than women. For example, in America, 1 in 100 adult men and 1 in 600 adult women has HIV (Carey et al., 1995). However, although the data is limited, among those with enduring mental illness, the gender difference is reportedly smaller (Carey et al., 1995). HIV rates for women with enduring mental illness range from 5.3% to 20% (Cournos & McKinnon, 1997). In New York State, AIDS was the leading cause of mortality among young women with psychotic illnesses (Susser et al., 1997), while in Los Angeles, among populations of people with enduring mental illness, being female was identified as one variable associated with engaging in one or more HIV risk behaviours (Tucker, Kanouse, Miu, Koegel & Sullivan, 2003).

In New Zealand, the rate of heterosexually acquired HIV is steadily rising, with similar numbers of heterosexual men and women diagnosed in 2007 (Ministry of Health, 2007). This is consistent with overseas studies that identify heterosexual contact as the fastest growing route of HIV transmission, and HIV rates for women increasing at a faster rate than for men. Unfortunately, there is no New Zealand data regarding HIV rates among people with enduring mental illness.

While a low-risk country for HIV, New Zealand does have high rates of Hepatitis B and Chlamydia (Ministry of Health, 2007). Again, no New Zealand data is available on Hepatitis B or Chlamydia rates for people with enduring mental illness. However, in America, rates of Hepatitis B and C among populations of people with enduring mental illness are 5 and 11 times higher, respectively, than the general population (Rosenberg et al., 2001). Randolph et al. (2006) in their study of 96 women with enduring mental illness, found that nearly a third had received treatment for a sexually transmissible infection (STI) in a 12-month period. Although limited,

Australian data has found similar high rates of blood-borne viruses and STIs among people with enduring mental illness than the general population (Hercus, Lubman & Hellard, 2005). Given the prevalence of Hepatitis B and Chlamydia in New Zealand, this suggests that women with enduring mental illness could be considered be a high-risk group.

Only one New Zealand study has investigated the STI risk among women with enduring mental illness. Coverdale et al. (1997) examined the sexual behaviours of sixty-six women with enduring mental illness who were living in the community. Each woman was individually matched for ethnicity and age with women who had no history of mental illness. They found that the women with an enduring mental illness were significantly more at risk for an STI than the control group. These risks included higher number of male sexual partners, and higher rates of reported sexual intercourse with suspected bisexual men. A third of the women also reported being coerced into unwanted sexual intercourse during the preceding year.

Davidson et al. (2001) in their Australian study had similar results to Coverdale et al. (1997). Using an interviewer-administered questionnaire to 234 outpatients, they examined the prevalence of risk factors for HIV/AIDS and Hepatitis C. Females made up 42 % of the sample. Over 50% of the women were sexually active, 57% of the women had not used condoms when with a casual sexual partner, and 10% had more than three partners over a twelve-month period. Due to the high rate of unprotected sexual intercourse among women, the authors suggest that women with enduring mental illness are at greater risk of HIV than their male counterparts. Randolph et al. (2006) also reported similar findings from their quantitative survey, with nearly two-thirds of the women not using condoms during sexual intercourse over a three-month period, and over two-thirds having sex with multiple partners.

These studies suggest that New Zealand women with enduring mental illness may be a high-risk population group. The low condom use when engaging in sexual intercourse, multiple partners, and reported high rates of HIV, Hepatitis B and C and sexual coercion support this claim (Davidson et al., 2001; Meade

& Sikkema, 2007; Randolph et al., 2006; Rosenberg et al., 2001). Recommendations from these studies included further research and the development of policy and practice guidelines (Coverdale et al., 1997; Grassi et al., 1999; Gray et al., 2002), targeted resources and strategies, and training and education programmes to address this serious personal and public health issue (Davidson et al., 2000; Lyon & Parker, 2003).

While these studies clearly highlight the sexual risk behaviours of women with enduring mental illness, the focus of these studies is the women's individual behaviours. However, such an approach does not consider the social context upon which these risk behaviour occurs. The wider societal influences are hidden. In order to address the high-risk sexual behaviours of women with enduring mental illness these factors need to be taken into account. The next section outlines some of the contextual factors: economic dependence, abuse, impact of mental illness, and access to sexual health knowledge.

Contextual Factors

Economic dependence

Women with enduring mental illness are often poverty stricken (Collins, 2001). The long-term impact of an enduring mental illness generally results in limited employment and economic dependence on government subsidies. As a result of not being able to meet basic needs, rates of sex trading or exchanging sex for money or goods have been reported between 21% to 30% (Cournos et al., 1994; Meade & Sikkema, 2007). This places women at great risk as sex trading often occurs with unfamiliar partners and the women will have limited access to safe sex measures (Weinhardt, Bickman & Carey, 1999). Limited income also reduces the likelihood of being able to buy condoms (McKinnon, Carey & Cournos, 1997). The need for economic survival can be seen to override concerns of engaging in risk related behaviours.

The high rates of women with enduring mental illness engaging in sex trading are more likely a reflection of their socio-economic position (Meade & Sikkema, 2007). This implies that women may engage in risky behaviours as a result of their socio-economic status rather than because of their mental health. In other words poverty may drive women to high-risk sexual behaviours. This suggests that when studies use comparison subjects to examine the sexual behaviours of women with enduring mental illness, participants also need to have a similar socio-economic status. Poverty-related issues need to be considered when researching sexual behaviours and when developing programmes around risk prevention.

Abuse

The impact of violence and abuse also influences sexual risk behaviours (Collins, Geller, Miller, Toro & Susser, 2001). Women with enduring mental illness report higher rates of sexual abuse than non-diagnosed women, with abuse rates ranging from 50 % to 75%, (Lombardo & Pohl, 1997; Read, 1998; Rosenberg, Goodman, Thompson & Mueser, 1999; Weinhardt et al., 1999), and experience repeated victimisation, with Bengtsson-Tops and Tops (2007) finding that 63% of women with enduring mental illness have been exposed to more than one episode of abuse.

Childhood sexual abuse experiences is associated with increased likelihood of engaging in risky sexual behaviours, such as multiple sexual partners, low condom use, and sex trading (Rosenberg et al., 1999). Meade and Sikkema (2007) examine the psychiatric and psychosocial correlates of sexual risk behaviours among 152 (70 women, 82 men) psychiatric outpatients. Rates of childhood sexual abuse are 63% for women and 33% for men. People with a history of childhood sexual abuse are significantly more likely to engage in multiple sexual partnerships, sex trading and unprotected sexual intercourse. The association between childhood sexual abuse and high-risk behaviour is attributed to the long-term emotional consequences of sexual abuse on interpersonal relationships. Given the prevalence of abuse among people with enduring mental illness, Meade and Sikkema (2007) recommend that

clinicians routinely assess for sexual abuse, and provide gender appropriate risk prevention programmes.

The long-term mental health implications of sexual abuse have been associated with a variety of psychiatric symptoms including depression, dissociation, anxiety, posttraumatic stress disorder, schizophrenia, eating disorders, somatization, borderline personality disorder, self mutilation, suicidality and substance use disorders (Brand, 2002; Rosenberg, Lu, Mueser, Jankowski & Cournos, 2007). The experience of childhood sexual abuse is also associated with severity of psychological disturbance. In a New Zealand study, Read (1998) reviewed the medical records of 100 admissions to an inpatient psychiatric unit. He found that compared to those with no history of childhood abuse, those with a history of childhood abuse were significantly more likely to be suicidal, first admission to hospital was at an earlier age, and had longer hospital admissions.

Women with enduring mental illness also report high rates of sexual coercion. Sexual coercion refers to sexual behaviour occurring because of threats of physical force, emotional abuse or financial incentives (Weinhardt et al., 1999). This includes coercion into unwanted sexual intercourse (Coverdale et al., 1997) and rape (Goodman, Rosenberg, Mueser & Drake, 1997; Lombardo & Pohl, 1997; Steiner et al., 1998). Under these circumstances women often have few options to manage their risk for infections. The women's physical and emotional safety is often a higher priority (Collins, 2001). Sexual coercion poses a serious threat to the sexual and mental health of these women for two reasons. Firstly, sexual coercion and forced sex may result in vaginal and anal tearing, pelvic inflammatory disease, genitourinary problems, STI's and HIV. Secondly, exposure to these episodes may impact on the women's mental health, and exacerbate their experiences of mental illness (Weinhardt et al., 1999).

These studies highlight how experiences of abuse and violence need to be considered in any study on sexual risk behaviours. Recommendations from these studies included clinicians routinely assessing for abuse and targeted

education programmes (Bengtsson-Tops & Tops, 2007; Meade & Sikkema, 2007). While abuse is experienced on a personal level, power imbalances underpin this experience. Williams (2005) argues that gender inequalities provide opportunities for serious abuses of power, as women are positioned to meet the needs, including sexual needs, of men. Sexist socialisation can cast men as having uncontrollable sexual urges and the initiators of sexual activity, and women as passive recipients (Jackson & Scott, 1996). Negotiation around condom use can be difficult when a woman has little control or power within a relationship. Similarly woman may risk violence or abuse when requesting a partner to use a condom (Few, 1997). These power imbalances impact on a woman's safety. Any programmes aimed at addressing these behaviours needs to take into account gender power relationships.

Impact of mental illness

The impact of a person's mental illness has also been linked with engaging in sexually risky behaviours. Davidson et al. (2001) note that mania in people with a bipolar condition often-results in an increase in sexual drive and risk-taking behaviours. Cognitive impairments either from schizophrenia or substance abuse also affect a woman's judgment and negotiation skills within sexual relationships (Collins, 2001). People with depression also report engaging in risky sexual relationships often due to feelings of despair and worthlessness or as a way to manage the symptoms (Ramrakha, Capsi, Dickson, Moffitt & Paul, 2000).

The experience of mental illness is very stigmatising (Ryan, Carryer & Patterson, 2003). Feeling stigmatised can lead to social isolation and feelings of distress and despair. This sense of isolation and stigma can affect a woman's ability to form permanent relationships, and lead to an increased likelihood of more casual sexual partnerships. For stigmatised societal groups, the condom can symbolise the barriers in society that make it difficult to form relationships (Joff, 1997). As such, condomless sex is seen as overcoming that stigma as it symbolises trust and acceptance.

This literature demonstrates that a person's mental state and associated stigma are important points to consider in the context of high-risk sexual behaviours.

Sexual health knowledge

Several studies suggest poor sexual health knowledge as another explanation for mental health clients engaging in risky sexual activities (Grassi et al., 1999; Lewis & Scott, 1997; Lyon & Parker, 2003; Woolf & Jackson, 1996). Grassi et al., (1999) when examining people with schizophrenia HIV risk behaviours and knowledge about HIV/AIDS, found poor understanding and many misconceptions regarding HIV transmission. A high proportion reported HIV risk behaviours, and 65% were not concerned about HIV infection. While the use of a survey limits any depth of analysis, they suggest that other factors rather than knowledge may impact on these behaviours. These include high levels of denial, impaired cognitions, and a lack of assertiveness in sexual situations (Grassi et al., 1999). Gender variables were not examined in this study.

Lyon and Parker (2003) had similar findings in their qualitative study of 16 rural women with severe and persistent mental illness. They found that many of the women knew very little about contraception and preventive health care, and had misconceptions regarding health care practices. Information about how to access primary health care was also lacking. Using thematic analysis, the women noted "difficulties in obtaining regular health services and communicating with (non psychiatric) health care professionals" (Lyon & Parker, 2003, p. 29).

Woolf and Jackson (1996), in their study concerning the sexual health knowledge of mental health clients, found that while answers from the yes/no questionnaire identified a good knowledge of HIV/AIDS and sexually transmitted infections, with between 72% and 94% correct, there seemed to be poor understanding of issues such as routes of transmission. They suggest this may be a result of the ambiguous nature of the questionnaire. However, equally significant was the finding that although people had good knowledge

of safe sex practices, some needed practical advice in how to use condoms. They recommend that for education about sexual health needs to be effective, a skills based training for mental health clients is necessary.

Given the poor knowledge about sexual health issues, the authors noted above recommend that mental health professionals routinely assess their clients' sexual health needs (Woolf & Jackson, 1996), and comprehensive sexual health educational programmes be implemented in mental health settings to address the underlying reasons for engaging in high risk behaviours (Grassi et al., 1999; Lyon & Parker, 2003). The assumptions underpinning these studies seem to imply that engaging in risky sexual behaviours occurs because of an individual failing, such as poor knowledge, lack of assertiveness or the person's mental state. The focus for poor knowledge seems primarily to be aimed at an individual, personal level.

However, other factors influence that knowledge. Sexual health education is often delivered at a primary health care level, and as noted earlier, women with enduring mental illness are often on limited incomes, so the cost of accessing primary care can be a barrier (Cook, 2000). As such, mental health professionals are in the best position to provide that information. Unfortunately mental health professionals often report feeling uncomfortable when discussing sexuality with their clients and as a result seldom inquire about this aspect of their client's lives (Cort, et al., 2001; Coverdale & Azariah, 2001; McCann, 2003; Park Dorsay & Forchuk, 1994; Pyke et al., 2002). The reasons for this reluctance include staff's attitudes towards sexuality; lack of education around sexual health issues and concerns about professional roles and boundaries (Collins, 2006; Cort et al. 2001; Pyke et al., 2002). Sexual health education for staff, the development of sexual practice policies and guidelines for staff, and better co-ordination between primary health care and mental health services are some recommendations proposed to address these issues (Collins, 2006; Coverdale & Azariah, 2001; Pyke et al., 2002).

The actual content of what should be offered in a sexual health education programme was the subject of a study by Lewis and Scott (1997). They surveyed 39 mental health clients to determine what topics they would like discussed. They matched these answers with those topics suggested by mental health professionals. Interestingly, the results show that the clients' preferences differed from those offered in programmes set by the health professionals. Clinicians' programmes tended to focus on anatomy and physiology and birth control. However, the mental health clients wanted education on the relational aspects of sexuality, such as where and how to meet people, how to maintain long relationships, dealing with unwanted sexual advances and sexual functioning. While the small number of respondents limits the usefulness of this study, the findings do raise the pertinent point that for sexual health programmes to be effective they must be based on the needs of clients and not professionally determined priorities.

This study highlights how clinicians' understanding of sexuality from a behavioural, individual biomedical framework is of limited use when dealing with the complexities of sexuality. Drawing on the work of Lewis and Scott (1997), Higgins, Barker and Begley (2006), in their literature review of sexual health education programmes for people with enduring mental illness, recommended that sexual health education must consider the wider aspects of sexuality, such as intimacy and relationship development. Such programmes assist people to develop skills to overcome the stigma, social isolation and loneliness often experienced with mental illness (McCann & Clark, 2004). Lewis and Scott's (1997) study also demonstrates the importance of researchers gaining knowledge directly from the individuals involved when considering how to address clients' needs.

In summary, many factors contribute to the high-risk sexual behaviours of women with enduring mental illness. These include poverty, abuse, sexual coercion, gender roles, female socialisation, mental state, stigma, limited sexual knowledge and staff attitudes. In order to understand the complexities of sexuality for women with enduring mental illness, a broad social context approach is needed. Two other main themes arose in the literature,

reproductive health and sexual dysfunction. These are discussed in the following two sections.

Reproductive Health

From my own clinical experience, questions about contraceptives and pregnancy were often issues discussed by the women and clinicians. The focus was generally around prevention of pregnancy and the risks associated with pregnancy. This approach was also echoed in the literature.

In a New Zealand study, Egan, Siegert and Fairley (1993) examined the use of hormonal contraceptives within a psychiatric setting. They collected information from clinical files, interviews with women who had been inpatients for more than six months, and their primary or charge nurses. Of the forty-two women prescribed hormonal contraceptives, fewer than half of the women had consented to their use, a third were not sexually active, and for some women, the administration was not legally authorised. Under the provisions of the Contraception, Sterilisation, and Abortion Act, 1977, only a woman with a serious intellectual disability – not a mental illness – could be given contraceptives without her consent. The hospital staff had prescribed nearly all the contraceptives, except one. They suggest that prior to the Mental Health (Compulsory Assessment and Treatment) Act 1992, it was wrongly assumed that any woman under the Mental Health Act could be given contraceptives compulsorily. They note that while consent is needed to administer contraceptives, if the woman is considered mentally disordered and incompetent to make that decision, under the Protection of Personal Property and Rights Act 1998, a welfare guardian can be appointed to make that decision. This study also focused on safe sex practices, and like similar studies, found that 90% of the sexually active women never used condoms. They suggest that, as a nurse had to be asked for a condom, this may have discouraged their use. Asking a nurse for a condom is also an example of how institutional practices can impede safe sexual behaviours.

In one of the first studies undertaken, Coverdale and Aruffo (1989) investigated the contraceptive use and pregnancy outcomes of 80 outpatient women. They found that a significant number of the women were at risk of unwanted pregnancies. Although the women stated they did not want to be pregnant, a third of the women had not used any contraception during sexual intercourse. Tubal ligation was one of main forms of contraception utilized. They acknowledge that the study did not consider the women's consent for a tubal ligation, and suggest such decisions be investigated. Over 30% of the women had had induced abortions. Of the 75 children born, 60% were being raised by other people.

Similar results were found in later studies by both Miller and Finnerty (1996) and Coverdale et al. (1997) where, compared to the control subjects, women with enduring mental illness had higher rates of induced abortions and fewer planned pregnancies. Reasons offered for high abortion rates included contraceptive failure, lack of social support, and pressure from health professional due to concerns about a woman's ability to raise her children. However, when the women choose to proceed with their pregnancy, they were then more likely to give up their children for others to rear (Coverdale et al., 1997; Miller & Finnerty, 1996).

Viguera et al. (2002) examined the pregnancy decisions of women with bipolar mood disorders. Due to the teratogenic risks associated with certain psychiatric medications such as lithium carbonate, sodium valproate and carbamazepine, the women were often counselled to terminate their pregnancy. Concern about this increased risk and the effect on foetal development were one of the reasons reported for a woman wanting to avoid pregnancy. Whilst one option to avoid the teratogenic risks would be to stop the medication, the impact of discontinuation was often a recurrence of illness symptoms. Accordingly, the fear of becoming unwell due to medication being stopped was the other main reason for choosing not to proceed with a pregnancy (Viguera et al., 2002).

These findings give an indication of the issues surrounding contraception and pregnancy for women. However, no depth of analysis is offered for the reasons behind these behaviours or the effects these decisions have on the women's mental health. Paternalistic attitudes appear to underpin the administering of contraceptives by staff without consent, and the results seem to question the women's capacity to make informed decisions. Pregnancy is also seen as problematic and the result of some individual failing such as non-compliance of contraception. This is despite the fact that changes in antipsychotic regimes have resulted in unplanned pregnancies (Gregorie & Pearson, 2002). This approach also overlooks the larger social context in which pregnancy occurs. For example motherhood and having children are often seen as the ultimate goal for women (Abbott, Wallace & Tyler, 2005). Interestingly, while the majority of literature specifically related to women with enduring mental illness addressed the issue of contraception and reproduction, this focus reinforces the notion that reproduction is solely a woman's concern. Once again the women's experience is absent from these studies.

Sexual Dysfunction

The prevalence of sexual dysfunction among mental health clients has been reported as higher than the general population (Wylie, Stewart, Sievwright, Smith & Walters, 2002). Two studies considered the rates of sexual dysfunction among mental health clients (Kockott & Pfeiffer, 1996; Wylie et al., 2002). Sexual dysfunction was defined as 'sexual satisfaction, erectile dysfunction and infrequency of sex' (Wylie et al., 2002, p.1) and 'hyposexual desire' (Kockott & Pfeiffer, 1996, p. 1). Results showed that, compared to the control group of non-mental health clients where sexual dysfunction was around 13%, sexual dysfunction among the mental health clients ranged from 36% to 49 % (Kockott & Pfeiffer, 1996).

Both studies suggest the causes of sexual dysfunction are multifactorial, although the person's illness and their medication were primarily responsible.

For example, people with schizophrenia who reported high rates of sexual dysfunction had higher rates of psychopathology and were more likely to be on medication. One side effect of such medication was decreased sexual function, which led to relationship problems and decreased sexual satisfaction (Kockott & Pfeiffer, 1996).

Reported rates of sexual dysfunction in women on conventional neuroleptics range from 30 to 93% (Wallace, 2001). Sexual difficulties surrounding desire, arousal and orgasm were the main problems reported. Women also reported the effect of weight gain on their body image (Volman & Landeen, 2007). Kaschak and Tiefer (2001) argue the cause of sexual dysfunction for women is not solely a biomedical factor, but rather the intersection of sociocultural, political, economic, psychological and relational factors. They recommend that clinicians examine their own values and assumptions about gender roles when addressing women's sexual problems.

Sexuality

As noted earlier only two studies examined sexuality in the broader context of identity and relationships (McCann, 2000; Volman & Landeen; 2007) McCann (2000) explored the sexuality of eleven people diagnosed with schizophrenia, and found that people openly discussed a range of intimate feelings, and all were hopeful about forming intimate and fulfilling relationships in the future. McCann concludes that clinicians need to show greater sensitivity and consideration towards the sexual needs of people with schizophrenia.

Volman and Landeen (2007) also examined the phenomenon of sexuality and schizophrenia. Using grounded theory methodology, ten participants with schizophrenia were interviewed regarding their sexuality. Participants viewed their sexuality as an essential core of their self and part of their lives. Sexuality was not limited to physical sexual behaviours, but included emotional, intellectual, social and psychological aspects. Having a positive

sexual sense enabled better management of the person's schizophrenia and their recovery. Finally, the authors recommend the only way to gain an in-depth understanding of sensitive issues related to sexuality is by hearing from the person's themselves. They encourage clinicians to 'open the door' to discuss sexuality for all people with enduring mental illness (Volman & Landeen, 2007, p.416).

Conclusion

In considering the sexuality experiences of women with enduring mental illness, the literature paints a complex picture. Firstly, compared to the general population, this group of women are seen to engage in risky sexual behaviours and have higher rates of sexually transmitted infections and HIV (Davidson, et al., 2001; Meade & Sikkema, 2007; Randolph, et al., 2006; Rosenberg et al., 2001), higher rates of abortion (Coverdale et al., 1997) and sexual dysfunction (Wallace, 2001). The contextual factors that influence these behaviours include; socio-economic status (Coverdale et al., 1997; Coverdale & Azariah, 2001), sexual coercion, and sex trading for money (Cournos et al., 1994; Meade & Sikkema, 2007), the experience of abuse and mental illness (Collins et al., 2001; Davidson et al. 2000), sexual health knowledge (Grassi et al., 1999; Lewis & Scott, 1997; Lyon & Parker, 2003; Woolf & Jackson, 1996), staff attitudes (Collins, 2006) and medication (Wallace, 2001).

These studies clearly identify that women with enduring mental illness are a population group with specific health needs. However, what is interesting about these studies is that the majority tend to focus on the behavioural risks associated with sexual activity. Sexuality is considered within a reductionist framework, and sexual activity, is seen as problematic. This approach may also reveal some of the researchers unexamined assumptions or prejudices towards this group of women and their sexuality. Indeed, by positioning sexual behaviours as problematic this could suggest eugenics in a disguised form. While not explicit, concerns surrounding women with enduring mental

illness engaging in sexual behaviour and certainly in having children may have shaped how some research has been undertaken.

Most studies were mixed gender studies. Utilising mixed studies disregards the powerful influence of gender on women's lives, and can render women's experiences invisible. For example, the role of relationships and intimacy are often viewed as central to women's sexuality (Kaschak & Tiefer, 2001). Both mixed gender studies and studies predominantly focusing on sexual behaviours overlook sexuality in its broader context and how men and women may experience sexuality as a distinctly gendered experience.

Little research has explored the experiences of women with enduring mental illness. Indeed this literature review suggests that in order for health professionals to have a better understanding and be able to address women's sexuality needs, researchers may need to shift from describing women's behaviours to exploring their actual experiences. The aim of my study is to add to the current literature by making visible the women's experiences of their sexuality, and in doing so to enhance the process of recovery.

In the next chapter I discuss the theoretical approach and methodology I used to inform my study.

Chapter Three: Theoretical Approach and Methodology

Introduction

The previous chapter outlined the research literature regarding the sexuality of women with enduring mental illness. These studies were largely focused on sexual activities and the influence of powerful contextual factors on these behaviours. Given the complexities involved and the health related consequences, the findings as reported in the literature review recommend that health professionals and services address the sexuality experiences for this group of women. To enhance this understanding and quality of care, the women's perspectives need to be incorporated into this knowledge.

The aim of this study was to gain that deeper understanding by exploring the sexuality experiences of women with enduring mental illness. As Janesick (2000) notes, our research aims determine the most appropriate methodology to be utilized. For this study a qualitative approach, informed by feminist theory was chosen. This chapter begins with an overview of the key feminist theoretical ideas that I have drawn upon, followed by a discussion of qualitative methodology, and my reason for choosing this approach. The main features of the research design including participant selection, data collection and analysis, and ethical considerations are also outlined.

Theoretical Approach

The theoretical ideas that have informed my study are those of feminist writer, bell hooks (1989 / 2000a / 2000b / 2004) and her notions of interlocking systems of domination, and postmodern feminist notions of identity. These ideas are expanded with the use of other concepts such as the politics of the personal and the notion of Other. My reason for choosing this approach arose from wanting to gain an understanding of the women's experiences, and as such, a theoretical framework that positioned gender as central to its analysis seemed appropriate. Although feminist theory offers a wide range of

theoretical perspectives and frameworks for gaining an understanding of women's gendered lives (Ramazangolu & Holland, 2002), the primary issue that underpins all feminist theory is gender inequality. Feminists then examine and analyse the causes for this inequality and domination, and also propose solutions to ameliorate these conditions (Kolmar & Bartkowski, 2005; Tong, 1998).

While working at Newtown Union Health Service, I became aware of the impact that social, cultural, and economic determinants had on people's lives. Therefore, I was drawn to those feminist theorists that considered not only the role of gender but also the role of other wider influences and systems in shaping women's experiences. As such, the writings of feminists of colour, in particular, bell hooks' (1989 / 2000a / 2000b / 2004) writings on the interlocking systems of domination, provided me with a suitable framework upon which to examine the women's experiences.

Feminist theory has also drawn upon the postmodern critique of grand theories, realist and positivist knowledge, and the universal human subject (Maynard & Purvis; 1994; Weedon, 1997). Individual identities are not seen as fixed or essentialist but rather constructed. Considering the construction of women with enduring mental illness subject positions provided me with a useful perspective upon which to examine the women's stories. These theoretical perspectives are discussed in more detail below, but prefacing this discussion are two other concepts relevant to my study; the personal is political and Other.

The Personal is Political

A central tenet of feminism has been its commitment to the politics of the personal. Weedon (1999) proposes that this commitment has transformed the political domain, as issues that were once considered private and hidden became public and visible. Traditionally, politics were only concerned with affairs of the state and public life, and issues such as "domestic and sexual violence, pornography, contraception, abortion, reproductive technology,

child care provision, the rights of women to define their sexuality and lesbian rights” (Weedon, 1999, p. 25) were seen as personal matters that belonged only within the realm of private life. Feminism challenged the public/private divide, as the exploitation and oppression of women was viewed as inherent throughout all aspects of society. The public/private divide was seen as maintaining the societal structures of domination, and only by bringing the private, personal lives of women into the public arena, could those structures and systems that supported the oppression of women be challenged (hooks, 1994; Jackson, Clare & Mannix, 2003).

The notion of bringing the personal into the public as a way of producing change seemed particularly relevant to the aim of this study. As discussed in the literature review, in order for health professionals to be better equipped at addressing the sexuality experiences of women with enduring mental illness, the women’s voices needed to be heard. The women’s personal experiences and insights need to be foregrounded and made public to enable services to provide more appropriate and suitable care.

Other

The notion of women as ‘Other’ has been a major critique within feminist scholarship. Although the meaning of the term ‘Other’ can vary, generally it considers the dominating relationship between Self and Other, to illustrate the relationship between man and woman (de Beauvoir, 2005; Macey, 2000). Existentialist feminist Simone de Beauvoir, in her highly influential work – *The Second Sex*, described how women are not constructed as autonomous beings, but rather defined in relation to men, and as such constructed as men’s other (de Beauvoir, 2005). As the Other is seen as a threat to Self, women are seen as a threat to men, and so relegated to the position of Otherness and subordination. The position of Other is one of no voice or subjugation. Feminism then represents the “refusal of the original ‘other’ in patriarchal human society to remain silent or to be the ‘other’ any longer” (King, 2005, p. 471). Feminism also has more recently extended beyond gender to give voice to all located as Other in society (King, 2005).

Society also constructs people who experience mental illness as Other, subhuman and inferior (Beresford, 2005; Johnstone, 2001). As one of the most marginalised, discriminated and disadvantaged groups in society, people with mental illness are, as Johnstone (2001) explains, highly stigmatised and experience the “stigma of difference” (p. 202). Culturally normative prejudices against people with mental illness then prohibit their participation in society.

The notion of Other was very relevant to the analysis of this study. As a sense of subordination and marginalisation arises from the position of Other in society, this suggested that for the women in this study, their experiences may have been intensified due to being constructed as mentally ill, and as women/other. Considering how these experiences affected the women’s sexuality provided a useful framework for analysing the women’s stories.

Politics of Colour

The elimination of patriarchal oppression is key to women’s liberation and emancipation (Brooks, 1997; Ramazanoglu & Holland, 2002). However, black feminists challenge this position of gender as the only source of women’s oppression. To focus only on gender, they argue, overlooks the impact of race, class, sexual preferences and age on women’s experiences (Lorde, 2005). Gender, race, class, sexuality, and the structures and systems that support these are viewed by black feminists as inseparable and interlocking, and need to be addressed to eliminate the causes of women’s oppression (Dicker & Piepmeier, 2003; Tong, 1998). In New Zealand, Maori feminists argue that feminism needs to focus not only on gender inequality, but all forms of iniquity, including Maori rights as entitled under Te Tiriti O Waitangi (Rei, 1998).

According to hooks (2000b), feminism is not only a movement to end sexist oppression but also:

A struggle to eradicate the ideology of domination that permeates Western culture on various levels as well as a commitment to reorganising society so that self-development of people can take precedence over imperialism, economic expansion and material desires (hooks, 2000b, p.26).

On a personal level, hooks (2000a) argues that both men and women are negatively affected by that patriarchy or male domination. Patriarchy, like any other system of domination, relies on a belief that one group is superior to another. This ideology results in an acceptance that the powerful can rule over and control the powerless (hooks, 1989). Patriarchal power, hooks (2000a) argues, can create barriers to loving, intimate relationships between men and women. Unlike other forms of domination, patriarchal domination will be encountered within the most intimate contexts; the intimate sphere of a relationship. It is the consideration of power and domination within intimate relationships that was particularly pertinent to this study.

On a wider societal level, hooks (1994) argues that the power of the mass media to define social reality and reinforce negative representations of marginalised people is another system of domination. This point seems particularly pertinent when considering that people with enduring mental illness are generally portrayed in the media as dangerous and volatile. As Johnstone (2001) explains, the stigma arising from such negative portrayals tends to increase the sense of marginalisation that people with enduring mental illness experience.

Hooks (1994) suggests one approach to change this system of domination is by critiquing and reconstructing these negative representations into more affirming and meaningful representations. This political aim fitted with the aim of this study – that the knowledge and understanding gained would challenge some of the attitudes of health professionals and positively affect how this group of women were positioned and constructed.

Hooks' analysis of the interlocking systems of domination provided a useful framework for this study. Recognition of the impact of patriarchy, race, class, heterosexism and the power of the mass media as systems of domination that can intersect, offered a valuable structure upon which the sexuality experiences of women with enduring mental illness could be examined.

Postmodern Feminism

Drawing on the writings of Jacques Lacan, Michael Foucault and Jacques Derrida, feminists embraced the postmodern concepts that identities and subjectivities are not universal and essentialist, but rather constructed through discourses, language and cultural practices (Mann & Huffman, 2005). Postmodern thinkers reject the modernist notion of a unified, fixed sense of self (Ramanzoglu & Holland, 2002). One's experience of subjectivity, or what one "perceives and comprehends as subjective" (Laurentis, as cited in Alcoff, 2005, p.433) is not shaped by an essential or natural identity but rather constructed by one's interaction with the world. Therefore, feminine and masculine identities are not something that we are born with, but rather occur as a result of the discourses that construct femininity and masculinity. Deconstruction of these identities is seen to produce a more in-depth understanding of the power that exists within these identities and can then lead to a decentered self, with multiple, fluid identities (Braidotti, 2003).

By drawing on postmodern theories of subjectivity and power, postmodern feminists were able to address the question of differences among women. Postmodern feminism, like feminists of colour, challenged the universal experience of women's oppression and the concept of women as a unified subject, and instead supported the notion of multiple subject positions (Dicker & Piepmeier, 2003).

Postmodernism feminism alerted me to the idea that woman was not a fixed reality and none of us had a natural self. Rather, who we become or our subject position is constructed in particular ways by language, cultural practices and discourses. This perspective raised for me the possibility that

one of the main differences between the sexuality experiences of this and any other group of women was largely due to being defined as mentally ill. Being positioned as mentally ill then changed and shaped the way the women's sexuality was understood or constructed. This provided a useful analytical framework upon which to consider the women's experiences.

The key feminist theoretical ideas that informed my study are presented in this section. These provided me with a suitable framework upon which to analyse and explore the women's stories. In the next section I discuss the methodological approach, including key feminist approaches to research, that I utilised to guide this research.

Methodology

This study utilised a qualitative methodology, informed by the feminist concepts discussed above. My reason for choosing this approach was determined by the aim of the study and the literature. I was aware that the majority of studies, both internationally and nationally, were quantitative studies, and the participants were of mixed gender. As I wanted to know how health professionals could better address the sexuality experiences for this group of women, and there was limited data about the women's experiences, the best way to gain this in-depth understanding and knowledge was to directly ask the women about their experiences and perceptions. Therefore, I chose a qualitative study, utilising individual unstructured interviews, followed by a focus group.

My choice of a qualitative approach also emerged from the recognition that positivist or quantitative studies were inadequate in the face of human complexities (Denzin & Lincoln, 2005). Qualitative research allows us to consider how individuals or groups of people see their world (Andrews, Sullivan, & Minichiello, 2004). The focus is not on establishing cause and effect relationships, but rather people's experiences and the interpretations and meanings they attach to them (Jackson, Daly & Chang, 2003; Holloway &

Wheeler, 1996). Roberts and Taylor (1998) categorise qualitative research as either interpretive or critical. Interpretive research aims to make sense and meaning out of things and, while critical research has a similar focus, it has another agenda: to bring about social-political change (Nielsen, 1990). For people with the experiences of mental illness, qualitative research is also seen as more empowering, as it allows for individual voices to be heard (Peterson, 2004). Having selected a qualitative approach, informed by feminist theoretical concepts, I also drew upon key feminist research practices, to guide me in this study; these are discussed in the following section.

Feminist Research Practices

Feminist research practices arose from a concern that existing methods of producing knowledge about social life were androcentric, reflected a patriarchal bias, and lacked concepts that drew upon women's experiences (Ramazanoglu & Holland, 2002; Westkoff, 1990). Feminist research aims to make visible and give voice to the diversity and differences of women's experiences. The aim of feminist knowledge is to understand the realities of gendered social life, the structures that support those situations, and to transform them (Fonow & Cook, 2005; Ramazanoglu & Holland, 2002). Although there are diverse feminist approaches, feminist research is underpinned by particular theoretical, ethical, and political concerns. These concerns are discussed next.

Objectivity / Subjectivity and the Research Relationship

Within traditional social science methods, the subject or researcher will attempt to be separate from the object or person being studied, as a way of achieving objectivity and protecting against the bias of subjectivity (Westkoff, 1990). However, feminist researchers, like other qualitative researchers, challenge this separation between researcher and participants, and the positivist emphasis on objectivity (Jackson et al., 2003). Rather than being objective, feminists state that the knowledge produced by traditional science

simply reflects the bias of the researchers and is androcentric (Nielsen, 1990). As such, claims of objectivity within research are unable to be guaranteed.

Rather than attempting to detach themselves in the pursuit of objectivity, feminist researchers position themselves in the research. Intersubjectivity and interaction by the researcher is encouraged (Webb, 1993). The researcher shares their own knowledge and experiences with the research participants, in the same way that research participants are expected to do. This intersubjectivity of meaning takes place within what Westkoff (1990) describes as a “dialectical relationship” (p. 60). Thus the researcher and the participant are viewed as humanly linked, and knowledge emerges from this relationship, and this dialogue (Westkoff, 1990).

Ethics of Feminist Research

Feminist research shares many of the same ethical concerns as other social science research. These include issues of confidentiality, consent, and avoiding harm. However, feminist researchers expand on these areas and also consider issues of power within the research relationship, as well as the ethical implications of representing the voice of women (Olesen, 2005). The fact that the words of the participant are objectified, inevitably positions the researcher in a powerful position. Feminist researchers then pay particular attention to the research relationship and the inherent power imbalance that exist within the research process (Olesen, 2005; Ramazanoglu & Holland, 2002).

As feminist research is commonly interested in issues of oppression and marginalisation, feminist researchers are particularly concerned about not repeating dominant power relations and being exploitative (Jackson et al., 2003). To address these concerns, feminist researchers engage in a reflexive process that critically examines and analyses the research relationship and the researcher’s power, the researcher’s own subjective interpretations and biases, and ways to respond appropriately (Fonow & Cook, 2005). As the nature of the research relationship underpins all feminist ethical concerns, discussion on how I attended to these and other ethical issues are outlined later in this chapter.

Politics

Inherent in feminist research is the connection between politics, ethics and epistemology. Although feminists draw from a wide variety of theoretical perspectives, what distinguishes feminist research is its political commitment to women. As Ramzanoglu and Holland (2002) explain, “feminist research is politically *for* women; feminist knowledge has some grounding in women’s *experiences*, and how it *feels* to live in unjust gendered relationships”(p. 16). As such, feminist researchers must consider the political, and as noted above, the ethical implications of how knowledge is produced and authorised, and to be accountable for the knowledge they produce. Ultimately, the aim of feminist research is to bring about political and social change and as hooks (2000b) explains, to transform people’s lives in a meaningful way.

As a nascent researcher, I found the process of considering the political implications of my study helped formulate my thinking. Initially, I had two concerns regarding the knowledge that I was producing. Firstly, the findings would only reinforce stereotypes about women with enduring mental illness, and secondly, the findings would only stay within the hardbound covers of my thesis. Rather than reinforce current thinking, I wanted the study to initiate change – a change in attitudes and a change in clinical practices. In the early stages of planning this study I informally discussed with mental health consumers my concerns and aims. Arising from these and other discussions, I made a commitment to the women involved in this study to disseminate the findings widely and, with an advisory group, develop these findings into policy and practice guidelines. This commitment to the women has helped me keep the political aims of my study at the forefront of my thinking.

Feminist research is underpinned by particular theoretical, ethical and political concerns that involve recognising how and for what purpose knowledge is created. These concerns influence the methods employed in a study. The following section outlines the methods I used for participant selection, data collection and analysis, and how the ethical issues were addressed. This chapter concludes with a discussion on reflexivity.

Study Design

Participants

When considering how to approach women as possible participants for my study, I decided to draw upon my links with the mental health consumer community and approached those services that were either targeted at or run by mental health consumers. Llewellyn, Sullivan and Minichiello (2004) note that approaching participants from specific groups about whom a depth of information is required is a common method employed by qualitative researchers. This allowed me to use both purposive and snowballing sampling techniques (Llewellyn, et al., 2004).

I rang and met with the managers from two mental health consumer activity centres and an art workshop to discuss my study. The two consumer run services then submitted my written request to their Management Boards for their approval (Appendix A). After receiving Board consent, and following ethical approval (discussed further under ethical issues), the service managers and I organised either morning or afternoon teas where I met some of the women who attended their services.

Numbers attending these meetings ranged from three to six women. At these meetings I outlined the aims of my study, including my definition of an enduring mental illness – that being a woman who had a formal diagnosis of schizophrenia, major depression, bipolar or personality disorder that was ongoing in nature. The women were also given an information sheet detailing these main points and their rights (Appendix B). Prior to using this information sheet, I had asked the managers to check the wording as a way of ensuring the written information was easy to read and understandable. Using clear and uncomplicated language in an information sheet is an important way of ensuring that participants are fully aware of what they are consenting to do (Minichiello, Madison, Hays, & Parmenter, 2004). As the issue of informed consent is an important ethical issue that all researchers need to consider

(Peterson, 2004), I considered the manager's feedback on my information sheet as one way of addressing this issue.

As discussed earlier, a key element of feminist research is reflexivity surrounding the power imbalance within the researcher-participant relationship (Lather & Smithies, 1997). In the beginning stages of the recruitment it was the power that I held as a mental health nurse, and not a researcher, that I felt could add an element of coercion to the exercise. Having been involved in mental health services for over 15 years I knew many women with enduring mental illness. These prior relationships, I felt, had the potential to offer positive spin-offs, but could also be coercive in pressuring the women to participate.

As a result I used several strategies to minimise this possible threat of coercion. Firstly, I asked the managers to organise the meetings, so the women were forewarned that I was the researcher. Knowing this, some women may have chosen not to attend the gatherings. At the end of the meetings I explained to the women that I did not expect them to make a decision about their involvement there and then, and instead, suggested that if interested, they could get either get back to me personally or contact me through the managers. I feel that these strategies, along with fully informing them of their rights, reduced the potential for the women to feel coerced into participating.

Of those women who attended these meetings, four women volunteered at the time of the meeting, one contacted me later, and three contacted me after hearing about my study via word of mouth. Interestingly, of the eight women who participated, I had – in some capacity or another – been involved in the nursing care of five of the women. This prior contact may have confirmed me as trustworthy in the minds of some of the participants, and highlighted to me the importance of trustworthiness within the research relationship (Llewellyn, et al., 2004).

For the eight women who volunteered, a suitable time and venue was organised. The individual interviews were held between October 2006 and February 2007, with a focus group in March 2007.

Data Collection

The Interview

Participation in this study was two-fold; an individual interview and a focus group interview. The decision to use individual and focus group interviews arose from informal discussions held with mental health consumers in the early stages of planning this study. It was felt the individual interview would allow for the more in-depth discussion of personal matters while the focus group would allow more general discussion on staff responses. This point is consistent with Owen (2001), who found that within the focus group format, women with enduring mental illness were quite reticent and reluctant to discuss very personal or sensitive matters. The process of consulting with consumers on their views and opinions as to the most appropriate interview methods to use also paralleled the aim of this study. Therefore, just as I was guided by the consumers' expertise and knowledge, the aim from this study was that health professionals also would be guided by the findings of this study to address the sexuality experiences for this group of women.

The individual interviews were held in a range of venues: the women's homes, various activity centres, and my workplace, while the focus group was held at a central, neutral location. The duration of the interviews was between 45 minutes and 2 hours. The conversations seemed to flow and the women were very forthcoming.

The Interview Process

The interviews began with a general introduction and I outlined the key points of the consent form (Appendix C). Given the very personal nature of the topic I was aware that either during the interview or afterwards the woman may experience interview stress (McCann & Clark, 2005), and have felt upset. While interview stress is not necessarily harmful, McCann and Clark (2005)

suggest researchers need to recognise that interviews can be stressful, and to be prepared for all possible responses. At the beginning of each interview I discussed with the woman how she would like to be supported if she did feel upset. We also discussed the various support agencies available to the women, and I supplied a copy of their names (Appendix D). I also organised for a staff member to be available if needed and their names were included on this list. Not surprisingly, all the women were well informed about services available, felt well supported and only two women took the list of the support services for future reference.

For the individual interviews I utilised an unstructured interview technique as the most appropriate method to gather data. This generated a free flow of information and produced a collection of rich data in the form of individual stories and experiences (Fontana & Frey, 2000). Although the interviews were unstructured, there were some key areas that I was interested in. These I presented as an aide-memoire (Appendix E), which I discussed with the women at the beginning of each interview. By informing the women about these areas, I hoped to lessen – to a small degree – the inherent power imbalance that existed between the women and me. The broadness of the aide-memoire ensured the discussion was focused on the overall aim of my study while at the same time allowing sufficient flexibility to explore the women's stories (McCann & Clark, 2005). I found after outlining and explaining the consent form, the topic, the issue of interview stress and the aide-memoire, discussion tended to naturally develop, and, as such, each interview did not need to be formally opened with a specific question. The interviews tended to flow easily and the women very quickly began discussing their thoughts and experiences.

For the focus group I utilised a semi-structured interview guide that was derived from the main themes that had emerged from the individual interviews. According to Fontana and Frey (2000), changing from an unstructured to semi-structured interview is common within qualitative studies, as interviews that occur later in a study tend to have questions that have arisen from the initial findings. Interestingly, only two points on my

aide-memoire were brought through into the semi-structured interview. This highlights how valuable unstructured interviews are for exploring topics and gaining data that represent the participant's perspective.

Data Analysis

Thematic analysis, which is defined as the systematic identification, coding and sorting of key themes that emerge from data (Ryan & Bernard, 2000), designed to make sense of data from unstructured and semi-structured interviews (Burnard, 1991), was the method of analysis employed in this study. Holland and Ramazanoglu (1994) suggest that the identification of themes within thematic analysis, involves three levels of conceptualisation. These include the terms and meanings emerging from the data, the interviewer's own field notes, reflections, and personal experiences and finally the use of feminist theory to interpret and code the data (Holland & Ramazanoglu, 1994). I found this a very useful framework for analysing the data. However I found that I added a fourth level and that was drawing on other research literature, especially qualitative studies. While these levels are presented in a linear fashion I found the process of interpretation a circular process, and this process is set out below.

All interviews were tape recorded, except for one. In this instance, the interview was held outside so the woman could smoke her cigarettes and unfortunately my extension cord was not long enough. Having to write down what was said was slightly problematic, but at times, when there was a gap in the questions while I completed my notes, more responses were offered. Upon reflection I feel these added comments may not have arisen if I had simply moved onto the next question.

Throughout each interview, I took notes of the main points discussed. These notes were read back at the end of the interview. This ensured that I had covered the main points and that I had properly summarised the interview. It also provided an opportunity for the woman to amend or add any additional

comments. This was one step I undertook to ensure I was constructing credible accounts of the women's experiences. Within feminist research, demonstrating credibility is considered an important strategy in the promotion of rigour (Hall & Stevens, 1991). After each interview I also took field notes about my observations and other salient points. These were then woven into my analysis of the data.

A transcriber or I typed out the taped interviews. Upon completion, each transcript was systematically read several times, and also checked against the tape recording. Notes were made and broad themes identified on the text. These were compared to my field notes and the main points identified at the completion of each interview. The broad themes were then drawn together to form an individual mind map from each interview. As a visual representation of similarities, mind maps are considered very useful for analysing qualitative data (Ryan & Bernard, 2000). Each of the eight individual mind maps were further re-examined for similarities and then amalgamated to form one mind map.

The themes on this combined mind map then formed the basis for discussion at the focus group. The utilisation of this focus group method was primarily for the clarification and validation of themes (John, 2004). Four of the eight women attended this meeting. Each theme and the key relevant points were presented on separate sheets of paper and were discussed. The women were also invited to write any other additional comments, and this gave the women the opportunity to write comments they may not have felt comfortable discussing in the larger group.

The focus group was also taped and transcribed, and again the main themes that emerged were developed into a final mind map. Whilst examining and analysing the main themes on the focus group mind map, the report *Te Aoitanga* (Department of Internal Affairs, 2007) was published. As I discussed in my introduction, the phrase 'out of sight, out of mind', which was reported in the forum as an explanation for the culture of that time, then

provided me with an overarching framework upon which to examine those themes. These findings are presented in my analysis chapters.

Ethical Issues

Ethical approval was sought and obtained from the Health and Disability, Central Ethics Committee (Reference CEN/06/06051). The key ethical considerations in undertaking this study were the safety of the women, confidentiality, working with Maori women and privacy. Safety was especially critical, as women with enduring mental illness are often seen as a highly vulnerable population group (Owen, 2001). I have outlined the strategies I employed to minimise the risk of coercion and reduce the potential for interview stress.

Confidentiality

To ensure confidentiality, details such as the names of individuals or services were deleted. Generally pseudonyms, chosen by the women, were used, but in a few situations the women wanted to use their own names. Initially, I found this slightly challenging, as it was not what I had outlined in my ethics proposal and most literature stresses the importance of ensuring confidentiality as a way of minimising harm to the participant (Olesen, 2005). Yet, I was also mindful of the importance of the research relationship, the power that I held, and the need for me to promote collaboration and demonstrate my credibility. Given these concerns, coupled with the fact that guaranteed confidentiality is generally considered unachievable, as even with pseudonyms people are often recognisable (Christians, 2005). To override the women's wishes and not allow them the right to name themselves seemed, in itself, inherently unethical.

Denzin and Lincoln (2005) suggest that in situations where participants are willing to be identified, it is critical that the researcher only publish material that has been mutually agreed upon. My decision to increase the validity of my findings, by returning the individual transcripts to the women for their comments and the opportunity to withdraw any statements (Dearnley, 2005)

was, in hindsight one strategy that addressed this issue. Prior to submitting this thesis, I also contacted the women to confirm the names they would like to me to use. The names chosen by the eight women who participated are: donna (with a small 'd'), Tina, Georgina, Rhonda, Sue, Jandy, P5, and Kaye.

Maori Participants

The need to consider different ways to uphold ethical research principles also applies when working with Maori. For Maori, research ethics “extend far beyond issues of individual consent and confidentiality” (Smith, 2000, p. 241), and need to be consistent with the provisions of Te Tiriti O Waitangi (Health Research Council, 2005). As the principles of the Te Tiriti include protection, participation and partnership, I was mindful as a Pakeha researcher that I needed to consult with Maori for support and their consent. Without such guidance I was aware I risked being culturally insensitive and simply reinforcing my dominant worldview. As such, I was fortunate to come under the guidance of a whaea (older Maori woman) from one of our local iwi. In the initial phase of the study I kept in contact with her as I worked closely with a Maori organisation and interviewed Maori women. I am very grateful for her support and wisdom. Maori critiques of research are similar to those of feminist researchers in respect of the researcher recognising the power dynamic in the research relationship, and the research being of benefit to the participants (Smith, 1999). I feel that utilising feminist research principles enabled me to engage with Maori in an ethical manner.

Privacy

Other situations when a person's right to privacy could be compromised were during the focus group discussions, and when the transcriber was transcribing the tapes. At these times confidentiality forms were signed (Appendix F and G). To further protect the identity of the women, all raw data was kept in a locked cabinet at my home; and all signed consent forms and confidentiality forms were kept in my locked office at work. Upon completion of this study, all the consent forms, tapes and data will be locked securely in the Social Science Archives at Massey University for five years and then destroyed.

Reflexivity

As noted earlier, a technique feminist researchers employ to demonstrate rigour is to engage in a reflexive process that critically examines and analyses the researcher's own insights and assumptions throughout the research process (Fonow & Cook, 2005). In this research, I have found engaging in reflexivity an extremely powerful process. This process has involved continuously writing in my journal, taking field notes, reading widely, and having discussions with my supervisor, other feminist researchers, and colleagues. Initially, being reflexive was a familiar process as I was used to undertaking monthly supervision when working as a clinician. Cutcliffe and Goward (2000) suggest that the process of self-awareness and reflective thinking that mental health nurses employ is similar to reflexivity that qualitative researchers undertake throughout the research inquiry. However, whilst familiar with examining my own values and beliefs, reflexivity in this research process required me to analyse the wider influences that were shaping my thinking. This wider examination was new for me, but, I believe, contributed to creating a profound shift in my thinking. This will be discussed in more depth in the Insight / Discussion chapter.

One of the most powerful reflexive moments I had was during the recruitment phase, and my realisation that the research literature I was presenting was extremely pathologising of the women's sexuality. This occurred at my first meeting for prospective participants, and I was presenting the literature that identified the high-risk sexual behaviours for this group of women. While talking, I noticed the women's responses, which initially seemed interested, change to one of almost disengagement. I sensed the shutters literally coming down. I was aware that the literature presented a very negative portrayal of their sexual activity, and positioned them as women who engage in high-risk sexual behaviours, contract STI's, and have unplanned pregnancies which are then probably terminated.

While I had seen the research as providing compelling evidence I realised how shaming it was to have one's intimate behaviours described in such a negative

light, and also felt extremely disappointed and saddened that I had in some way contributed to this shame. Not surprisingly, none of the women gathered volunteered to participate. The literature recommends that health professionals routinely discuss aspects of a person's sexuality, yet I realised that unless I approach the conversation in a more affirming manner then it would be unlikely that many women would volunteer to participate. This reinforced to me the power that I had as a researcher to either perpetuate negative stereotypes and ignorance, or, to use this opportunity to expand and extend current thinking (Smith, 1999).

As a result of this experience, at the next gathering I decided to change my approach and presented instead the small amount of research literature (McCann, 2000; Volman & Landeen, 2007) that positioned sexuality in the broader sense, and discussed the importance of intimacy and relationships; and this time the women stayed engaged. From this and the next meeting I was able to recruit the majority of the women. This example highlighted several points for me. Firstly, the majority of the literature pathologised the sexuality of this group of women, secondly, I had accepted and then reinforced that pathologising view, and finally, by engaging in a reflexive process, I now had the opportunity to create knowledge that was not stigmatising but rather extending and life affirming. I realized that while one of the aims of this study was for health professionals to have a better understanding of the sexuality experiences for this group of women, to do this, I too needed to have a better understanding.

Conclusion

This chapter has identified and discussed the key feminist theoretical ideas that have informed my study, my research methodology and the key feminist research principles that I drew upon. The research methods I employed and how I addressed ethical issues have been described. The combination of individual interviews and the focus group were an important aspect of the research design. This chapter concluded with a reflexive example, illustrating

my power as a researcher to either maintain certain beliefs or to change current attitudes. The next two chapters (Chapter Four and Chapter Five) present the findings from my analysis of the women's stories. Chapter Four, titled 'Out of Sight' discusses those experiences the women identified as having an impact on their sexuality.

Chapter Four: ‘Out of Sight’

Well I got into a relationship with a guy... And basically I wiped myself out in that relationship. I stayed around this person who was so destructive with me, that in the end, I actually couldn't talk when other people were around and when I left him, I just didn't know what I was, what I liked, or anything about me... So I'd kind of got to the point where I allowed myself to be completely rubbed out – like a rubber (Sue, Int, p. 5).

Introduction

In this and the following chapter I present the main themes that emerged from the women's stories. I examine these themes against the background of the literature review, and the feminist theoretical writings and concepts that were identified in Chapters One, Two and Three. As noted in Chapter One, the phrase ‘out of sight, out of mind’ provided an overarching framework to analyse the themes that emerged from the women's stories. Sexuality by its very nature is often a personal private matter and one's sexuality is often ‘out of sight’. The hidden experiences that impacted on the women's sexuality are presented in this chapter. The women's sexuality experiences were also overlaid by their mental health experiences. The term ‘out of mind’ seemed suitable because it kept this context foregrounded, and these are discussed in Chapter Five.

When representing the women's voices in the text, I have drawn upon quotes either from the individual interviews (referred to as *Int*), or the focus group (*Focus*). Within a quote, when I have deleted words to allow for ease of reading, I use ellipsis points, represented as ... and when ideas are presented that were not spoken sequentially this is represented as ...//... The number quoted refers to the transcript page, if needed for validation.

As noted 'Out of Sight' refers to the hidden, sometimes secretive experiences that impact on the women's sexuality. These 'out of sight' negative experiences often resulted in the women's sexuality being 'rubbed out' In the following two sections I describe the women's experiences of sexual and verbal abuse. I then explore the effects of female socialisation upon the women's mental state. How the women manage the impact of the stigma when forming intimate sexual relationships and the impact of heterosexism is then described. Finally, the effects of prescribed medication on the women's experiences are explored.

"Like a horror movie": The effects of abuse

*Sexual abuse affects your whole being around your sexuality
(Jandy, p. 10).*

Several of the women spoke about the impact of childhood sexual abuse on their mental health, their self-esteem, and their ability to negotiate adult sexual relationships. The women experienced, among other things anxiety, depression, sleeping difficulties, trauma, and disassociation under duress, and all were linked to their past sexual abuse experiences. Georgina movingly described the lasting effects of her sexual abuse experiences:

I was molested from 8 years onwards ... I was raped 6 times, once is enough. To this day, it is haunting me, it is so real it feels like it just happened ... I'm 52 ... I feel so lonely (Georgina, Int, p. 1-2).

Georgina's words powerfully illustrate the lifelong impact of sexual abuse. Her experiences of abuse continue to live on within her. Even after forty-plus years, the experiences are very real and vivid, and the trauma of re-living these experiences causes Georgina to feel isolated and disconnected from others. Feeling socially isolated and cut off from others are all aspects that are frequently reported as arising from the experience of sexual abuse (Bengtsson-

Tops & Tops, 2007). Georgina, went on to describe how these experiences also affected her mental health:

These images keep haunting me, images of men coming out of the walls. If you stay by yourself too long, that is what happens. Seeing hallucinations, hearing things, it was like a horror movie ... All the little things I can remember. Lots of things I can't get over (Georgina, Int, p. 3).

The isolation Georgina experiences seems to exacerbate her mental distress. If she withdraws from others for too long, the experiences are intensified and become visible. The hallucinations are seen by Georgina, and by their very nature, unseen by others. Georgina clearly describes the relationship between her sexual abuse experiences and the psychological consequences. This relationship between a person's experience of sexual abuse and the experience of mental illness has also been reported in other studies (Read, 1998; Rosenberg et al., 2007), and for Georgina, her experiences of sexual abuse also appear to have undermined her sense of confidence.

The experience of sexual abuse not only affected the women's mental health but also the forming of relationships with others. Sue eloquently described the impact of sexual abuse upon her mental health and her sexual relationships:

I actually feel that with the sexual abuse, I feel like I've got quite close to madness ... And I found that if someone was attracted to me, it was almost an obligation to have to be in a relationship or to do something with them. It was like the impulse for my actions came from outside, not from me. I wasn't tuned towards myself and my own needs or anything, I was tuned towards meeting the needs of others and survival (Sue, Int, p. 5-6).

In this instance Sue felt it was her responsibility to fulfil the needs of others and not her own. Meeting others' needs was one way Sue ensured her survival and self-protection, as the consequence of not complying was potentially life

threatening. The passivity and subservience reported by Sue, has also found to be a common behavioural response arising from the experience of sexual abuse (Plumb, 2005; Williams, 2005). As others do not consider Sue's needs it becomes difficult for her to assert her own, and as result, her desires and needs become hidden and veiled.

Given these experiences, it was not surprising that Sue viewed sexual relationships as stressful and chose to withdraw from them:

Part of the reason why I don't have [intimate sexual] relationships is because I don't think I can handle the mental stress of a relationship (Sue, Int, p. 12).

Engaging in a sexual partnership is seen as difficult and by withdrawing from sexual relationships, this enables Sue to protect herself. This self-protection is particularly important as often the experience of sexual abuse can leave a person feeling powerless and vulnerable to other abusive relationships (Plumb, 2005). For Sue, an unseen effect of her sexual abuse experiences is that she perceives sexual relationships as unsafe and as such avoids and withdraws from them. Sue's comments illustrate how the experience of sexual abuse can influence a person's sexual expression.

For some women, the need to protect themselves affected not only their engagement in intimate sexual relationships, but also engagement in any close relationships. Limited involvement was a form of self-protection, and an essential way to manage one's mental health. Kaye described how as a result of experiencing abuse, she avoided getting close to people:

I am really too scared still. I'm fine meeting people, I do really well on the acquaintance front, but it's getting too close ... That's why I won't even go flapping; I'd like to. I don't think it is really possible to understand why people get scared of getting close ... It's always who is going to hurt me next? So I just don't get close to anyone, because they're just going to end up hurting you ... and if they hurt me, is it

going to be what ultimately kills me ...//... The trust thing is big. Trust is very very big. If you've been abused in the past that pretty much throws trust out forever (Kaye, Int, p. 5-6, 60).

For Kaye avoiding close friendships and relationships, including sexual relationships, is one way of defending herself from something that may ultimately “hurt” or “kill” her. Kaye’s words show how the experience of sexual abuse, which generally involves the betrayal of trust by a close adult or relative, can undermine a person’s ability to trust others or even themselves (Plumb, 2005). For Kaye, even flating with others was considered unsafe, and while withdrawal from others may be the safest option for Kaye, it also shows how the experience of abuse can contribute to a person’s sense of isolation and aloneness.

The women’s stories reveal the impact of sexual abuse upon their lives. Sexual abuse is usually secretive, with hidden consequences. The women spoke of the unseen effects of sexual abuse on their mental health and in the forming of relationships, both casual and intimate. To manage these experiences the women physically withdrew from others; their sexuality and identity became less visible and hidden from others.

Several of the women spoke of the effect of verbal abuse on their mental health and overall sense of identity. Verbal abuse, like the experience of sexual abuse, had unseen consequences. Sue described doubting she would ever heal from the impacts of verbal abuse, and the effects were so pervasive and damaging, she felt her identity was erased:

That’s the thing [verbal abuse] that made me hide it all away ... Just that rubbing out process is so damaging ... It doesn’t feel like there’s anything to offer anybody, anything there to even offer it with ... what an incredibly negative impact that has had on my sexuality (Sue, Int, p. 22).

For Sue the impact of verbal abuse is so destructive, she feels she has been rubbed out and has nothing left to offer others. Ramiro, Hassan and Peedicayil (2004) note that the experience of verbal abuse can often slowly and gradually undermine a person's confidence and self worth. Sue's comments echo this experience, as she is left feeling empty and drained and needing to hide away, out of the sight of others.

P5 also spoke of the effects of verbal abuse and felt it was harder to heal from verbal abuse than it was from physical abuse:

You can get over a hit, more so that you can get over the words. Because that was how my parents controlled me, by words. Whereas with physical abuse, it's nothing. For me it was nothing (P5, Int, p. 9).

P5's comments illustrate how "words", can have a more controlling effect than being physical assaulted. The impact of verbal abuse is possibly more controlling, because as a child that was how P5's parents managed her, and as such, it is this sense of being controlled as an adult, that makes it more difficult to overcome.

P5's experience like Sue's, illustrate how verbal abuse can diminish and demean one's sense of identity and agency. The consequences of verbal abuse, like sexual abuse, are often 'out of sight', but impact on the women's notions of self worth, relationships with others, and sense of isolation. The effects of abuse, both sexual and verbal, are wide reaching and can interlock to control how the women express their sexuality.

"Putting on a smiley face": The effects of female socialisation

Another theme that arose when discussing aspects of sexuality concerned the relationship between female socialisation and mental health. P5 spoke of the effect of prescribed female roles on her mental health and her depression:

I didn't realize I had learnt to put on a smiley face for everyone and I just kept closing up and closing up and deep down inside it was chewing away (P5, Int, p. 10)

For P5 there is a disjunction between her external presentation and her internal world. Her (“learnt”) “smiley face” hides what she is feeling, and her comments illustrate the hidden mental health consequences of conventional female roles that foster submissiveness, passivity, lack of assertiveness and appeasement (Williams, 2005). Feminine socialisation, which discourages women from expressing powerful emotions, such as anger (Stoppard, 1997), also silence P5 so her feelings are suppressed, and remain ‘out of sight’.

P5 also described other powerful controls that combined to subdue her expression of feelings:

Well one of my biggest stumbling blocks was feeling like I always needed permission and not validating myself; not feeling good about myself was number one. And giving myself permission to be a woman, to have a say and not feel threatened. I always felt threatened that something was going to happen to me, I was gonna get the bash, or something like that (P5, Int, p. 7).

For P5, feeling “threatened” has a silencing influence, silencing her from saying things, from being herself and from being a woman. Her comments illustrate how threatening behaviour, especially violent behaviour, can act as form of social control (Jackson & Scott, 1996), resulting in a sense of disempowerment. Her words describe the unseen effects and hidden consequences of such behaviours.

The women's stories make visible those hidden and “out of sight” aspects that influence their sexuality. The experiences of sexual abuse, verbal abuse, and female socialization intersect, and impact on the women’s mental health, identity, and connection with others, to then shape and control the women’s sexuality.

The next section outlines specifically the impact of the women's mental health diagnosis upon their sexual relationships.

“Calling you mental”: The effects of stigma

The impact of the women's mental health experiences on their intimate sexual relationships and their choice of sexual partner were themes that often arose. Georgina spoke of her current and past partners and how she only chose partners who also had similar mental health experiences:

I feel safer with someone with a mental illness, because they will not judge you. I don't like people calling you mental (Georgina, Int, p. 2).

Georgina's comments demonstrate the personal effect of stigma towards people with experiences of mental illness, as she avoids putting herself in an unsafe position in which she may be judged or labelled as “*mental*”. Her words illustrate how the experience of stigma associated with mental illness positions her as Other, and the outcome of this othering process, which affects her on a personal and social level, influences her intimate sexual relationships. Georgina's experience clearly highlights how the stigma associated with mental illness, can result in that person becoming socially excluded and marginalised (Ryan et al., 2003).

Unlike Georgina, Tina did not necessarily choose partners who had experiences of mental illness, but she was cautious and careful about disclosing her mental health experiences:

I kind of had like a rule for myself that it wasn't something that I'd just tell anyone, but it wasn't a secret either. I felt when beginning a relationship, I felt it was really important really early on to let the person know, and when I didn't feel they were going to run away because of it. ... I feel like the kind of people I chose to form

relationships with were trustworthy enough to kind of listen and take it in (Tina, Int, p. 11).

Tina's comments suggest there is a degree of risk in talking about her mental health experiences. Disclosure can be problematic. Tina takes care with whom she makes such a disclosure and she waits until she feels there is a sufficient degree of trust that the person will not "run away" or reject her. For Tina's own self-protection, and her fears of being rejected, she needs to keep her mental health experiences partly hidden and concealed. Tina, like Georgina, chooses partners who will not judge her, but instead will listen and accept her.

In addition to choosing a safe time to disclose her mental health experiences, Tina also spoke of her partner needing time and support to come to terms with her diagnosis.

With Chris [pseudonym], I think I told her maybe after a month, and it was just when our relationship was getting quite serious and kind of trying to decide where we were going with it and we went out for dinner and I just told her a little bit about it, and I think she was kind of ... I think it was a lot of information to take in, and she kind of talked to some of her friends about it and just got some support about it. ... but she didn't move away or anything you know, she was still there in the relationship. So I think she kind of just worked through it herself and asked questions (Tina, Int, p. 12).

Tina suggests that timing was important for her and her relationship with Chris, and after a month, she discloses a small amount of her mental health experiences. This suggests that up until that time, there were good reasons for keeping such experiences secret and out of sight. Revealing a "little bit" about her mental health experiences was "a lot" of information for her partner, so Tina allows time for her partner to understand the implications and consequences of her disclosure. Tina's comments indicate how big the gulf is between those who have experiences of mental illness and those who don't, and how the experience of stigma enlarges this gulf, and shapes people's

behaviours. For Tina, she bridges the gulf and repositions her identity by disclosing only small amounts of her mental health experiences.

A person's mental health experiences can also be blamed for difficulties within a relationship. In this incident, Tina talked about her partner attributing the cause of their relationship problems to her mental state and not their relationship:

I was grumpy to him about something, and he said have you taken your medication? And I said you do not have the right to say that and if I'm grumpy at you, I'm grumpy for a reason ... But I think that was just a sign of our deteriorating relationship (Tina, Int, p. 11).

By Tina's partner proposing that her being *grumpy* is arising from her failure to take her medication, this then deflects the attention away from him, and puts any other cause for her feeling irritable 'out of sight'. This individualising approach to the cause of emotional states is a position that is upheld and maintained by psychiatry. Williams (2005) argues that psychiatry with its focus on "diagnosis, individual pathology and medicalised responses to distress" (p.162) detracts from causes that may lie outside of an individual. From this perspective, external relational aspects can then be overlooked as factors contributing to a person's distress.

Georgina and Tina's experiences highlight the impact of their mental health experiences and stigma on their sexual relationships. Again these experiences are generally unseen. The women manage these experiences either by choosing partners with similar experiences or by disclosing only when they feel the relationship has some future. The women's stories reveal the hidden consequences of stigma that impact on their sexuality and sexual expression, and psychiatry's contribution to this discourse.

“Pretending to be someone else”: The effects of heteronormativity

Three of the women participants were openly ‘out’ as lesbian. The two older lesbians spoke about needing to hide their sexual orientation and the impact this had on certain areas in their lives such as their relationships with family, the sexual relationships they entered into, their choices in life, and their mental health. Self-protection and safety forced the women to hide and, in some circumstances, deny their identity. While wanting an adult sexual relationship, some of the women found that the power and dominance of heteronormativity made it too difficult to be openly ‘out’ as a lesbian and as a result they engaged in heterosexual relationships.

I knew I was a lesbian from the age of about nine I think. Because of my background I was scared that that's who I was, and I hid it. ... I wanted children, so I got married, which wasn't what I wanted to do. That was a horrific experience, which didn't help towards my mental health ... and then I ended up on my own and my sexuality came to the fore again. But I was terrified, because by this time I had been living this life of how people saw me and I started doubting myself. And I didn't know where to go, what to do ... and eventually I just snapped under that and everything else (donna, Int, p. 4).

Donna's comments can be understood within the context of heteronormativity and heterosexism (Weeks, 1985). Although donna knew she “*was a lesbian*” from a young age, but she had to hide her sexual orientation, and, to have children, got married. For donna there was a disjunction between what was externally her “*life*”, and her internal attractions and desires. The pressure of living in the external world as a heterosexual and at the same time knowing she was lesbian contributed to the doubts donna had about her own identity. Having to hide and conceal one's lesbian identity has been attributed to causing adverse mental health effects (Meyer, 2003), and for donna, needing to keep her identity hidden also affected her mental health:

I mean for me, I had lots of issues, but it wasn't the fact that I was lesbian that caused them - it was the fact that I wasn't able to be who I am, and I had to hide it, and I had to pretend to be something, somebody else (donna, Int, p. 8).

For donna, keeping her sexual orientation hidden contributes to her mental distress, as she must hide who she is. “*Pretending to be ... someone else*”, indicates it is not just a part of her, but also her whole self that is kept hidden in order to become that someone else.

Jandy also spoke of the pressure to conform to societal expectations, to hide her sexual orientation and to present herself as a heterosexual woman:

Some of us we actually hid it, our sexual orientation, by trying to conform to what society wanted, by trying to be seen as having a partner of the opposite gender (Jandy, Focus grp, p. 3).

The comments from donna and Jandy illustrate the power of heteronormativity to shape people's lives. The force of these norms meant donna and Jandy had to suppress and keep ‘out of sight’ their lesbian identity, affecting their mental health and wellbeing.

However, once ‘out’ and open about their sexual orientation, Jandy and donna spoke of people viewing their lesbianism as the cause of their mental illness.

I've had that thrown at me and I just keep saying, no, [my mental illness] ... it's actually because I had the abuse as a child, and no I didn't become a lesbian because of that abuse either (Jandy, Int, p. 9).

Jandy's words suggest that people identify her lesbian sexual orientation as a source of pathology. Either her lesbianism caused her mental illness, or she became a “lesbian” as a result of her childhood “abuse” experiences. As a

result, Jandy has to carefully negotiate these claims by clearly positing the abuse as the main cause of mental illness.

Donna had a similar experience when she recalled a staff member who suggested that donna manage her mental health by entering into therapy for her lesbianism, and getting herself a boyfriend.

I had one particular worker probably for about three or four months, and I just came out, ... and she tried telling me that perhaps if I was to look at that, perhaps I could resolve some of my issues. And I said, oh, how do you mean? And she said, well why you are a lesbian? You know, do you think maybe you need to do some therapy around that and find yourself a nice bloke? (donna, Int, p. 6).

In this incident it seems the worker considered donna's sexual orientation to be a cause of donna's mental distress, and something that could be cured with therapy. The staff member's approach may be informed by homophobia, whereby being lesbian or gay is constructed as something abnormal (Owen & Khalil, 2007), and highlights how problematic it can be to reveal one's lesbian sexual orientation.

All three lesbian women however reported that social attitudes toward being lesbian or gay had changed, with a sense that today, society was generally more accepting. Tina, who was younger than the other two, spoke of lesbianism being viewed by her generation much more positively:

I kind of perceive lesbianism as quite a cool thing, like it was just a bit different and interesting and you know since the kind of renaissance that happened around AIDS and that kind of stuff. I think that the image of people who are gay has really changed ... I was from that generation anyway that was quite accepting, so even if I came across people who weren't accepting of it, they were usually a different generation and not people I admired (Tina, Int, p. 13).

Tina's comments suggest a combination of factors have contributed to lesbianism now being viewed more positively. These factors can be seen as reshaping the identity and social positioning of lesbian and gay people, and while Tina's experience is generally positive, unfortunately lesbians continue to be disproportionately exposed to prejudice, discrimination (Meyer, 2003), and homophobic attitudes from mental health staff (Owen & Khalil, 2007). This suggests that while some attitudinal changes have occurred, significant shifts are still required to overcome the ongoing effects of heteronormativity and heterosexism.

Although the women reported a positive change in societal attitudes towards lesbians, they all spoke of the stigma associated with mental illness, which had made coming out as a mental health consumer more difficult than coming out as a lesbian. Tina described it as "*double coming out*":

I do feel sometimes like being a lesbian with experience of mental illness, it's like a double coming out ... I was used to coming out as a consumer, and I think it's a much harder thing than coming out as a lesbian, in terms of stigma and discrimination that society places (Tina, Int, p. 13).

Jandy also had a similar experience:

It was a huge and bigger thing coming out as a mental health consumer than as a lesbian ... And as a result some people dropped away ... because of the stigma (Jandy, Int, p. 4).

Jandy's comments reveal the isolating and marginalising effect of stigma. For Jandy, the effect of being positioned as a person with experiences of mental illness, and hence Other, causes some people to move away. For both women the experience of stigma associated with this subject position makes disclosure more difficult, and also suggests the experiences of stigma and discrimination may be intensified as they are positioned as women who are lesbian, and who have a mental illness.

The women's experiences highlight how societal attitudes and assumptions can shape a person's life and their sexuality. The effects of heteronormativity and heterosexism required the older women to initially hide their sexuality, and while overall society may be more accepting towards lesbianism, the women's comments illustrate that powerful stigmatising attitudes towards people with mental illness still persist that reinforce their position as Other.

“Who would actually like to be bigger”: The effects of medication

Find me a woman anywhere who would actually like to be bigger. Or enjoys putting on weight. Even if she can lose it again fairly easily (Kaye, Int, p. 18).

A theme that consistently arose was the change in the women's identities associated with medication. Weight gained from the side effects of medication affected the women's self-image and relationships with others, and led to feelings of shame and embarrassment.

My main side effect was weight gain. That definitely had an impact on my self-esteem and my feelings of worth. It was a bit of an issue when I had a boyfriend, but once I was single, it was more of an issue (Tina, Int, p. 11).

Weight gain is a very common side effect of nearly all psychotropic medication (McDevitt, Snyder, Miller, & Wilbur, 2006), and for Tina, the weight she gained negatively affects her self-esteem and confidence. Tina shows how powerful the connection is between body image, identity and one's self esteem as the changes to her weight and body image are felt on both a personal and relational level, and being single intensifies these effects.

Kaye also gained weight (nearly doubling her weight) when she started on medication for a physical health concern, and although a change of medication

saw Kaye lose some of that weight, the effect on her self-image and self-esteem continued:

I am very bitter about the weight gain thing. I've lost a lot but not all of it and I have never recovered from that. I still absolutely hate the way I look ... it's incredibly distressing. I feel a lot of my potential may have been ruined because of that drug (Kaye, Int, p. 16).

Kaye's comments reveal how weight gained from the side effect of medication can have lasting, significant physical and emotional consequences, as the weight gain effects her identity and sense of ability. The effects are both immediate and long term, as she dislikes her physical body, and feels her future aspirations have been damaged. Among people with enduring mental illness, the medication side effect of weight gain has been noted to be particularly burdensome, and contributing to the social exclusion and marginalisation that people experience (McCann & Clark, 2004; Schulze & Angermeyer, 2003), and Kaye's comments echo this experience.

Kaye identified two other factors that contributed to her feelings of guilt; the current obesity debate, and staff viewing her increased weight as a psychological failing rather than a medication side effect:

I feel as guilty as hell, because of being bombarded with all this obesity stuff. The obesity nearly killed me. But the interesting thing was I was blamed pretty much by everyone for the weight gain ... It was suggested to me that people comfort eat and make themselves fat to avoid relationships and anybody finding you attractive. It was put to me that way, and yes I'm very aware of that, but this was drug induced, and I was being blamed for it ...//... I know people who have been on [physical health related] drugs who do not have a psych history at all, and they have never been blamed for their weight gain. Never (Kaye, Int. p. 16-17).

Kaye's story illustrates how weight gain is often seen as an individual failing, even when, as was the case for Kaye, the cause is pharmacokinetic. Kaye experiences blame being apportioned to her both on an individual and societal level and the burden of these unseen factors are so powerful it "nearly killed" her.

As a result of these wide-reaching effects, Kaye felt doctors should give more recognition to the impact of weight gain on women's experiences.

That is the worse thing that doctors are still prescribing these drugs, and as far as informed consent goes, well weight gain is one thing that is still rarely, if ever mentioned and if it is, it's downplayed so much, that it is made out it's not going to be a big problem. I think the weight gain in females is an issue whether you want a relationship or not. I think we're probably so influenced by media and Hollywood and everything that ... I don't think most of us want to be anorexic or anything, there is this influence whether we think we are or not. And basically ... even if you are a size 16, you know you don't look good. And you can't feel good (Kaye, Int, p. 16-17).

Kaye's comments capture how powerful norms can shape and influence a woman's identity and self worth. To minimise the controlling effect of these cultural norms upon a woman's life, Kaye suggests, compromises the notion of informed consent, thus implying, that issues related to gender also need to be considered in any discussion on medication use.

Both Tina and Kaye's comments illustrate the consequences of weight gain arising from prescribed medications. While weight gain is visible, other unseen, out of sight factors are apparent. The change in appearance affects the women's self esteem, their identity and potential. Powerful cultural norms influence ideal body size and these norms intersect with psychiatry, and its reliance on medication, to dominate and control how the women express their sexuality.

Conclusion

In this chapter, the women have outlined the 'out of sight' and unseen experiences that affect their sexuality. These experiences include both sexual and verbal abuse, female socialisation, the stigma associated with mental illness and with being lesbian, and the medication side effect of weight gain. The consequences of these experiences were also generally hidden, and affected the women's mental health, their relationships with others, identity and self-esteem. The 'out of sight' experiences, combined with their unseen consequences, interlock to influence and control the women's sexuality.

In this chapter I have discussed the hidden and secretive experiences that affected the women's sexuality, thus the title 'Out of Sight'. As I was also interested in whether the women had felt staff had addressed their sexuality experiences, and any suggestions for improvement, the main themes that emerged from that discussion are presented in the next chapter. Titled 'Out of Mind', chapter five discusses the staff responses to the sexuality experiences of women constructed as mentally ill, or out of their minds.

Chapter Five: ‘Out of Mind’

Introduction

This chapter examines how the women experienced staff attitudes towards their sexuality. I begin the chapter by providing a general overview of the women’s experiences of staff attitudes. I then explore the women’s experiences of staff responses from various clinical settings, including community residential services, acute units and long-stay inpatient units. Issues regarding staff availability and client confidentiality are then presented. Throughout this chapter I use the phrase ‘out of mind’, to argue that the women’s experiences suggest they have been positioned as women who are mentally ill. This chapter concludes with the women’s suggestions for how staff and clinical services could improve and be more responsive to their sexuality experiences.

“A lot of staff are really iffy about it”: The attitudes of staff

The women considered their sexuality to be an important aspect of their identity and wellbeing. However the response from staff seldom seemed to reflect this view, with several women reporting that health professionals appeared reluctant to discuss their sexuality. Georgina observed that:

A lot of the staff are really iffy about it ... Some don't feel comfortable ... It depends on the staff (Georgina, Int, p. 2-3).

Georgina notices staff reactions that she interprets as feelings of discomfort. This sense of discomfort is not unexpected, as health professionals often report feeling uneasy and awkward when discussing sexuality related matters with people who experience enduring mental illness (Collins, 2006; Cort et al., 2001; Pyke et al., 2002). While some staff may have discussed issues related to Georgina’s sexuality, for Kaye this never occurred:

I don't think anybody even asked me if I had a partner, or boyfriend or girlfriend ... I mean it is not something I've brought up openly, willingly...but at the same time I was never asked either...but if people that I had a pretty good relationship with, if they'd asked me ... yeah, I would have said (Kaye, Int, p. 11).

Kaye reports that none of the staff have asked about whether she is in a sexual relationship, and again this is not surprising, as nurses often report feeling awkward initiating these discussions and as such, either do not ask, or else wait for the client to raise the topic (Collins, 2006). However, as is evident in Kaye's situation, waiting for the client to raise the subject may result in it not being discussed at all. While staff may be reluctant to discuss sexuality related topics with Kaye, she was willing to discuss these matters with someone she trusted. This willingness of people with enduring mental illness to discuss their sexuality is consistent with findings from other studies (McCann, 2000; Volman & Landeen, 2007), but unfortunately Kaye did not have this opportunity.

Rhonda spoke of staff viewing her engaging in sexual activity as abnormal and making the assumption that she had never been sexually active:

The so-called experts see it as being abnormal ... Because I wasn't in a relationship, they decided that I never had one ... They made an assumption that I had never been in a sexual relationship (Rhonda, Focus grp, p. 21).

Rhonda's comments suggest that staff were unable to see her as a sexually active woman, and her story illustrates how health professional's perceptions can at times pathologise a person's sexuality (Deegan, 1999). In this situation, it seems that staff may have positioned Rhonda as Other, and it is this positioning that has shaped how staff respond to her.

Jandy believed a person's sexuality was an important aspect of one's identity, and as she was interested in how mental health services addressed the issue of sexuality, she approached staff to discuss this topic:

I spoke to [a mental health organisation] about it [sexuality] and it is kind of like they didn't want to know. It is like it is in the too hard basket ...//... and sexuality is, it's part of your very being, it's part of who you are (Jandy, Int, p. 2-3, 7).

From Jandy's experience it appears that while she views sexuality as important, for this mental health organisation the notion of sexuality may not have been a priority. This lack of responsiveness towards sexuality related issues has also been reported in other studies, as Collins (2006) found that barriers operated at both an individual and institutional level within some mental health services to limit the sexual expression of people with enduring mental illness. It is possible that Jandy may have encountered some of these barriers.

There were times when the women did discuss their sexuality with staff. Tina spoke about her experiences and impressions, whilst as an inpatient on an acute mental health unit:

I think the first conversation I had with the doctor about sexuality issues was when I was about to leave the hospital, and it was mainly around contraception - they just wanted to check I was taking contraceptives. Well I took it as basically saying that, well you're pretty crazy, so you're probably irresponsible. Yeah, and because you're crazy the worst thing that could happen would be for you to get pregnant right now. I was happy to talk about the stuff, just a little indignant that they thought I might not use contraception (Tina, Int, p. 1).

Tina's experiences offer insights into how the sexuality of women with enduring mental health illness is viewed from within the medical model. Tina

is willing to discuss her sexuality, but the doctor only discusses her sexuality upon her discharge. This suggests that prior to her discharge her sexuality was not overtly considered an important component of her mental wellbeing. However, when the topic of her sexuality finally is discussed the focus is primarily on contraception and avoiding pregnancy, and the wider relational aspects are not considered. This focus on pregnancy prevention has also been reported as the main priority for other mental health providers (Collins, 2001). Tina interprets the focus on contraception as coming from the mindset that because she has been mentally unwell, her decision-making abilities regarding contraception would then be impaired. Tina's story shows how the experience of mental illness can then shape and influence how others will construct a person's sexuality and, not surprisingly, Tina finds this approach annoying.

While sexuality was not explicitly discussed, Tina described the boundary setting rules in the unit as very helpful, especially as some people were more overt with their sexuality:

Within the ward, a lot of people in the ward are kind of elevated or they are just a bit more vulnerable, so sexuality, it's kind of more to the surface ... And I remember once, I developed quite a close friendship with one of the guys on the ward, and he was kind of flirty and I mean we never crossed any boundaries, but it was good that there were boundaries in the ward, like not going into each other's rooms, and stuff like that, that kind of had a bit of safety about it (Tina, Int, p. 2).

Tina's comments suggest that a person's sexual boundaries can be affected when they are unwell. Given that a person may be in a vulnerable position, the external boundaries and rules in this situation can be seen to help a person re-establish some control over their actions and enhance their personal safety. Generally, as a result of concerns surrounding a person's mental state and capacity to consent to sexual behaviour, sexual activity on acute psychiatric units is prohibited (Ford, Rosenberg, Holsten, & Boudreux, 2003). Client protection is critical, and in Tina's example the staff's primary focus in regard to a person's sexuality also seems to be safety and risk aversion. While this is

extremely important and essential, it does appear that other aspects of a person's sexuality may not have been considered.

In another incident, Tina described how a staff member had implied that her giving a woman a shoulder massage in the open day ward was not appropriate:

I was really interested in massage, and there was a woman on the day ward that I got on with quite well, so I gave her a shoulder massage, and the nurse came up and said you can't do this in the day hospital – you have to go into a private room. ... The nurse said to me something like, it'll make other people uncomfortable or maybe because you're giving her a massage and not everyone. I didn't really get what her reasoning ... But [staff from a community mental health provider] go into the day ward and give every one a foot rub. I was kind of confused about that. I'm just rubbing her shoulders and I felt like it gave it the wrong connotation (Tina, Int, p. 2-3).

Adding to Tina's sense of confusion regarding the massage episode was the fact that it seemed acceptable for others from an outside organisation to give a massage, but not for her. This suggests that certain behaviours may be viewed differently depending upon how that person is positioned. So for Tina, as an inpatient, her physical contact may have been viewed from within certain safety parameters and therefore considered inappropriate, while the behaviour of staff from the mental health organisation was viewed within a more favourable and acceptable perspective. Again Tina's experience highlights how certain behaviours, including displays of human connection, may be judged and perceived differently when a person's is perceived as mentally ill and constructed as Other.

While staff from the acute mental health units were seen as actively discouraging sexual activity between clients, staff from the long-term rehabilitation units were considered to have a different approach. Jandy spoke of staff knowing that people were engaging in sexual activity in the hospital grounds, but choosing to ignore it:

It wasn't healthy because it was done in the grounds and other places and staff just turned a blind eye (Jandy, Focus grp, p. 18).

Jandy's comments suggest that either due to unit regulations or a lack of privacy, people were forced to be sexually intimate in public places like the grounds of the hospital. By turning a "*blind eye*" the staff looked but did not see; making invisible the human desire for sexual intimacy and sexual expression among people with enduring mental illness. At the same time, turning a "*blind eye*" also suggests that sexual activity in the grounds was only condoned and seen as acceptable because the people who were engaging in that activity were people with a mental illness.

Another activity Jandy felt staff turned a "*blind eye*" to, or more concerning, seemed to accept as the norm, was the practice of sex trading for cigarettes. This was where female clients traded sexual activities in exchange for cigarettes:

They [staff] turn a blind eye to the buying and selling of women's bodies in exchange for cigarettes ... it was a currency and the currency went, 'a smoke for a kiss, two for a cuddle and four for all the way. Four smokes for a poke' (Jandy, Focus grp, p. 17).

Jandy's words suggest that by accepting the practice of sex trading for cigarettes, staff are condoning, albeit covertly, the economic exploitation of women's sexuality. Sex trading or sex in exchange for goods or money is a common experience among women with enduring mental illness, and according to Weinhardt et al. (1999), generally involves a degree of coercion as women are often economically disadvantaged to meet their financial needs. The need for women with enduring mental illness to exchange sex for cigarettes both reflects the limited economic opportunities available to them, and the commodification of their sexuality, and the response of staff could be seen as supporting these systems. By staff overlooking such activities they and the hospital system could be seen as condoning and reinforcing systems that

exploit a dependence on tobacco, and controls the women's sexuality. Finally, by staff condoning such behaviours as sexual activity in public places and sex trading this suggests the staff may have viewed the women's sexuality from within a certain perspective or position. By constructing the women as mentally ill, this enables certain activities that fit within that position to then become permissible and acceptable.

The women also reported that staff attitudes varied often depending upon where they worked. Georgina's partner had been resident on both a long-term inpatient unit and also a supported community house, and when living in the community house, Georgina had felt the staff were much more accommodating of their relationship than when he was on the inpatient unit:

The staff at [inpatient unit] they have a dumb attitude. Rude as nurses. I was going up every day to see him. I wasn't going to bugger off. Then he moved to [name of community housing provider]. The staff there they have much better manners, they are not rude, their attitude is not rude. That is the only time I get to see him. I get so lonely and I miss the one I love. My wish for the future is to live with him. (Georgina, Int, p. 3)

Georgina contrasts the behaviour of the staff at the inpatient unit who she considered to have a "dumb attitude" with the staff at a community house, whose actions seemed to be driven by a more respectful stance. A more positive approach from the community housing staff may indicate that sexual relationships are seen as a human right and valued as important for a person's recovery and quality of life (Volman & Landeen, 2007). One possible explanation for this may be that in the community the main priorities are for client's to live life fully and meaningfully, as opposed to the safety and acuity needs in the inpatients units. Also, the majority of staff in community housing providers tends to be non-professionals, with some providers employing staff specifically for their consumer expertise (Moxley & Mowbray, 1997). The difference in approach could possibly reflect the greater influence of the consumer staff, as having had experiences of mental illness, these staff are

probably less likely to position the people they are working with as Other. As Moxley and Mowbray (1997) explain, the aim for consumer involvement in service provision is that consumers will bring to their roles an empathy and understanding that those with formal training often cannot. As Georgina's words illustrate, the need for intimacy and sexual expression is a universal one, and the staff at the community house seemed more able to accommodate this human need.

Tina also spoke of staff that worked in a community setting being generally more open and willing to discuss her relationships. However, in one situation she described not readily disclosing aspects of her relationship as she sensed staff might have been slightly judgmental:

I broke up with my boyfriend. But we didn't let go of our sexual connection, I just didn't feel like I could let go completely – and I didn't tell my worker that! I just said that we'd broken up. I guess that was a quite a lot to withhold in a way, because it had a big effect on how I was feeling ... it was pretty confusing ...//... I felt like the [staff] might disapprove. I felt a little bit of judgement there, but I mean she was a very non-judgemental kind of person (Tina, Int, p. 4-5).

Tina's story illustrates how perceived attitudes can create barriers to a therapeutic relationship. Even though Tina felt the staff member was non-judgmental, she was concerned she may have been negatively judged for maintaining a sexual relationship with her ex-boyfriend. Tina goes on to explain feeling particularly concerned about how staff perceived her, because she had just been through a difficult period in which she needed to be hospitalised:

Interviewer: *So, I could be wrong here, but I'm wondering, is that [not disclosing] about you wanting to look good in their eyes?*

Tina: *Definitely yeah. I think I really wanted to prove myself in a positive way. I think that was really important to me because ... I*

wanted to kind of prove to myself ... I'd been in hospital ... I'd just been through this terrible, embarrassing experience, and felt like an absolute idiot, and I wanted to recover from that (Tina, Int, p. 5).

A helpful way for Tina to manage these feelings of shame and embarrassment surrounding being unwell, is to present herself in a positive light. It is important for Tina not to reveal something else, for which she could be disapprovingly judged. Tina's story demonstrates the power of societal norms and attitudes in shaping people's behaviours. For Tina, concerns that her relationship may not have been seen as subscribing to social norms of sexual behaviours and relationships, coupled with the shame and stigma associated with mental illness, inhibits her disclosure. Cook (2000) argues that people with mental illness often internalise the disapproval society holds towards their sexuality, and from Tina's story she reveals how these social norms and assumptions can intersect to control and silence aspects of people's sexual lives.

The women's experiences offer insights into how health professionals, organisations and possibly society, may view the sexuality of women with enduring mental illness. The women's mental health diagnosis influences how others respond to their sexuality. Being constructed as mentally ill or 'out of mind', the women are either considered asexual and therefore sexuality issues are irrelevant and inappropriate, or their sexuality is seen as problematic. From this perspective, sexuality is predominantly viewed from the behavioural aspect and, therefore, the focus is on avoiding pregnancy. This positioning allows for sexual behaviours that are possibly considered socially inappropriate (sexual activity in hospital grounds and sex trading), to then be condoned and allowed. Being positioned as Other also allows for the human need for intimacy and closeness to be overlooked. The individual, institutional and societal barriers that exist can both inhibit and silence staff and the women from addressing their sexuality experiences.

“You don’t want your sex life getting into your file”: The notion of confidentiality

Another factor the women identified as impacting on discussions surrounding their sexuality was time and confidentiality. In both inpatient and some primary health care settings the nurses were seen as too busy and not having the time to discuss sexual concerns.

The nurses are always in a hurry, they have got no time. It really helps if the nurse has time to talk about these things, and it’s confidential (Georgina, Int, p. 1).

Georgina’s comments imply that the nurses did not view her sexuality-related issues a priority, as they were busy with other things. However, when the nurses were available, the need for confidentiality was essential. For Georgina, knowing that the discussion with her nurse was confidential gave her the reassurance to talk about her sexuality.

Kaye questioned the whole notion of confidentiality, especially knowing that all discussions she had with her community mental health nurse were documented in her mental health notes, which any member of the mental health team could then access:

There’s also the issue in the system that we know damn well everything we say gets put down in the notes ... and within five minutes, everybody else, everybody else knows. ... I’d like to know that if I said something to my community nurse, that it is in confidence. But more often than not they go running off and tell the psychiatrist or their team leader. You know there isn’t that patient confidentiality. It’s a load of bullshit basically. It certainly is in the mental health system ... it’s bad enough when you are trying to hide the fact that you want to go and cut your wrists, but you know, you don’t want your sex life getting into your file either (Kaye, Int, p. 11-12).

Clearly for Kaye the fact that whatever she said to her nurse would then be discussed with others undermined her sense of confidentiality. Not only are her personal and private issues going to be discussed with others, but also they are documented, and therefore accessible for the wider mental health team. Kaye also implies that talking about one's sexual relationships is more embarrassing, shameful and personal than talking about self-harming. Underpinning this point seems a concern about how others will judge Kaye. She implies staff judge her when she discusses her thoughts of self harm and suggests this judgement and disapproval might be greater if she were to talk about her sexual relationships. As McCann (2000) explains, confidentiality and trust are essential features needed to encourage clients to discuss their sexuality, and for Kaye this lack of confidentiality and degree of trust creates a barrier for her to talk about the very intimate and personal aspects of her sexuality.

Kaye further expanded on her concerns surrounding confidentiality, particularly the content of what was documented:

You don't even know how they're documenting it ... even how it gets recorded can be misinterpreted, completely. Not necessarily maliciously. And once it is written down, it is never removed. And a lot of people can access those notes (Kaye, Int, p. 12).

Kaye's comments suggest that staff may make certain assumptions or interpretations about her behaviour that may be inaccurate. Once they are written down these assumptions can then become fixed, definite and unable to be removed. Her comments highlight the power of the written word to shape and influence others' impressions of her and, in some way, shape her identity.

Kaye acknowledged she was more trusting of the documentation processes of health services outside of the mental health system, such as her GP or Family Planning. She explained the reason for her difficulty in trusting mental health staff arose from previous traumatic admissions into psychiatric hospitals:

How can you trust staff in the mental health system when – especially when you've been hurt by them? Badly. (Kaye, Int, p. 13)

Kaye's comments regarding lack of trust highlight the legacy of the mental health system in which people have received harmful treatment (Department of Internal Affairs, 2007). The impacts are ongoing in that they affect Kaye's level of trust in staff and the system and as a result she is more trusting of health providers outside of the mental health system. The information she gives to her GP or Family Planning staff about her sexuality is documented within a system that Kaye possibly sees as less harmful and safer. One possible explanation is that outside of the mental health system, Kaye's mental health diagnosis may have less impact on how others perceive her sexuality. Another possible explanation is that for services such as GP or Family Planning, sexuality related issues may be more readily discussed. Therefore engaging in sexual activity is less likely to be pathologised, and more likely to be viewed as a normal part of human behaviour and life.

“Affirming of what a person wants”: Suggestions for staff

All the women made suggestions for how staff and services could better address their sexuality experiences. These suggestions could be seen as a rejection of their psychiatric identity, the associated negative constructions of their sexuality, and the reconstruction of a positive affirming identity. To facilitate discussions about sexuality the women stressed the importance of being able to trust staff, and approaches that promoted that trust included acceptance of that person and their lifestyle.

It's got to be a situation where you can trust that person as much as you can possibly trust anybody (Kaye, Int, p. 33).

Is it safe to talk to this person about my sexuality? Or what kind of reaction am I going to get from them? You've got to get a feeling you

can trust that person ...//... What helps with that trust is when health professionals accept our choice of lifestyle (donna, Int, p. 2-3).

As Kaye and donna's comments suggest, trust is essential to any discussion about a person's sexuality, especially when discussing sexuality risks eliciting a harmful response. As mentioned in the previous chapter, what seems to make this disclosure more unsafe is when the other person is a staff member and therefore in a greater position of power and dominance. Underpinning this need for safety implies a need for staff to accept the women and their identity as sexual subjects.

Other suggestions made by the women that would demonstrate acceptance of their identity included, staff to be affirming of their sexuality, and supportive of their sexually intimate relationships:

I think affirming your relationship is really important. Or, even if there isn't a relationship, they [staff] need to be affirming of what a person wants around that (Tina, Int, p. 16).

It's really important that staff support us, even if there is never going to be a relationship, supporting that potential is still really, really important (Sue, Focus, p. 12).

Both Tina and Sue's comments highlight the importance of recognising and supporting the sexual aspect of a person's identity, and the value of intimate relationships. Acknowledging the role of relationships in women's lives is especially important, as relational aspects are considered central to women's sexuality (Kaschak & Tiefer, 2001). In Ritscher et al.'s (1997) survey of women with severe mental illness, they also found that personal relationships were identified as central to the women's lives and a key part of their identity. Given its importance, Tina felt that staff should recognise both the positive and negative aspects of a person's relationship:

I guess a lot of the time relationships aren't perfect, and I think sometimes health professionals in general can negatively judge relationships ... they kind of hear the bad stuff, because often that's what a person will talk about, and I think it is important to appreciate that relationships are a whole thing - that a person wouldn't be in them if they weren't providing some kind of benefit. And if the mental health professional is able to appreciate the benefit, the person might kind of feel more trusting in terms of what they disclose (Tina, Int p. 17).

As Tina's comments imply it is important for staff to recognise the benefits of any relationship within a person's life. Disapproval of a woman's relationship may then have significance consequences for that woman, as her sense of identity will also have been questioned. As Tina suggests, sexual relationships are generally accepted as part of the rich tapestry of human life and for staff to discourage such behaviours may position this group of women as different to others in society.

The women also suggested that staff have training around heterosexism and homophobia.

The nursing and mental health profession need to look at and understand lesbian or gay culture. To learn and understand about homophobia, and for professionals to know that the gay culture isn't a stereotypical thing; that gay people range from somebody who definitely doesn't look gay, to somebody who can be very butch looking (donna, Int, p. 28-29).

The need for staff to improve their knowledge related to sexual orientation is consistent with findings from Welch, Collings and Howden-Chapman's (2000) New Zealand study of lesbian's experiences of mental health services. The most common anti-lesbian experiences reported in their study were mental health staff failing to recognise the impact of living in a homophobic society. Particular areas identified included a lack of recognition and

understanding of the conflict around disclosure of one's sexuality, the legal rights of partners, and relationship and family difficulties (Welch et al., 2000). This suggests that while staff may not have been overtly homophobic, the more subtle forms of discrimination and heterosexism were still apparent. As heterosexism renders lesbians invisible and silenced (McEvoy, 2000), the women's suggestions are one way to make visible the sexuality experiences of lesbians with enduring mental illness.

The women felt that staff attitudes towards lesbian and gay people had changed, and were now slightly more accepting. The fact that more staff were openly 'out', support groups were available, and a shift in public perceptions had occurred, were identified as contributing towards this change among staff. A change in staff attitudes also suggests a change and re-positioning in how lesbian and gay people are socially constructed, thus enabling people better access to claim their identity as lesbian or gay. In this study, this repositioning also seems to have made it safer and easier for the women to claim their identity as lesbian.

Another area the women identified as important was in regard to their personal safety when on inpatient and residential units. The women spoke of being sexually harassed and threatened by some of the men, and donna described her experience whilst on an inpatient unit when a male client was being sexually inappropriate:

When I was in (inpatient unit, name deleted) there was one guy who had some kind of sexual problem, and he just kept flaunting himself, he'd go naked and stuff like that. I asked the staff to tell him to stop it, but it wasn't picked up. The staff, they put it down to him being unwell and crap like that. Anyway it was put back onto me saying I had to accept that he wasn't well and I needed to accommodate that. Too bad that I wasn't well either (donna, Int.p. 16).

When donna approached staff for assistance to manage his behaviour, she felt unsupported in their response. Donna felt that, rather than setting firm limits

with this man, staff made excuses about his interactions, blaming his mental state, and implying she be more accommodating and understanding of his behaviours.

In this incident it seems the staff were not fully cognisant of the effect of this man's behaviour on donna. They appear to have minimised the impact of his behaviour, and in doing so, almost condone it. While donna was asked to be more understanding of the man's behaviour, it seems the staff may have been implying that the problem was in fact her response to his behaviour. Unfortunately events of sexual harassment are not uncommon within psychiatric units, with many women reporting sexual abuse or intimidation while being hospitalised, and not feeling unprotected by staff (Glenister, 1997; Harris, 1997; Ramsey-Klawnsnik et al. 2006). As donna's words suggest, she too was unwell, and needed a more effective and understanding response from staff.

Given the potential for sexual harassment and abuse within inpatient units the women identified a need for separate male and female wards. Jandy, who had been involved in a review of the local mental health services spoke of her suggestion to ensure the safety of women within inpatient units.

I wanted separate male and female wards, total separate service. Because where you will still have shared spaces, so they are around, you are just so vulnerable (Jandy, Int, p. 24).

Jandy's comments illustrate that the current trend towards integrated male and female wards may actually be undermining the safety of the women. As noted earlier, and echoed by Jandy, mixed gender wards increase the likelihood of abuse occurring (Grant, 2003) and women are particularly vulnerable in these settings. Given that women are at increased risk of abuse whilst on these units and as reported in Chapter Four, the impact of abuse on a woman's mental health, her identity, and sexuality, Jandy's suggestion of separate spaces for women and men, could be one way, from an organisational level, that mental

health services show their acknowledgment of the sexuality experiences of women with enduring mental illness.

Conclusion

The desire for intimacy, love, and sexual expression is a common human need. However, the women's experiences revealed that when constructed as mentally ill this dimension of human need became pathologised, and shaped and influenced the attitudes and approaches of some staff. In some settings this positioning was also reinforced at an institutional level. For example, the condoning of sexual activity in the hospital grounds and sex-trading, and the use of mixed gender wards were identified by the women as experiences that denigrated their sexual identity. Although the women's stories showed how these norms and practices could interlock to control aspects of their sexuality, the women were all able to re-position themselves and state how they would like health professionals to address their sexuality experiences. The women's suggestions can be seen reclaiming their identity as fully human sexual subjects. These issues are explored in more depth in the following chapter.

Chapter Six: Insight / Discussion

Introduction

Powerful systems interlock to oppress the sexuality of women with enduring mental illness. These systems include patriarchy, the medical model, heteronormativity, and the stigmatisation of mental illness. These systems have material effects on the women's lives and how the women are located in society. Although it is often hard to see these interlocking systems, the women's stories make visible the effects of these systems. These systems are often maintained and upheld by mental health providers.

The previous chapters, Chapter Four 'Out of sight' and, Chapter Five 'Out of mind' explored in detail the women's sexuality experiences. In this chapter, the significance and relevance of these experiences is brought into view. This 'insight' into the women's experiences are drawn together and discussed within two overarching frameworks, 'Interlocking Systems of Domination', and 'Other'. The chapter concludes with my own insights and reflection on undertaking this research.

Interlocking Systems of Domination

The women's experiences revealed that sexuality was an important aspect of their lives, well-being and identity. These findings were not surprising given that sexuality is often considered a central aspect of one's being (WHO, 2004). The women also identified experiences that at times rendered their sexuality invisible. These experiences included the impact of both sexual and verbal abuse, the stigma around mental illness and its influence on forming intimate sexual relationship, female socialisation, sexual orientation and the double 'coming out' experience as a lesbian and as a mental health consumer, and the use of prescribed medications. The women's experiences make visible powerful systems that controlled their sexuality. As hooks (1989) argues, systems interlock to dominate and control aspects of women's' lives. For the

women in this study, these systems often intersected to make their sexuality invisible.

Abuse

Several of the women spoke of their experiences of sexual and verbal abuse and its impact on their mental health. The link between sexual abuse and mental illness has been found in other studies, with rates of sexual abuse among women with enduring mental illness between 50-75% (Lothian & Read, 2002; Wells, 2004). Similarly, verbal abuse has been associated with depressive symptoms and is considered to be as harmful as other forms of interpersonal violence such as physical violence and sexual abuse, (Cocker et al., 2002; Ramiro et al., 2004). The women's experiences of hallucinations and depression echoed the above findings.

Long-term abuse is a form of social control. For those in a subordinated position, abuse encourages passivity, submissiveness, and being amenable to others in positions of dominance (Williams, 2005). Although the literature on verbal abuse is limited Ramiro et al. (2004), suggest the less evident consequence of verbal abuse is that it can reduce a person's psychological ability to deal with adverse events and is detrimental to notions of confidence and self worth. For the women in this study, the experiences of verbal abuse resulted in them feeling controlled, effaced and diminished.

While the impacts of physical abuse are often visible, the effects of verbal and sexual abuse are hidden. As hooks (2004) theorises that patriarchy, or male domination, is expressed and maintained through sexual and verbal abuse and that abuse, like other rituals of power, ensures the domination of another person. One of the effects of abuse can be to undermine a person's sense of identity and agency. The women's experiences of feeling lonely, and needing to withdraw from others as a form of self-protection, as well as their diminished sense of connectedness with others, illustrate some of the invisible and dominating effects of abuse.

Given the potential for long-term adverse physical and mental health effects associated with abuse, Cocker et al. (2002) recommend that clinicians screen for psychological as well as physical and sexual forms of violence. The effect of abuse reported in this study supports this recommendation. The women's experiences of abuse affected their mental health. It also affected their sexuality, their sense of identity and their relationships with others. These findings add weight to the recommendation that clinicians consider not only the physical and mental health effects of abuse, but also how these experiences affect a person's sexuality.

Socialisation

Gender roles and female socialisation also impacted on the women's sexuality. Gender roles work in ways that are not always visible. They are often 'out of sight' but powerfully influence what are considered socially acceptable ways of self-expression. Female socialisation tends to position women in the role of having to accommodate others, sometimes at the expense of their own sense of entitlement (Williams, 2005). Conventional female roles that promote appeasement and submissiveness can then function to suppress feelings and emotions, leading to a loss of self-awareness and depression.

Hooks (2000a) argues that assertiveness can be seen as a threat to femininity as female socialisation encourages women to deny their own feelings and emotions. The weight of social expectations can make it difficult for women to take a position of agency and assertiveness. Javed and Gerrard (2004) note that gender roles lock women in the relatively powerless position of 'Other'. It then becomes an easier and more rewarding option to 'be compliant' rather than resist the gender roles by being 'self-assertive' (Javed & Gerrard, 2004). In this study, the women's descriptions of feeling submissive, silenced and obligated to meet the needs of others illustrate the power and controlling nature of gender roles. These feelings impacted not only on the women's mental health, but they also influenced how the women expressed their sexuality.

Sexist socialisation also constructs male sexuality as predatory and rampant, and female sexuality as passive and as a dampener of men's desires (Tolman, 2001; Jackson & Scott, 1996). As women are positioned to meet the sexual needs of men (Williams, 2005), this can make it more difficult for a woman to draw upon her sense of power when negotiating a sexual encounter. Female socialisation, combined with the subordinating effect of abuse, can make it difficult for women to articulate their own sexual desires.

Stigma of Mental illness and the Medical Model

The experience of the stigma associated with mental illness also influenced how the women expressed their sexuality. Mental illness is considered one of the most stigmatised of illnesses (Johnstone, 2001). The social exclusion and marginalisation that arises from stigma limits a person's active participation in society and their access to citizenship entitlements (Pilgrim, 2005). In this study, the experience of stigma impacted on the women's sexual relationships. The women either chose partners who had similar experiences, or partners who the women felt would be accepting of their mental health experiences. This highlights how the experience of stigma can influence not only a person's social identity, but also the way a person will engage with others (Ryan, et al., 2003).

The women's experiences illustrated how the influence of the medical model makes the stigma of mental illness more problematic. Stigma draws upon powerful labels that are historically and socially specific (Pilgrim, 2005). Historically, people with enduring mental illness are seen as dangerous, violent, and different (Beresford, 2005). These societal attitudes are perpetuated today. They inform and are reinforced by the practice of psychiatry. Within the institution of psychiatry, the medical model regards mental illness as a brain disease or biochemical dysfunction (Double, 2005). The cause of person's mental distress is seen as a brain disorder – it is an individual failing. This diagnosis positions the person as essentially and biologically different from a non-diagnosed person, and as Other. As Double (2005) explains, "The objectification of the mentally ill in the biomedical

model can make psychiatry part of the problem rather than necessarily the solution to the problem of mental illness” (p. 68). Psychiatry’s reliance on the medical model with its focus on individual pathology and diagnosis can be seen as contributing to the stigma associated with mental illness.

The institution of psychiatry can also intersect with other powerful systems to reinforce gender roles and sexist socialization. Psychiatry’s utilisation of the Diagnostic and Statistical Manual of Mental Disorders (DSM), defines not only what is constructed as abnormal behaviour and thus a mental disorder, but also constructs “what society can expect as normal behaviour” (Crowe, 2000, p.584). Crowe argues that the DSM and the resulting diagnostic systems reflect certain gender, class and cultural biases that serve to maintain oppressive power relations within society. Women are therefore more likely to have their experiences viewed as signs of a mental illness because of the way society constructs gendered subject positions.

Heteronormativity and Heterosexism

Western sexuality is shaped by heteronormativity, and the idea that a loving, lasting couple is essentially heterosexual (Plummer, 1995). In this study, heteronormativity was especially visible in the accounts of women who had experienced heterosexism; or the construction of heterosexuality as normal and healthy, and homosexuality as abnormal and deviant. For lesbian women, heterosexism was experienced on varying levels. The older lesbian women encountered people who viewed their lesbianism as the cause of their mental distress, and this became particularly problematic when the people were health workers and in positions of power. The women’s experience of heterosexism within the mental health system raises issues about the power of mental health system to shape and maintain normative structures such as heteronormativity.

Up until 1973, homosexuality was defined as a mental disorder within the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Klinger, 2002). The decision to delete homosexuality from the DSM occurred as a result of political pressure that challenged the pathologising definitions of

homosexuality (Weeks, 1985). Although removed from the DSM, attitudes did not change over night, and while today there is a greater acceptance of lesbians and gays, women in this study reported experiencing negative stereotypes towards their sexual orientation.

One effect of negative stereotyping and the associated experiences of stigma, prejudice and discrimination, is that lesbians are viewed as having particular mental health needs (Meyer, 2003). Hellman (1996) suggests lesbians with chronic mental illness may be doubly disadvantaged as they face both the stigma of being lesbian and of having a mental illness. The women's experiences in this study support this point, as they discussed the double 'coming out' as a lesbian and as a mental health consumer.

However, an unexpected finding was that the women found it more stigmatising to disclose about their mental health experiences than being lesbian. This may suggest that while societal attitudes towards lesbian and gays have shifted, very negative, discriminating views towards people with mental illness are prevalent. One possible explanation is that the cause of mental illness is commonly seen as arising from within a person, something in the person's nature that is inherently wrong, unpredictable and dangerous, and therefore a threat to public safety. While being seen as lesbian or gay is generally considered less of a threat to others. The fact that the government has made it a priority to counter the stigma and discrimination associated with mental illness, and promote social inclusion and recovery through projects such as the Like Minds, Like Mine (2007) and the work of the Mental Health Commission (2004), suggests that widespread societal discrimination is seen as a public issue that requires a policy response. The pervasive effect of this discrimination offers one explanation for the women finding it more difficult to disclose their mental health experiences than their sexual orientation.

The women's accounts of homophobic and heterosexist attitudes from some staff, as reported in this study, were also found in a New Zealand study of lesbian's experiences of mental health services (Welch et al., 2000), with nearly 30% of the respondents reporting some form of discrimination. Deegan

(1999), a renowned mental health consumer activist, asks mental health professionals to consider:

How are inpatient units and community-based programs organized to be inclusive of people who are gay, lesbian or bi-sexual? How are gay, lesbian and bi-sexual men and women who also have major mental illness assisted in coping with the double discrimination they encounter? How are issues of staff homophobia and heterosexism addressed in programmes? If these issues are not being addressed, what does that say about assumptions regarding the sexuality of people diagnosed with major mental illness? (p. 25).

Deegan's (1999) critique that a heterosexist bias exists in many mental health services was confirmed by the lesbian women in this study. By not addressing these issues of homophobia and heterosexism, the dominating assumptions appear to be that a person's sexual orientation, their homosexuality or bisexuality, is irrelevant and separate from their mental health needs. Deegan's questioning of staff assumptions could also be considered more broadly in regard to the sexuality of all people with an enduring mental illness. While I discuss this in more detail in the following sections, the overall experiences described by the women in this study suggest that mental health providers did not consider the women's sexuality of importance and of value. Deegan's comments, like those from the women in this study, support the notion that sexuality is an important component in a person's care and needs to be considered when addressing a person's mental health needs.

Identity

The cultural norms upon which female bodies and identities are shaped can act as a form of social control. Within feminist literature, the female body represents the "cultural marker of sexual difference" (Crowe & Alavi, 1999, p. 31) and a woman's self identity is often determined with and through her body. A woman's control over her appearance is often viewed as the most socially condoned form of power available to a woman (Caplan & Cosgrove,

2004). The women in the study described the impact of weight gain (a side effect of the psychotropic medications they were prescribed) on their notions of self-image and their feelings of worth. The sense of embarrassment and shame, reported by the women, of their bodily changes, suggests how the experience of weight gain can contribute to a women's sense of inferiority or Other.

The women's comments about weight gain also raise the issue about how large bodies or 'obese people' are viewed in society, and the medicalised view of what is considered a 'normal' body (Ryan & Carryer, 2000). Ryan and Carryer (2000) argue that for those whose body weight is considered more than normal, "powerful cultural assumptions are attached" (p.36) to their personal identity. 'Overweight people' are often considered to be unhealthy, out of control and failures. Generally, weight gain is seen as an individual process and blame is apportioned individually, even when, as was evident in the study, the cause of that weight gain is pharmokinetic. The experiences of the women in this study illustrate how psychiatry's reliance on the medical model and medication can reinforce this individualising apportioning of blame.

It could also be argued that the weight gained from medication can further marginalise and stigmatise women with enduring mental illness. The domination of the medical model within mental health services means the prescribing of psychiatric medication to relieve a person's mental distress is one of the main treatments provided. However, the side effect of these medications that result in larger body sizes may actually contribute to the stigma, marginalisation and social isolation of people with mental health experiences. Weight gain has been referred to as the stigmata of mental illness (Schulze & Angermeyer, 2003), and the women's accounts of weight gain negatively impacting upon their sense of self worth and notions of social inclusion, illustrate how the medical model, with its reliance on medication, can contribute to that experience of stigma.

Various interlocking dominating systems are evident in the women's experience of weight gain from prescribed medications. These include patriarchal views of ideal female body size, the medical model of what is considered normal body weight, and psychiatry's reliance on medication. These systems intersect and impact on how the women view their bodies, their sense of self, and their relationships with others. These systems and their associated cultural assumptions regarding body size were then reinforced by mental health staff who individualised the cause of the women's weight gain as some personal failing.

In this discussion on the 'Interlocking Systems of Domination', the women's experiences have revealed several systems that controlled and influenced how they expressed their sexuality. These included experiences of abuse, female socialisation, stigma associated with mental illness, heteronormativity, the medical model, cultural norms of ideal female body size, and psychiatry. These experiences intersected and interlocked to affect the women's sense of identity, self worth, mental well-being, and connection with others. In the following section I present my insights into the attitudes of some health professionals, as reported by the women, towards their sexuality, and include suggestions that would enable staff to be more responsive to the sexuality experiences of women with enduring mental illness.

The Other

The women openly discussed their sexuality with me and were very generous and forthcoming with their experiences. Raising the topic of sexuality in a general way allowed for a depth of discussion and was consistent with other studies in which people with enduring mental illness have freely discussed the subject of sexuality (McCann, 2000; Volman & Landeen, 2007). However, the women reported that health professionals were generally reluctant to discuss sexual issues, and this finding concurred with other studies (Collins, 2006; Pyke et al., 2002), and possibly accounts for health professionals traditionally

not addressing or prioritising the sexuality needs of people with enduring mental illness (Cort et al., 2001).

Several factors can contribute to this reluctance, including the health professional's own attitude towards sexuality. As Carr (1996) explains, sexuality is controlled by social expectations and beliefs, and as a result, the sexuality and sexual behaviours of certain social groups (including people with experiences of mental illness), have become stigmatised. These beliefs and misconceptions influence the attitudes of staff. As noted previously, health professionals generally tend to view people who experience enduring mental illness as either asexual, or that their engagement in sexual activity is inappropriate and likely to inhibit recovery (Buckley & Wiechers, 1999; Dobal & Torkelson, 2004). These beliefs, along with a concern that raising the topic may encourage sexual expression (and the enduring influence of eugenics), may contribute to health professionals' general reluctance to discuss sexuality related issues. Unfortunately, this ambivalence can also reinforce and promote stigma and social exclusion, as it reiterates the undesirability of people with enduring mental illness expressing their sexuality. The attitudes of some health professionals, as reported by the women in this study, appear to echo these beliefs.

This study further demonstrated that when sexuality related topics were discussed they tended to be concerned with the avoidance of pregnancy. This raises two issues: firstly a woman's competence to manage her own fertility, and secondly, eugenics. Cronin (2004) argues that doctors often hold sexist assumptions regarding women's decision-making abilities around fertility, and often assume that women are in need of contraceptive advice. These beliefs may intensify when a woman's identity is constructed as 'having a mental illness'. Underpinning these concerns is the influence of eugenics which, historically, has resulted in the involuntary sterilisation of many women with enduring mental illness (Deegan, 1999), the administration of hormonal contraceptives without consent (Egan et al., 1993) and, until 1992, made it illegal for an unmarried women under the Mental Health Act (1969) to consent to sexual intercourse. Currently, eugenic ideas are still influential within

psychiatry with the dominance of the genetic model of mental illness and psychiatric research (Schulze et al., 2004). Within the clinical setting, eugenic influences may also account for the women in this study, like those in other studies (Collins, 2001), feeling that pregnancy prevention was the main priority of mental health providers.

While the women found that staff did not openly discuss sexuality issues, covert attitudes were reported (particularly from staff in the long-term rehabilitation units), which seemed to condone both the practice of sexual activity in the hospital grounds and sex trading. Unfortunately, these findings were not surprising, as I had encountered similar activities and attitudes in my own clinical practice. The condoning of sexual activity in public places like hospital grounds, raises the issue of the needs and rights of inpatient residents to sexual intimacy. Even though it is known that clients of long-term units do engage in sexual activity, most units do not uphold this right to sexual intimacy but rather view sexual activity as problematic (Dobal & Torkelson, 2004). Deegan (1999) argues that rather than seeing sexual activity as being problematic, it is the institution's lack of private and dignified places in which consenting adults can be sexually intimate that is the problem. It could be argued that this lack of a private space is because people with enduring mental illness are positioned in society as Other. It is unlikely that sexual activity in the gardens would be condoned if members of the general public were engaging in it. However, when a person is constructed as Other, this allows for behaviours that might otherwise be considered unacceptable and degrading to be permitted and condoned.

The practice of sex trading, raised in this study and reported in others (Cournos et al., 1994; Meade & Sikkema, 2007), reflects both the lack of economic opportunities available to women with enduring mental health experiences and the commodification of their sexuality. Clarke (1996) argues that under the system of patriarchal domination, the use of women as a sexual commodity by men positions women as property or object and thus innately inferior. Central to this practice is what Jackson and Scott (1996) refer to as the construction of female and male sexuality, in which women are seen as the

“provider of sexual services and men the purchasers” (p.24). Such practices they argue also intersect with other oppressive aspects of women’s sexuality such as sexual violence and the precedence of male sexual needs (Jackson & Scott, 1996). By staff condoning the practice of sex trading, this suggests they are also supporting and maintaining those systems and the subject positions available to women.

Staff attitudes and practices may also reflect a widely held belief that people with enduring mental illness are either incapable of meaningful sexual relationships (Buckley et al., 1999), or that there is something deviant about the notion that they may be involved in acts of sexual intimacy. As such, staff may accept, albeit covertly, certain sexual behaviours based upon these assumptions. If people with enduring mental illness were viewed as capable of meaningful relationships then long-term units could provide more dignified, respectful settings in which people could engage in intimate sexual behaviours, and staff could actively address the sexuality aspects of a person’s care. The women’s stories in this study suggest that staff attitudes and practices are informed and shaped by the construction of people with enduring mental illness as Other and female constructions of sexuality. These influences intersect and appear to provide the basis for certain sexual behaviours to be permitted and condoned. Eugenic ideas also seem to intersect in this matrix, resulting in anxiety about reproduction becoming the main focus of staff attention.

Telling of Sexual Stories and Recovery

All the women described how improvements in staff attitudes and approaches could help foster discussions about their sexuality. They sought to encourage a change in attitude, particularly an affirmation of the women’s sexuality. The women’s suggestions can be seen as an attempt to make visible what was invisible, and a challenge to the identities that had been constructed around their sexuality. The telling of one’s story is seen as crucial for self-recovery, and for the process of moving from Other (hooks & Mesa-Bains, 2006) to a position of authorship. From a feminist perspective, the voicing of women’s

personal experiences is an important process of politicisation and emancipation. As hooks (1989) states that “oppressed people resist by identifying themselves as subjects, by defining their reality, shaping their identity, naming their history, and telling their story” (p. 43). The suggestions made in this study can be seen as enhancing the opportunities for the sexuality stories of women with enduring mental illness to be told.

However, for the women’s sexuality stories to be heard there needs to be a strong community of support ready to receive and listen to them. Plummer (1995) argues that sexual stories or stories of intimacy “focused around the erotic, the gendered and the relational” (p. 6) will only emerge when the surrounding culture makes it safe to be told. The more stigmatised and marginalised a person or group is, the less likely their stories will be told and heard. Plummer theorises that the telling of one’s sexual story sits within a powerful hierarchical framework, in which certain sexual acts are given value and voice depending on their position within this hierarchy. This sexual hierarchy influences whose stories will be told and whose will be silenced. Within this hierarchy, the voices of married, reproductive, heterosexual couples are the loudest, while “the elderly who speak of their desires may be looked at suspiciously...and ‘underclass’ sexualities are silenced” (Plummer, 1995, p. 30).

Plummer (1995) adds that gender, race and class also intersect this hierarchy, making some stories harder to be told and heard. Although mental illness is not a category included in these examples, it does suggest that in the sexual hierarchy, the experience of mental illness impacts on its positioning, its societal value, and consequently how the sexual stories are told and heard. For the women in this study, the practices of staff are possibly reflective of where women with enduring mental illness are positioned in this hierarchy, thus resulting in the women’s stories and voices being silenced. The suggestions for staff identified in this study, can be seen as strategies for creating a safe and supportive environment and community, within which the women’s sexuality experiences and stories can be acknowledged and heard.

The building of this positive culture in which the women's sexual stories can be voiced is essential for the process of recovery. According to Watkins (2003), the expression of one's sexuality and engaging in intimate relationships are considered important aspects in the journey of recovery. Recovery generally involves occupying social positions from which one has been excluded and to claim one's citizenship and, in this instance, intimate citizenship. 'Intimate citizenship', a term coined by Plummer (1995), describes a person's rights and responsibilities in matters of intimacy, desire and sexual expression. Recognising intimate citizenship means the stories of people whose sexuality has been pathologised and silenced can be then be told and heard. Incorporating this concept into the recovery approach would then allow for the unheard sexuality stories to be voiced and integrated into a person's care. The suggestions proposed by the women in this study provide staff with ways to further facilitate the women's access into this sphere of citizenship and recovery and, at the same time, remind staff that the human need for intimacy, love and connection is universal.

Reflection on the Research Process

The systematic way that my thesis is set out suggests that the research process has been a linear one. I started with my questions and aims, researched the literature, undertook the interviews, analysed the data, and reached my conclusions. However, this organised approach contradicts the bewilderment that I have at times felt, and the divergent paths that I have set out along.

The first issue of confusion and then insight for me was around the literature. As noted in Chapter Two the majority of the literature clearly described the risky sexual behaviours of women with enduring mental illness (Coverdale et al., 1997; Randolph et al. 2006). The underlying assumption of these studies seemed to be that sexuality of women with enduring mental illness was problematic. As I discussed in Chapter Three in the Reflexivity section, when I presented this literature to prospective participants this had a shaming effect, and I felt saddened that I had in some way contributed to that shaming

experience. Fortunately, there were a few studies that presented sexuality in a broader and more positive way (McCann & Clark, 2004; Volman & Landeen, 2007), and I decided to discuss only those studies when recruiting the women.

The second main area of confusion that emerged around the literature occurred during the interviews. While the literature presented the women's sexuality as problematic, the women did not talk about their sexuality in that fashion. The women's experiences were simply not present in most of the literature that I had come across. This led me to examine the possible reasons for the majority of research literature presenting the sexuality of women with enduring mental in such a problematic way. Reading more widely I encountered the concept of eugenics, and its current influence within psychiatry, including psychiatric research. This led me to theorise that the influence of eugenics not only informed some practices within mental health services, but also it had shaped some of the research focused on the sexuality of women with enduring mental illness. I also came to the realisation that the eugenic concerns had also shaped my own attitudes, and even the way I had started to undertake this study. In Chapter One of this thesis, I discuss in detail the concept of eugenics. As this is my introduction chapter this implies that my concern about eugenic influences were at the forefront of my thinking, however this awareness and insight only surfaced in the midst of this study.

Utilising feminist theory to inform my study has allowed me to examine in depth the interlocking structures that dominate the women's sexuality, as well as the impact of being constructed as mentally ill. Had I considered the women's stories with my own preconceived notions of sexuality derived from the literature, then the findings of this study may have reflected a more behavioural, individualistic, and eugenic approach. The process of writing reflexively, a key feature in feminist research, allowed me then to examine not only my position of power within the research process, but also my own biases and prejudices. While this has been challenging, engaging in a reflexive process has highlighted for me that I am not a "disembodied 'objective' knower" (Lather & Smithies, 1997, p.xiv) but rather connected to the knowledge that emerged from this research relationship. From this

relationship, I believe my personal consciousness has been raised, and as a result, significantly changed my understanding of the sexuality experiences of women with enduring mental illness.

Conclusion

This chapter illustrates how powerful invisible systems interlock to dominate and shape women's experiences of sexuality. This chapter shows how the women experience being positioned as Other and how this positioning influences the care they receive from mental health providers. However, the women clearly identified ways to resist the attitudes of staff and were able to claim subject positions in which they were a 'sexual citizen'. Claiming this position is considered an important aspect in the process of recovery and citizenship. The insights from this chapter make visible the sexuality experiences of women with enduring mental illness. The chapter also offers suggestions to enhance the 'insight' of mental health professionals.

The next chapter, Chapter Seven, summarises the main points of this thesis, in particular focusing on creating a culture where sexual stories can be heard. Chapter Seven also includes recommendations suggested by women and my own analysis, and I conclude with a discussion on the limitations of this study, and identify areas for further research.

Chapter Seven: Conclusions

Introduction

The aim of this study was to explore the sexuality experiences of women with enduring mental illness. Throughout this thesis I have used the phrase 'Out of Sight, Out of Mind' as an overarching framework upon which to explore the women's experiences. While the women saw their sexuality as an essential component of their identity, the response of mental health providers was often one of silence and taboo, and experienced as a strong message, that limited their potential to be a sexual citizen.

In this chapter I conclude this thesis by arguing that powerful interlocking systems operate to control the sexuality of women with enduring mental illness. I also argue that accessing the position of intimate citizenship is essential in the process of recovery, and conclude with recommendations that would enable the creation of a culture within mental health services in which sexual stories can be told, and suggestions for further research.

Creating a Culture for Sexual Stories

The women's stories revealed powerful social, cultural, historical and medical practices that operated as a system of control over the women's sexuality to render their sexuality hidden and veiled. These often unseen practices included sexual and verbal abuse, heteronormativity and heterosexism, social norms that influence the women's notions of identity and self worth, and the impact of stigma associated with mental illness. These powerful systems not only shaped and influenced the responses from mental health providers but at the same time were reinforced and reproduced by the actions of some staff and services.

The women's stories illustrated that these 'out of sight' experiences had material effects upon their lives; affecting the women's mental health, their

sense of identity, their ability to make connections with others and their sense of social inclusion. The women's stories highlighted the need for health professionals to attend to this aspect of a person's care, and to create a culture in which the women could openly discuss their sexuality. The creation of a culture where it is accepted as normal to discuss sexuality and tell personal sexual stories can be seen as one way to resist the marginalisation and stigma associated with being positioned and constructed as mentally ill. Recognition of the personal aspects of the women's sexuality is, in itself a political act, as it will help reveal those structures that attempt to silence and control their stories, and at the same time it will support the women to claim access to the subject position of sexual citizen.

Access to this sphere of citizenship is a critical aspect of recovery. For people who experience mental illness, recovery involves regaining one's personal power and sense of belonging as well as being recognised as "whole human beings" (Mental Health Commission, 2004, p.7). For mental health services to support people in their recovery, this then requires a commitment from staff to be responsive to the sexuality experiences of women; to genuinely engage with this aspect of the women's identity; and to recognise the importance of intimacy and love.

The women's experiences have brought to light the need for a mental health culture that is supportive of a person's sexuality and sexual expression. This requires a change in mental health providers' practices and attitudes. However, given that the experience of one's sexuality is shaped and influenced on many levels, it is essential that change occur not just at an individual and organisational level but also at a societal level. The following recommendations consider these three areas, and have arisen from the women's suggestions and my own analysis of the women's stories. They are designed to create a culture in which the women can tell their sexual stories, thus enhancing the women's access to intimate citizenship and recovery.

Recommendations

Individual

The recommendations for individual practitioners to enhance intimate citizenship and recovery are:

- That mental health staff address the topic of sexuality, in its broadest sense and not just as a sexual activity. This topic is to be seen as an essential component of a person's care and recovery, and sexuality related issues are to be incorporated into everyday practice.
- That the professional development for mental health staff include an understanding of the social and cultural norms that influence and shape a person's sexuality, including the stigma associated with mental illness, and psychiatry's contribution to this system of control.
- That the professional development for mental health staff include an understanding of the impact of gender, especially in regard to female socialisation, and also the effect of weight gain secondary to prescribed medication use, upon a woman's identity and feelings of self worth.
- That staff routinely enquire about a woman's experience of abuse, especially sexual and verbal abuse, and have an understanding of the effect these experiences have upon a woman's mental health and her sexuality.
- That the professional position of all mental health staff is one of accepting all sexual orientations, and having an understanding of the effect of heteronormativity, heterosexism and homophobia on the mental health of lesbian, gay, bisexual, and transgender people, and also the practices that uphold these beliefs.

Organisational

The recommendations for mental health providers to enhance intimate citizenship and recovery are:

- That policy and clinical guidelines are established that provide staff with clear guidelines on how to address the sexuality experiences of people with enduring mental illness. Women and men with enduring mental illness need to be involved with development of these policies and guidelines to ensure their acceptance and appropriateness.
- That staff are provided with on going education and skills training regarding sexuality, and engage in regular clinical supervision to examine their own values, beliefs and attitudes towards sexuality.
- That separate female only spaces are allocated within inpatient units to enhance the women's safety and lessen the potential for abuse.
- That long-term mental health units provide inpatients with private and dignified settings for sexual intimacy, and systems are established to ensure client safety and the promotion of safe sexual expression.
- That documentations systems are further developed to enhance confidentiality and trust to discuss sexuality issues. This could involve a dual system in which clinical notes that are accessible to the clinical team only contain the main areas that were discussed regarding sexuality, and the more private matters are documented in a separate file, only accessible to those directly involved in the person's care.

Societal

The societal recommendations to enhance intimate citizenship and recovery are:

- That projects such as the Like Minds, Like Mine, that are designed to counter stigma and discrimination associated with mental illness, incorporate gender issues and rights to sexual citizenship into their programmes.
- That people with experience of mental illness are trained and supported to deliver the sexuality programmes for mental health services. As a result of their experiences, people with enduring mental illness are best placed to challenge stereotypical and discriminating attitudes towards their sexuality, and at the same time, leading and delivering these programmes will enhance their leadership skills and abilities, and participation in society.

I believe the implementation of these recommendations on an individual, organisational and societal level, will help challenge and counter some of the barriers that position sexuality as problematic, and instead will help create a culture within mental health services that is supportive of a person's sexuality and sexual expression.

Limitations

The limitations of the study became apparent to me as I was undertaking the analysis of this project. As a nascent researcher, drawing on postmodern feminist theory, I became aware that my analysis was just one construction based on my interpretations of the particular issues that were being presented. Throughout this study, I have been mindful of, and attempted to keep, the women's voice in the foreground rather than let my own voice dominate.

However, at the same time I know I risked essentialising the women's experience, therefore, I acknowledge that one's experience of subjectivity is not fixed but rather multiple identities are possible, and as such, this thesis, is my representation of the women's stories and their experiences.

The small number of women involved in this study could be seen as a limitation of this study. Despite the size, I feel this study is able to further the understandings of women with enduring mental illness. All the women were resident in the same region; as such the women's accounts of staff's responses were possibly only a reflection of the culture of those services. However, similar experiences have also been reported in other international studies.

Further Research

The women in this study have brought 'to sight' some of their sexuality experiences. This study has also revealed the need for further research to enhance this knowledge and understanding. As the women in this study were all living independently in the community, a qualitative research project about the sexuality experiences of women currently resident on long-term units, or living in supportive accommodation, would be useful. This would address some of the residential issues raised in this study, and assist with the development of policies and guidelines relevant to those settings.

In recent years feminist research has turned its attention to the body as an object of investigation (Fonow & Cook, 2005). Turning the feminist lens to the impact of prescribed psychotropic medications on the body and cultural norms of appearance would also broaden our understanding of the issues that surround medication use and the experience of mental illness.

To further complement the findings of this study a qualitative research project exploring the sexuality experiences of men with enduring mental illness would help strengthen knowledge around gender and sexist constructions of sexuality. By utilising a Foucauldian theoretical approach this would enable a

deeper understanding of the discursive constructs that surround and define what sexuality is.

Finally, a study that examined the attitudes and approaches of staff and services that already integrated sexuality related issues into their care of a person would provide some useful insights for all mental health providers. This study could involve mental health staff, and those from primary health care providers for example, sexual health specialists, youth health workers and family planning. The aim would be to identify those experiences, including education or training programmes, which have led to the formation of a positive attitude toward issues of sexuality and the benefits these bring when providing care. By drawing upon the knowledge and expertise of those staff members that already practiced in this way, would enhance the development of educational programmes, and policies and clinical guidelines to support staff to integrate this aspect of care into their therapeutic relationship. It would also assist in the creation of a culture in which sexual stories can be told and heard.

The knowledge from these future studies would assist with the implementation of the above recommendations. However awaiting further evidence before changes occur within services may represent a missed opportunity for mental health providers to support women with enduring mental illness, to develop their potential for intimacy, sense of community, re-shape their identity, and recovery – the time to enact these recommendations is now.

The women in this study have shown that their sexuality is an important aspect of their identity, their wellbeing and humanness, and not something to be hidden and kept 'out of sight'. The need to have one's sexuality valued and respected is a universal one and it offers health professionals a significant opportunity to make a positive difference. Not to do this risks reinforcing women with enduring mental illness as 'out of their minds' and different from others. As Sue described:

Sexuality ... I think that's one aspect of dealing with a mental health problem – that's one thing that I feel I've been completely alone with ... and I feel like I'm separate from the rest of humanity (Sue, Int, p.3).

Intimate citizenship is central to recovery. To make recovery possible staff must start exploring ways of breaking down barriers, and reducing that separateness. Individual actions, organisational and wider social changes have been identified. Undertaking these changes will help collapse the gap between 'out of sight' and 'out of mind' and offer staff valuable 'insight' into the importance of sexuality to a person's life and sense of wellness.

Appendix A: Letter to Services requesting participation

Kia ora

Good talking with you the other day. As we discussed I was wondering if any women that attend your service would like to participate in my study. Plus also what would be the best way to do this with regard to respecting protocol?

Briefly the aim of my study is to explore the sexuality needs of women with enduring mental illness. That is women who have been given a formal diagnosis of Schizophrenia, Depression, Bipolar and Personality Disorder. To date there have only been a few studies, and only one New Zealand study. However findings from these studies have found that women with these mental health experiences have high rates of sexually transmitted infections, HIV, sexual coercion, sex trading, sexual abuse, sexual dysfunction, engaging in risky sexual behaviours, and abortions. The impact this has on the women's sexual and mental health and overall quality of life is very significant. Plus there is also the impact of stigma and the effect this has on a women's ability to form intimate relationships.

It is certainly an area that needs to be addressed better by service providers and health workers. However, in order to do this effectively, the voice of the women needs to be heard and integrated into what is already known. This is where I see my study sitting.

Therefore I would like to invite women from your service to participate. I plan on having an interview with the women, either individually, or with whanau present, for approximately an hour. The women will then be invited to attend a group meeting with all the women involved to discuss how they would like their sexuality needs addressed by service providers and health professionals. However if they only want to participate in the individual interview that is fine.

The women will also be invited to report back the findings to the various services involved, and health professionals. The findings from this study will be used to develop policy and practice guidelines for service providers and health professionals, and the women will be invited to participate in this if they wish.

In return for the women's and your service's participation, I am prepared to organise for any health related workshops or education sessions that the women identify as needed.

I am able to come and discuss this with you and the whanau if you wish. Thanks for taking this to your management committee. I have also attached a draft information sheet that I would give to the women, outlining the study.

Look forward to hearing from you.

Thanks again for you support

Joanna Davison



Appendix B: Information Sheet

Kia ora

My name is Joanna Davison. I am a registered nurse who is studying at Massey University, doing some research for my Masters degree.

I have been working in the area of mental health nursing for over 15 years. I work at Whitireia Community Polytechnic in Porirua, teaching nursing students, in the Bachelor of Nursing programme.

Before that I worked at a primary health care service, Newtown Union Health Service. While I worked there, I became aware that the women I met who lived with an enduring mental illness, were very keen and interested to talk about their sexuality. They often talked about things like wanting a partner, safe sex, contraception, the effect medication had on their sexual function, and their self-esteem. It seemed that the health professionals and services the women were seeing did not ask about their sexuality. I looked into the research on this and found that, while there is not a lot of information, this group of women experience high rates of sexually transmitted infections, being pressured into sex, and sexual problems. These things can of course effect a woman's sexual and mental health, and their overall quality of life.

This is a very important issue. However, in order for us as nurses to provide better care in this area, we need to hear how it is for the women. Therefore, the aim of my study is to talk with you about your sexuality needs, and how you would like these needs to be addressed by us as nurses, other health professionals and service providers.

So, if you are a woman who is either currently, or in the past, received care and treatment within the mental health services, I would you like to hear from you. I expect we might talk together for about one hour. I'll be asking you about your sexuality needs and whether or not your nurse or doctor has ever talked with you about these. Plus I would really like to hear how you think nurses, doctors, other health professionals and service providers can do better in meeting these needs.

I am also planning to organise a follow up meeting with all the women who have been interviewed, so we can talk about the issues that have been raised. Again, I hope this will last approximately one hour's duration. However, if you only just want to talk to me that is fine. I don't want you to feel pressured into coming along to the group meeting. It is entirely up to you whether you wish to come to this meeting.

To guarantee your privacy and confidentiality, you and the other women, can choose the place where we can meet, e.g your home, or private room in the drop-in centre. At any time you can withdraw from the study. This is your right. You can also choose not to answer a question. If you should decide to withdraw I'll give you the tapes and written report from our interview. It is also important to know that if you do withdraw from the study this will not effect your involvement in any current or future health care service.

If you agree, the interviews will be recorded on a tape recorder and then be typed up by a typist. I will return the written copy to you and you will be able to say if it is correct and remove any pieces, sections you are not happy with. I may also ask if some of your words could be written up in the final report. Again I will only do this if it is OK with you. I'll also give you written copies of our interview and a summary of the final report.

I am aware that this is a very personal topic. Therefore, before we start the interview, we will sort out what supports you would like should you start feeling stressed. I will also have the contact details of a support person you

could ring. Remember at anytime you can end the interview, and you don't need to explain why.

To guarantee your confidentiality, your real name will not appear in the written report. If a personal name is used, it will be a false name or pseudonym, chosen by yourself. No material which could personally identify you will be used in any reports on this study. All information, the tapes, discs, written reports, your consent sheets will be kept in a secure, locked cabinet. Only myself, Dr Annette Huntington who is my supervisor, and my typist, will see their content. At the end of this research the written record of your interview will be locked securely in the Social Science Archives at Massey University for 10 years.

As I said above, when I have finished my study, you and the other women will get a copy of my final report if you wish.

In summary you have the right to:

- Say no to being involved
- Withdraw at any time
- Have your privacy and confidentiality protected
- Turn off the tape recorder at any time
- Ask questions at any time
- Receive written reports of the interviews and final report.

If you would like some more information about this study, I am more than happy to meet with you, and your friends or whanau to answer any questions you may have. See my details below.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone

0800 42 36 38 (4 ADNET)

This study has been approved by the Central Regional Ethics Committee.

If you wish to be part of this study I can be contacted at the following address:

Joanna Davison
Nursing Centre of Learning
Whitireia Community Polytechnic
Private Bag 50 910
Porirua



If you wish to contact my supervisor regarding this research, Dr Annette Huntington, she can be contacted at Massey University (04) 8015799 ext 6315.



Appendix C: Consent form for participants

Consent Form:

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right not to answer any question if I do not want to.

I know I can end my participation in the study at any time without having to provide any reason or explanation.

I understand that Joanna (the researcher) will discuss with me about ending the interview, if it appears to be causing me some undue stress.

If I withdraw I understand that any material that I have contributed will be destroyed and not be used as part of the study.

I have the right to agree/ disagree to my interviews being tape-recorded.

I also understand I have the right to ask for the tape- recorder to be turned off at any time during the interview.

I agree to give information to Joanna on the understanding that I will remain unidentifiable. I also understand any information I give that could personally identify me will not be used in any of the report on this study.

I understand that Joanna will give me a written copy of my interviews and I have the right to remove or change any part I have said.

I agree to participate in the study under the conditions set out in the information sheet.

I would like to include the following conditions.

Participant _____

Date _____

Appendix D: Counselling and Support Services

The following is a list of Counselling and Health Services that you may find helpful in addressing some of the issues we talked about today.

Sexual Abuse Help Foundation, 24 hour
ph 499 7532

Wesley Inner City Counselling Services
ph 384 7695

Salvation Army
ph 389 0594

Relationship Services
ph 0800 735 283

Sexual Health Services
ph 0800 188 881

Warmline – Peer Support for mental health consumers
Ph 0800 200 207

CATT (Crisis and Assessment Treatment Team), 24 hours
ph 494 9169

Plus from your own service

_____ (name of support person and
phone number) is available if you wish to discuss any issues that we talked
about today.

Appendix E: Aide Memoire

- Experiences talking with health professionals about sexuality
- Access to sexual health services
- Stigma and intimacy
- Negative sexual health experiences
- Pregnancy
- Recommendations



Appendix F: Focus Group Confidentiality Agreement

I _____ (Full Name - printed)
agree to keep confidential all information concerning the project, 'Exploring
the sexuality needs of women with enduring mental illness'.

This includes the names and content of what was discussed in the focus group
I will not retain or copy any information involving the project.

Signature: _____

Date: _____



Appendix G: Transcriber's confidentiality agreement

I _____ (Full Name - printed)
agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature:

.....

Date:

.....

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