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Experiences of Mental Health Consumers : An Exploratory Qualitative Study of Expectations and Perceptions of Mental Health Services in Western Australia

Dawn Anne Barrett
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Expectations and Perceptions of Mental Health Services in Western Australia

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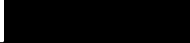
A Report Submitted in Partial Fulfilment of the Requirements for the Award of
Bachelor of Arts (Psychology) Honours
Faculty of Community Studies, Education and Social Studies
Edith Cowan University

October, 2000

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Experiences of Mental Health Consumers: An Exploratory Qualitative Study of Expectations and Perceptions of Mental Health Services in Western Australia

Abstract

The National Mental Health Strategy was launched in 1992 and endorsed consumer-provider collaboration as an integral part of mental health service delivery in Australia. Feedback on services is generally elicited through evaluation of existing services. Rather than being an evaluative study of existing services, this qualitative project explored the experience of being a mental health consumer within the framework of the consumer's expectations and perceptions of service delivery in Western Australia. One male and seven females, aged between 22-55 participated in the study. Several themes and sub-themes under the broad headings of Expectations, Experiences, Perceptions emerged. The themes highlighted consumers had no expectations of mental health services. However, management of illness and staff interactions produced a psychological response. For those who experienced negative interactions with staff fear was a dominant psychological response which changed over time from illness-related distress to fear of re-hospitalisation. All consumers reported an over-reliance on the use of medication and provided wider explanations for their episode of illness. A fourth category Reflective Comments, highlighted the inadequacies of the present services and the need for integrated biopsychosocial approaches. This small-scale study promotes a wider inquiry into the experience of being a mental health consumer in Western Australia. In particular, the differences in the experiences of private and public patients warrant further investigation.

Author: Dawn Anne Barrett
Supervisor: Dr Lynne Cohen
Submitted: October, 2000

Declaration

I certify that this thesis does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any institute of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature:  _____

Date: 16 November 2000

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

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For a project such as this, I am indebted to many people for their co-operation, support and guidance and take this opportunity to acknowledge them.

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Introduction

Background

Lifetime prevalence and incidence rates estimate one in five Australians will experience some form of mental health disorder (Burdekin, 1993). Although most are expected to recover, it is further estimated only 3% of these individuals will seek specialist mental health services (Burdekin, 1993). Driven by the paucity of epidemiological research in the area of mental health, the Australian Bureau of Statistics conducted a nationwide survey in 1997. Henderson, Andrews and Hall (2000) observed in the national sample of 10,600 persons aged 18 and over, figures indicated 17.7% of the Australian population reported at least one common mental disorder and 64.6% had not contacted health services in the previous year. In Western Australia, 18% (one in five) people surveyed (4,400 respondents, aged 18 and over) had some mental disorder in the past 12 months. Thirty-nine percent of these individuals used a health service and 32% consulted a general practitioner (GP); less than 1% was admitted to hospital (ABS, 1998). Nonetheless, despite the low rate of hospital admittance, mental health service delivery remains an area of particular concern in Australia.

The impact of mental illness on the community in economic and social terms is considerable (Whiteford, 1992). Prior to 1992, in the absence of strategic planning or policy, the Federal Government of Australia spent over \$2.5 billion on mental health (Ragg, 1994). More recently, the Federal Government has nominated mental health as one of the five National Priority Areas (ABS, 1998). In 1992 the Health Ministers of Australia endorsed the first National Mental Health Strategy (NMHS) in an effort to meet the needs of individuals who are affected by mental illness

(Australian Government Publishing Service [AGPS, 1992]). This landmark legislation set in motion an agenda of nationwide mental health policies and reforms through an approach that ensured collaboration between policy-makers, service providers, consumers and carers.

The brief of the NMHS was and continues to be, wide-ranging and responsive.

The primary aims being:

- the prevention of mental illness;
- the promotion of mental health;
- the reduction of the impact of mental illness on the individual, the family and community; and
- the protection of the human rights of people with a mental illness. (AGPS, 1992)

In the subsequent year, in keeping with human rights obligations Dr Brian Burdekin, the Commissioner for Human Rights in Australia conducted an inquiry “... on the premise that individuals affected by mental illness have the same rights as other members of our community” (Burdekin, 1993, p. 11) The inquiry consulted widely with service providers, consumers and carers and reported, “...the cost of mental illness in terms of human lives and suffering is enormous” (Burdekin, 1993, p. 15) The findings in the Report of the National Inquiry into the Human Rights of People with Mental Illness (Inquiry) supported the conclusions that “... current neglect in terms of violations of the most fundamental rights of Australians affected by mental illness ... demand an urgent, concerted and effective response” (Burdekin, 1993, p. 15)

Of particular note was the spectrum of recommendations emanating from the Inquiry that targeted all aspects of mental health care ranging from legislation and policies, to issues related to treatment and service delivery. Underpinning the commitment to 'reform policy', the Inquiry reiterated the expectation by mental health consumers of optimal mental health care and that their views are considered at all points of the mental health system in any endeavour that enhances service delivery (Burdekin, 1993). Consequently, the NMHS and the supporting evidence of the Inquiry laid the blueprint for change in mental health services in Australia, and notably, through the 'participatory structure', gave mental health consumers a legislated platform from which to have their 'voices' heard.

The Evaluation of the National Mental Health Strategy: Final Report (1997) examined the NHMS against the 38 objectives outlined in 1992 and reported positive outcomes in various domains. In particular, advisory processes with consumers and carers had been established at national and state levels (AGPS, 1997). However, despite the wide collaborative structure in place, some persistent concerns remained. Using an area Case Study approach to examine the translation of policy into practice, the Steering Committee conducted a qualitative and quantitative study with 400 and 900 participants respectively. The Committee reported disquiet was expressed at service end points some five years after the initiation of the Strategy. The qualitative details of the concerns were not elaborated in the Final Report (AGPS, 1997).

Mental health in Western Australia

Historically, the latter part of the 1990s is a landmark time in the area of mental health in Western Australia. Of note was the replacement of the Mental Health Act (1962) with the Mental Health Act (1996) which states it is: "An Act to provide for

the care, treatment, and protection of persons who have mental illnesses, and for related purposes.” With a new legislation in place, the State Government of Western Australia responded to concerns raised nationally and locally about mental health issues. Established in 1996, the Mental Health Taskforce (Taskforce) set about constructing a collaborative structure for wide consultation between policy makers, service providers, consumers and carers. The Taskforce examined areas related to legislation, resourcing and structuring of an effective mental health system in Western Australia. The Report of the Ministerial Taskforce on Mental Health (Report) recommended that consumer evaluations were essential and that consumers provide “... feedback on their experiences of the services ...” (AGPS, 1997, p. 14). In addition, the Report stressed the value of a mental health system that was “... informed by the community’s needs ... [and that] ... most importantly people going to mental health services must be assured of being treated with respect, courtesy and helpfulness when they seek assistance ...” (pp. 19-20). This commitment was embodied in the Mental Health Act (1996) in which the Objects of the Act state in part: “(a) to ensure that persons having a mental illness receive the best care and treatment with the least restriction of their freedom and the least interference with their rights and dignity ...” (Mental Health Act, 1996).

Summary comments on Australian mental health legislation

The overview of mental health reform since 1992 demonstrates the Australian government’s commitment towards meeting the needs of Australian people affected by mental illness through legislation, policy and collaboration between all parties with vested interests. In addition, the government has articulated its commitment through an escalated allocation of funds from \$250 million for the period 1992-1998

to \$328 million for the period 1998 to 2003 (HDWA, 1999). This course of action is commendable given the unchanged estimation of incidence and prevalence rates of mental illness remaining at one in five during this time frame (AGPS, 1998).

In an economy that is increasingly vigilant, effective and equitable distribution of resources is essential to meet the fundamental aims of the NMHS. Implicit in these aims is the recognition, addressing, and where it is deemed necessary, redressing the unmet needs of consumers through the process of 'being heard'. However, although policy and reform is generally initiated at a macro level, the strengths and limitations of a mental health system that places high priority on a 'participatory process' is ideally scrutinized on a micro level by examining the experiences of recipients at service endpoints. Research and education in this area has been identified as a priority (AGPS, 1992; 1997). The Federal Government of Australia and the State Government of Western Australia take cognizance of this through the aims and objectives expressed in legislation, policy, and through principles of practice endorsed in the National Standards for Mental Health Services (AGPS, 1996).

What is mental illness?

Belle (1990) stated one of the most positive associations in psychiatric morbidity is the link between poverty and mental disorder. This has been established through psychiatric epidemiological studies. McBride (1990) highlighted the effects of stress on physiological, psychological and social wellbeing. Dalgard, Bjrk and Tambs (1995) in a ten year follow up of 503 individuals reported that for those individuals who had an external locus of control, 'buffers' against stress were more effective when social support networks were in place and protected against the

development of mental disorder. However, orthodox psychiatry categories and labels people with mental difficulties within the framework of a medical model (Wallcraft, 1998) and this approach comes under scrutiny (Breggin, 1991, Caplan, 1995). An opposing challenge to the perspective that considers 'the mind' a physical entity susceptible to disease or illness is the assertion that 'madness' is a social and politicized construct (Chamberlin, 1990; Szasz, 1974; 1990).

Emergent from the dichotomy of biological and psychosocial perspectives contemporary perspective acknowledges illness, including mental illness, impacts on an individual's well-being on many levels and accordingly promotes the full array of biopsychosocial influences on cause, prevention and intervention (Sobel, 1995). This multidimensional perspective recognizes that disruption to psychological well-being impacts significantly on the individual's quality of life and has wider implications for the community and society.

The patient's voice

Psychiatric hospitalisation was examined nearly 40 years ago from a sociological perspective (Goffman, 1961). Since then various aspects of mental health care have come under scrutiny. In particular, models of consultations in the clinical setting are explored in an attempt to bridge the gap in communication between clinician and patient. More recently, Mead and Copeland (2000) articulated the voice of the consumer through their own experiences. Highlighting the domains of hope, education, responsibility, advocacy and peer support, they stressed recovery goes beyond symptom control. They also emphasised changes in the attitudinal aspects of the interaction between mental health professionals and patients are essential.

Commenting on the patient-centred approach, Toop asserted (1998) initiating, integrating and implementing a 'sustained partnership' model of adult-adult interaction advances a holistic approach, enhances the clinician's knowledge about the patient, allows for appropriate care and accommodates the patient's participation in the clinical encounter. The salient features of the triadic relationship between doctor, patient and nurse cultivate a climate of trust and participation. Opie (1998) endorses this view and argues the need for commitment and support of organizational structures to promote this style of interaction through training. Adopting this practice, she claims, is insightful and sensitive to the patient's needs.

Communication between clinician and client is key to any therapeutic relationship. Examining interactions between clients and service providers (276 physicians and 136 nurses over 412 visits at a primary care clinic) Campbell, Mauksch, Neikirk and Hosokawa (1990) reported on five provider styles with dimensions that include affiliation, control, somatic, psychosocial and information indices. The authors claim a general approach style favours the provider and limits exploration of the patient's needs. They further note this approach fails to enhance the providers' expertise and denies the opportunity to practice the 'art of medicine'; elements of which include empathy, friendliness and warmth.

Workplace practices using different approaches such as employing consumers in the care and support of other consumers, has been the focus of enquiry and practice. On the premise that service delivery will be enhanced by the employment of consumers in the clinical setting, Paulson, Herinckx, Demmler, Clarke, Cutler and Birecree (1999), using qualitative and quantitative methodologies, examined the practices of a group of consumers and non-consumers in an Assertive Community

Treatment program. The authors reported there were significant differences in the 'culture' embodied in the work practices of both groups. Non-consumer workers were more preoccupied by task completion whereas consumers placed more emphasis and importance on "being there" despite both groups being equal on services provided. The authors suggested future directions in research examine the culture of workplace practices and therapeutic outcomes.

The culture of workplace practices is often dictated by workplace guidelines. However, factoring in cultural nuances inherent in country of origin and/or other belief systems comes under legislated scrutiny. It has been supported in the NHMS (1992) and in professional ethics such as General Principles III(b) of the Australian Psychological Society (1999) which states: "Members must be sensitive to cultural, contextual, gender and role differences and the impact of those on their professional practice on clients. Members must not act in a discriminatory manner nor condone discriminatory practices against clients on the basis of those differences." Guided by these imperatives, exploring the clinical encounter at a micro level is advocated from a cross-cultural perspective. Examining the client's idiopathic perspective against the broader cultural background is promoted as being sensitive to needs, alleviating patient distress and improving quality of life (Campinha-Bacote, 1994; Lopez & Guarnaccia, 2000).

Similarly, Chrisman (1980) promotes culture-sensitive care within the framework of three principles: knowledge, mutual respect and negotiation. The approach supported by exponents of culturally sensitive and culturally appropriate care echoes the core values of the sustained partnership model endorsed by Toop (1998) and reinforces the intrinsic universal value of patient-centred care. Callan and

Littlewood (1998) found in a study using qualitative and quantitatively methodologies, people diagnosed with a psychiatric disorder from ethnic backgrounds reported satisfaction of services when their explanatory model of illness and the doctor's explanatory model concurred.

However, in the area of mental health, involvement of people diagnosed with a psychiatric disorder in clinical decision-making poses unique challenges (Wong, Clare, Gunn & Holland, 1999). Inherent in the challenges is determining whether or not a patient is 'capable' of making health care decisions. Kent and Read (1998) report that mental health professionals with biological orientation (rather than psychosocial) are less likely to believe active consumer-provider collaboration would result in enhanced therapeutic outcomes.

Caslyn, Winter and Morse (2000) conducted a study using a non-equivalent control group design to examine the impact of choice on mental health consumers with a severe mental illness. The sample consisted of individuals who were homeless at baseline. Both groups were assigned to a modified Assertive Community Treatment program although only one group was given a choice of five treatment programs within their group. The authors reported those individuals who were given choice took more initiative, and met with their case managers more frequently than those individuals in the no choice group who were just assigned a case worker. Although there were no significant changes other than increased income for the choice group, the authors suggest that choice alone is not a sufficient element towards a successful outcome but rather, perception of choice is an influential element.

Contemporary perspectives on mental health consumers' views

Deinstitutionalisation, followed by the changing dynamics between health care and economies have brought accountability, cost-effectiveness and service delivery of the mental health system under scrutiny (Ferry, 1996; Kavanagh, 1997). However, according to Williams and Wilkinson (1995) although views of consumers, embedded in rights and privileges, are vital towards bridging the traditional gap between patients and clinical practitioners, the views of mental health consumers "... appear [to be] most conspicuous, and politically most intricate ..." (p. 560). Emergent views from contemporary reform policies advocate that people diagnosed with a mental illness are 'consumers' (Burdekin, 1993). And, in a 'consumerist' society this expression assumes an understanding ranging from "... quality assurance to ... the genuine extension of democratic processes ..." (Brandon, 1992, p. 164).

The concept, of working more closely with the public, according to Williams and Wilkinson (1995), generates a paired action. Firstly, the authors claim, "... the views of service users are brought into decision-making procedures; and secondly, services are modified on the basis of such views." (p. 560). Likewise, Bhugra (1997) agrees to the reciprocity inherent in the concept of eliciting needs and providing services suited to those needs. This is supported in studies where views and evaluation of services by consumers is deemed to enhance service delivery (Leavy, King, Cole, Hoar, & Johnson-Sabine, 1997; Lebow, 1982; Leese, Johnson, Slade, Parkman, Kelly, Phelan & Thornicroft, 1998; Wallace, Robertson, Millar & Frisch, 1999).

International studies

Inviting consumers of mental health services to express their views about service delivery is a relatively new concept (Lebow, 1982). In addition, the idea is embedded in quality assurance using the construct 'satisfaction' and has generally elicited formal evaluation of services by in-patient populations from the service providers' perspective (Hall & Dornan, 1988). A majority of these studies report high levels of satisfaction (Lebow, 1982). However, several limitations to this approach in mental health settings have been identified and include insensitivity of the instruments (Carr-Hill, Dixon & Thompson, 1989); the lack of qualitative data related to existing services (Parkman, Davies, Leese, Phelan & Thornicroft, 1997; Shields, Morrison & Hart, 1988); and, the perceived reluctance of consumers to express their views of services while under care (Cang, 1989). Crawford and Kessel (1999) reiterated that a climate of mutual understanding and consultation is essential for dynamic change to be effective and effected at ground level.

International qualitative studies

Studies that include a qualitative dimension examining the experience of being a mental health consumer are relatively uncommon. Those that do, reveal dissatisfaction in areas generally not included in the evaluation of existing services suggesting a plethora of unmet or previously unidentified needs of mental health consumers (Goodwin, Holmes, Newnes & Waltho, 1999).

Rogers, Pilgrim and Lacey (1993) conducted a national study in the United Kingdom of 516 mental health consumers and ex-consumers using a questionnaire and semi-structured interview format. The latter being included because according to the authors "... it ... illuminate[s] those finer details of the subjective experience

of users that are obscured by, or submerged in, the more quantitative data ...” (p.

14). Several major themes emerged from the qualitative research centering on treatment issues, problems in living and access to appropriate care. The authors observed, the understandings of mental illness by recipients of mental health services incorporated social and psychological factors. However, the authors noted although it is argued that psychiatric practice is not limited to a medical model, these claims were not supported in the study.

Over a four-year period Goodwin et al. (1999) administered a modified version of the Service Satisfaction Questionnaire to 110 inpatients of acute and rehabilitation wards of a psychiatric hospital in rural England. In addition, a semi structured interview format was used to “... elicit more subtle views ...” (p. 44). The results of the quantitative analysis suggested a slight trend in higher satisfaction over the period of the research. However, the qualitative data did not reflect this other than some positive comments about the hospital decor. Thirteen themes emerged from the data analysis: Tangible environment; non-tangible environment; institutionalization; power and control; rules and policies; talking, counselling and listening; respect; hospital as prison; information; caring and sympathy; medication; relaxation and activities; and practical help. The authors concluded it is only through examination of practice that the needs of psychiatric patients are met more appropriately.

Relying solely on a non-directive approach Letendre (1997) examined 38 focused accounts of individuals who experienced psychiatric stay in two hospitals in Quebec, Canada. The dominant themes to emerge from the data related to: admission to the psychiatric ward; hospital environment and rules; medication,

relations with staff and the post-hospitalisation period. Letendre (1997) concluded five processes were involved in the hospitalisation experience, however, he stated "... the domination process, concerning the patient relational with institutional personnel, has important consequences and forms the background for the course of the hospitalisation experience ..." (p. 296). The findings of this study prompted him to emphasise a poignant reminder that "... the subject speaks from a position of powerlessness ..." (p. 296).

On the other hand, eliciting and addressing previously unrecognized needs of consumers and carers through a culture that embodies 'primacy of the person' has demonstrated enhanced service delivery for the consumer, carer and the service provider (Wallace et al., 1999). Using a focus group approach with 23 clients and 28 family members, the researchers examined three main themes: Quantity and quality of care; Individuality and Partnership. Continuity of care emerged as a key area of concern for clients and families. This was seen to be particularly important in order to facilitate a therapeutic relationship particularly with those professionals who favoured a biopsychosocial approach. Using information provided in the focus groups, strengths were identified and weaknesses were addressed in an effort to provide a service that met the needs of the client in a more appropriate way.

In a study examining the experiences of 27 women who underwent psychiatric care, Miedema and Stoppard (1994) report hospitalisation was seen as a refuge from daily stresses in living. The study found although women sought refuge from unsatisfactory home situations, poverty and other social stressors, they were critical of a system where they had little control. The authors argue for service delivery

systems to take into account the psycho-social needs of women and gear services to meet those needs more appropriately.

Qualitative studies in Australia

Australia is a pluralistic society that places unique demands on culturally appropriate and culturally sensitive health services in Australia (Chu, 1994). Assimilation, acculturation and the mitigating socio-political factors that instigate migration have an impact on mental health (MacDonald & Steel, 1997). As all psychiatric disorders are diagnosed on symptom-based, observable behaviours, sensitivity to cultural and linguistic nuances is vital for clinical assessment and treatment. Consequently, studies in Western Australia have focused on groups identified 'at-risk'.

In a qualitative study of 37 individuals from five ethnic backgrounds, Martin (1998) highlighted the needs of clients from culturally and linguistically diverse (CALD) backgrounds. The illumination of needs identified in this study relates primarily to experiences of cultural and linguistic barriers to accessing and receiving culturally appropriate services. In addition, the study highlight that some participants felt inappropriate care had a negative psychological impact. The importance of using culture sensitive and culture appropriate approaches in examining idiopathic perspectives and addressing them with sensitivity is therefore essential in mental health settings.

In 1998 the West Australian Association for Mental Health conducted a review of tertiary and secondary services of mental health services in Western Australia. The primary aims of the review were "... to identify what could be done to improve consumer, carer and not for profit community mental health service satisfaction ...

provided by four major mental health inpatient services in the metropolitan area” (p. 1). Data provided by focus groups highlighted difficulties in accessing appropriate care. Of note, the respondents echoed the broader understandings of mental illness and the need for pertinent care that was reported in the United Kingdom by Rogers, et al. (1990). Unfortunately the richness of the “personal experiences” of the participants in the focus group is constrained by methodology.

Wadsworth and Epstein (1998) conducted a participatory research study between a mental health consumer organization and staff of a major public psychiatric hospital in Victoria. Using methodology that employed ‘dialogue’ between key respondents, the study focused on exchanging information on experiences of consumers and staff and explored the ‘closed loop’ of communication. Reflecting on the gap that exists between mental health professionals and consumers, the authors concluded that shrinking the distance between the two perspectives might serve to enhance the impact of mental health practice on consumers’ perceptions and experiences.

Summary comments on international and Australian studies

Eliciting the views of mental health consumers has largely been embedded in evaluation of services provided. Few studies examine the experiences of mental health consumers through qualitative approaches. National and state mental health policies reiterate commitment to meeting the needs of mental health consumers in Australia. Research and education remain priority areas on the reform agenda. However, despite this, a search of the major databases (Medline, Psychlit., CINAHL and Expanded Academic ASAP) for studies that examine these experiences proved elusive. In particular, studies published since the launch of the NMHS in 1992

appear to be absent. 'In-house' qualitative studies conducted in Western Australia highlight the need for culturally appropriate and culturally sensitive care for CALD clients. As well, a study using a focus group identified difficulties and deficits encountered in mental health service delivery in Western Australia.

A conceptual framework

Eliciting views of health services consumers is generally conducted using survey methodology and is measured by what people received against what they expected. However, qualitative research according to Calnan (1988), identifies that people often have no expectations about health services *per se*. People seek help to address physical, psychological, social, or a combination of needs in these spheres. Therefore, more important for the consumer is whether or not the health care professional has the ability to communicate appropriately and meet the consumers' needs with sensitivity. The experience of health care received then shapes the perception of the consumer and future expectations are revised against the background of the experience.

The commitment of the NMHS to meeting the needs of people with a mental disorder is promoted in mental health settings through the National Standards for Mental Health (1996). Monitoring of performance is an integral component of practice standards. However, the Final Report of the Evaluation of the NHMS indicated perceptions of service delivery remain issues of concern. Guided by this scenario, a conceptual framework is provided in Figure 1.

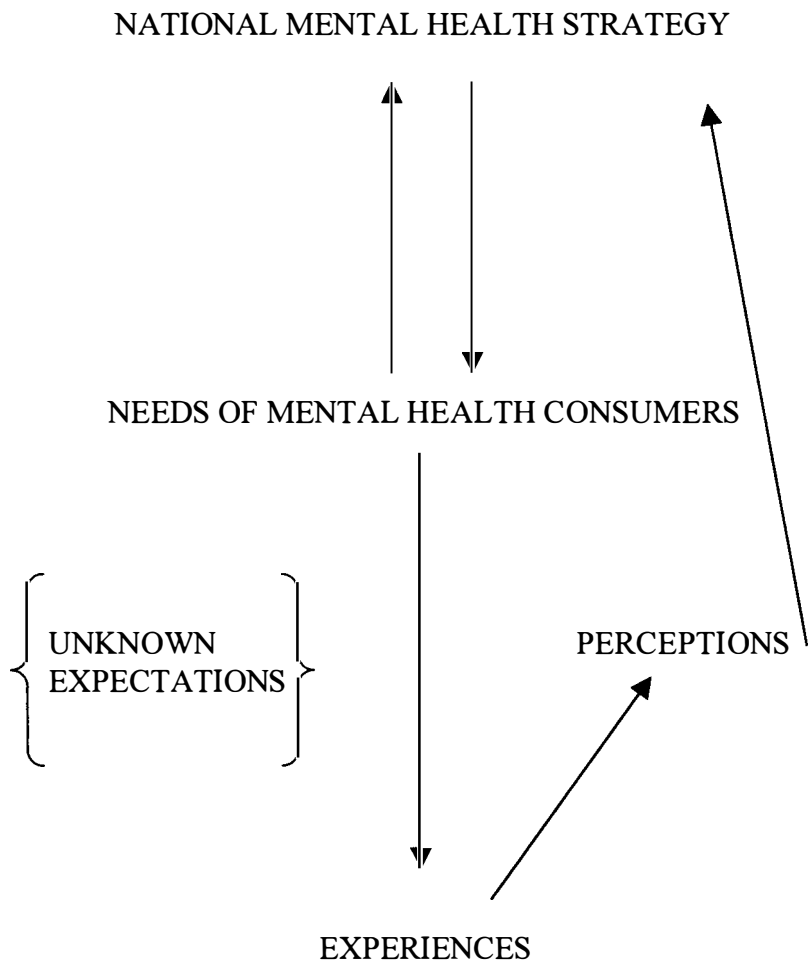


Figure 1. Conceptual framework for expectations and perceptions of the process of ‘being heard’ by consumers of mental health services in Australia. (Adapted from Calnan, 1988).

Methodological approach

Qualitative research impacts on the participant, researcher, interviewer and people affiliated with it. It serves a special purpose in the area of illness by providing a psychosocial function for patients where the process of narration conveys meanings of experiences for the researcher (Viney & Bousfield, 1991), and where relevant, for the transcriber (Gregory, Russell & Phillips, 1997). Interpreting data from focus groups is influenced by the facilitator and by the group dynamics and does not accommodate deeper understandings. Despite this, the data is informative and permits assumptions to be tested for an identified group (Breakwell, Hammond & Fife-Schaw, 1995). On the other hand, individual experiences, whether in a clinical setting or research setting, facilitate the exploration of the richness of experiences and reveal 'truth' (Gray, 1997; Susko, 1994). Riessman (1990) endorses the use of language as a resource to be shared between listener and participant in an effort to create reality. In qualitative research, she claims, the process of retelling of the experience and the activity of listening and questioning ensures that "... the moral character of the protagonist is sustained." (Riessman, 1990, p. 1195).

Until recently views of mental health consumers have largely been elicited through quantitative approaches using questionnaires and have examined the construct of satisfaction of services. It is only in the last two decades that studies examining the experiences of mental health consumers using qualitative methodology have been promoted. Due to the numbers involved, previous studies have collapsed experiences of mental health consumers into broader thematic categories. In that respect, the methodology used in this study differs.

This study, using a small sample, employed a cross case approach. Due to the relatively smaller numbers involved in the study, it was envisaged the data process would generate more precise themes and would enable the 'teasing out' of the intricacies of the experiences as viewed through the eyes of the recipient of services.

According to Miles and Huberman (1994), generalizability in a cross case analysis refers to the process of examining themes within a case and then examining them against other cases in an attempt to explore diversity. The similarities and disparities in conditions that emerge, give strength, meaning and aids generalizability. In other words, it is an approach that enables the specificities of the data to be examined more closely and for relationships to emerge. This process demands that each case is examined thoroughly before proceeding to examine the dynamics in other cases.

The semi-structured format of the interview schedule used in this study aided in the analysis by providing a time-structured orientation to the events, and facilitated the protection of the sequence of events in each case. The cross case analysis approach also accommodated the integration of stories by examining each story within its own framework and allowed the research to reflect the story against the framework of another story. This methodological approach countered, in part, the limitation of a small sample.

Definitions

Mental disorder/illness

The [West Australian] Report of the Ministerial Taskforce on Mental Health (1996) provides a definition for mental disorder/mental illness as stated below.

“A Mental Disorder can be characterized as follows:

Any psychiatric disorder that has seriously interfered with one or more aspects of a person’s life, such as employment, accommodation stability, physical health, emotional well-being or interpersonal relationships. The severity of a mental disorder can be defined in terms of the disabling effect it has on a person’s life, rather than whether it is acute or chronic, short or long term, or whether it conforms to a specific diagnostic category. The definition would refer to disorders with psychotic symptoms, such as schizophrenia or bipolar affective disorders, as well as disorders such as depression, anxiety disorders, eating disorders, personality disorders, obsessive compulsive disorders, adjustment reactions and post traumatic stress disorder.

The term “mental disorder” is preferred to “mental illness” because the latter implies that medical treatment is the preferred option, rather than a range of interventions.” (p. 21).

Mental health consumer

The health consumers’ movement in Australia adopts the term ‘consumer’ because, according to Wadsworth and Epstein (1998), it is the understanding that “...a consumer is presumed to have choice.” (p. 353). It is also the preferred referent in policy directives. It is from this referent’s perspective that expectations, experiences and perceptions are examined.

Expectations

According to Shoop and Wright (2000) "... expectations are hopes or prospects for occurrences which may lead to success..." (p. 13). Accordingly, this study elicited the participants' expectations of service delivery prior to first, and where relevant, subsequent hospitalisations.

Needs

Baldwin (1998) notes the difficulties in defining 'needs' in mental health settings and highlights the tension between the priorities of service providers and consumers. He observes that individuals '... should remain at the core of service design and planning (p. 6). As this study focuses on the expectations and perceptions of consumers of mental health services in Western Australia, for the purpose of this study, definition of 'needs' will be the guided by the participants.

Experiences

For the purposes of this study, experiences are defined according to the definition provided by The Australian Little Oxford Dictionary as a "... personal observation or contact; knowledge ... based on this ... [and/or] ... event that affects one"

Perceptions

According to Anderson (1995) "... perception involves more than simply registering the information that arrives at our eyes and ears." (p. 36). Key to perception is the interpretation of that information (Anderson, 1995). Therefore, perception is operationalised as the interpretive explanation participants provide for events, and/or, visual or verbal information.

Mental health services

The Australian National Standards for Mental Health Services (AGPS, 1997)

defines mental health service as:

An organization that provides, as its core business, primary, secondary and, in some cases, tertiary treatments and support to people with mental disorders and/or mental health problems. A mental health service should be specialized and complimentary to other health services. (p. 52).

Due to the scope of this project, mental health services in this study will refer predominantly to inpatient hospitalisation with limited exploration of services pre- and post-hospital care.

Aims of the study

The primary aim of this project is to explore the experience of being a mental health consumer within the parameters of the consumer's expectations and perceptions of psychiatric hospitalisation in Western Australia. The experiences will be examined against the background of the NMHS, which is underpinned by the principles of giving mental health consumers 'a voice'. It is also anticipated this project will highlight unmet or unrecognized needs as perceived by the consumer. It is envisaged this pilot project will provide an exploratory framework for a larger study.

Special note:

The referent participant, patient, respondent and consumer are used interchangeably in this study and operate in the context used. The identifier Case Study is used when appropriate.

Method

Recruitment of Participants

After ethics approval was obtained from the School of Psychology contact was initiated with mental health consumer groups in Western Australia by telephone and followed by correspondence (see Appendix A). The study was also advertised in community centres using flyers placed on notice boards (see Appendix B) and promoted through word of mouth.

Participants

Eight mental health consumers (1 male and 7 female) participated in the study. The ages of the participants ranged from 22 years to 55 years.

All eight participants had been given a psychiatric diagnosis on discharge and received hospital care in private and public hospitals within metropolitan and rural Western Australia (see Figure 2). As well, all participants had been hospitalised at least once since the endorsement of the National Mental Health Strategy in 1992. The hospital stay ranged from 3 days to a month.

Case Study 5 and 6 were privately insured and were hospitalised in the same private hospital, although two years apart. The remaining four of the six participants was public patients and hospitalised in metropolitan public hospitals. Case Study 1, 2 and 3, were patients in the same hospitals although at different time periods. One participant, a public patient, was hospitalised in a public hospital in rural Western Australia. With the exception of one participant, Case Study 7, whom the researcher had met on one previous occasion, the researcher knew none of the other participants.

	<i>Case 1</i>	<i>Case 2</i>	<i>Case 3</i>	<i>Case 4</i>	<i>Case 5</i>	<i>Case 6</i>	<i>Case 7</i>	<i>Case 8</i>
Hospital 1 Metro	x	x	x					
Hospital 2 Metro	x							
Hospital 3 Metro		x	x					
Hospital 4 Rural				x				
Hospital 5 Metro			x					
Hospital 6 Private					x	x		
Hospital 7 Metro							x	
Hospital 8 Metro								x

Figure 2. Utilization of private and public hospitals by Case Study 1-8 in metropolitan Perth and rural Western Australia since 1992.

Four consumers, one male and three female, were placed in a locked ward at least once during their hospital admission/s. Two female consumers had involuntary status at their first and only admission.

The diagnoses in this heterogeneous group are detailed in Table 1. All participants, with the exception of Case Study 7 are on medication. Case Study 1, 3 and 4 have been in hospital on more than one occasion; it is their current diagnosis.

Table 1

Psychiatric diagnosis given to Case Study 1-8 on discharge from hospital

Diagnosis	Number of participants
Anxiety/Depression	2
Obsessive/Compulsive disorder with depression	1
Endogenous depression	1
Post-partum psychosis	1
Bipolar disorder	3

Profiles of participants

Case Study 1

Case Study 1 first entered the hospital system twenty years ago via a court order for disruption he caused after smoking marijuana. He was 18 years old and at university at the time. He was diagnosed with schizophrenia; a diagnosis that was later revised to bipolar disorder. He has never married, alludes to not having a partner, and works part-time intermittently. Although he continues to take medication, he requires intermittent hospitalisation and is a public patient. A case manager sees him on a regular basis.

Case Study 1 lives in the family room with his mother who was not present at the time of the interview. He recalls the first admission saying:

... when I look back at the experience, I had a big lot of marijuana and that's when I had my first, really severe attack when I was still experiencing a big surge of marijuana so ... I did some very stupid things and the police got me and ... then I went to court and the judge was there and he said you can try going into hospital, so that's what happened the first time.

Case Study 2

Case Study 2 is single and in her late 30s. Eighteen months ago she was involved in helping some friends renovate a home in a country town in Western Australia. During her stay she witnessed a male friend beat one of his children. Coming from a “dysfunctional” background and a history that included rape, distressed, she took her belongings and lived on a rocky outcrop for three days and nights. Friends returned her to Perth where she grew increasingly paranoid and fearful over the next two weeks. During this time she was working as a part time chef. As her condition spiralled her parents’ request for emergency psychiatric care was unsuccessful. They called the police who transported her to a teaching hospital. She was later transferred to another hospital, made an involuntary patient, where she spent the next month, including some days in a locked ward. Discharged from hospital with a diagnosis of bipolar disorder, she had minimal contact with a case manager and now attends an outpatient clinic intermittently. Although advised by her doctor to continue anti-psychotic medication, which she refuses to take, she has been symptom-free for several months. She continues taking anti-depressants. She

is unemployed and works as a volunteer gardener sporadically. She is a public patient.

Case Study 2 lives alone in a bed-sitter flat where I interviewed her over several hours. She relates the events that occurred two weeks prior to her hospital admission:

I went up to [country town] to help build a kitchen and I had a disagreement with the guy who owns the property there because he was hitting his child and I witnessed that and that really hurt me because I thought he could be trusted. Anyway, I had a disagreement with him and I ended up on a rock and I was on it for three nights and three days ...

Case Study 3

I interviewed Case Study 3 in her home. Although she was alone at home at the time of the interview, her son and his pregnant wife were living with her temporarily. She is a highly creative and artistic 55 year old mother of two. Divorcing her violent and abusive husband some years ago, she has never remarried and does not have any long-term relationships. She entered the mental health system approximately twelve years ago after a particularly abusive episode involving her husband and the children. She has been given several different diagnoses including borderline personality disorder, post-traumatic stress syndrome and most recently, bipolar disorder. She is on regular medication and has been an inpatient of various metropolitan hospitals in

Perth over the years. She is active in consumer related activities and is a public patient.

She shared her experiences in an interview that lasted several hours and relates her life story prior the first hospital admission, stopping only to compose herself saying:

But then also at the same time, before I had lost my mother and not long after my dad had died of cancer and I had nursed him for nearly two years ... I had worked at the same time and I had all this abuse going on and all my money was being taken off me and then my dad died ... I had my mother, looking after her again and I was getting all these flashbacks of being with her when we were kids, like this catatonic person that she was all the time, never ever there because she had shock treatment, we used to take her for her shock treatment when we were eight years of age. She was like catatonic ... I mean, we had malnutrition twice before we were five you know... flashbacks of what it was living with a mother with a mental illness and more so with the sexual abuse that we, I experienced ... I had depression all my life without even realizing it. I had actually tried to commit suicide at sixteen. I certainly had a lot of panic attacks... and I had anorexia at a very early age, didn't know that's what it was, but knowing what I know now, I had that. And, my ex, ... was very abusive, verbally, mentally, and emotionally. He used to bash the kids, bash me, abuse them, sexually as well ...the last straw was, my

husband was a gambler, my dad was a gambler as well, and my son was thrown to the floor by my husband ... he is an epileptic as well my son, and ... started kicking him about the head, which is what he used to do anyway and that was the last straw ... I was going to take the kids, jump in the car and commit suicide with the kids and me. I just wanted to get off this earth basically.

Case Study 4

Case Study 4 is a 29 year old, divorced mother of two. She was admitted as a public patient to a rural general hospital on two occasions over the past ten years with a diagnosis of depression and obsessive-compulsive disorder. When aged eight, her infant brother died from sudden infant death syndrome. She developed obsessive-compulsive disorder soon after. She continues taking anti-depressants, has access to a self-help group and a psychologist.

In an interview lasting just over an hour in a neutral office, she recalled her experiences:

My parents being separated ... my mum being the bitch that she was. my brother's death was another huge factor ... I had enough of everything. I was married and I had no ability to respond to my husband. He was expecting me to love him and I couldn't love anything.

Case Study 5

Case Study 5, in her 40s, is a wife and mother of two young adults. Following the departure of her youngest child from the family home, she developed panic attacks and was treated at her request as an inpatient at a private hospital. She has a diagnosis of anxiety-related depression and continues to take medication. She was an inpatient for eight days approximately three years ago. It is her only admission.

At her request, Case Study 5 was interviewed in my home where she recounted:

I felt terrible, just felt appalling and by then I sort of realized it was an anxiety and it was also that this particular crisis was precipitated by having sinus X-rays and going to ENT and being told there's absolutely nothing. ... I had asked the GP to do some blood tests and I had very high bilirubin and I panicked again. That was a general panic and that whole episode with Dr X and now it appeared something was wrong with my liver, it flipped me over the edge and I finally went into a real crisis of total depression where ... I felt this terrible heaviness.

Case Study 6

Case Study 6 is in her 20s and at university, who was hospitalised within the past year for anxiety-related depression. She spent three days as an inpatient in the same private hospital as Case Study 5 did two years earlier. She takes antidepressants and is continuing her university studies.

The interview with Case Study 6 was relatively brief at just under an hour and was conducted in her family home. She lives with her parents. Although initially shy and softly spoken, Case Study 6 soon warmed to the interview situation and recalled her experiences with minimal prompting.

I had been away and then I came back to uni[versity] for the start of semester and found myself increasingly worried about units that I was choosing, whether I had made the right choices and not really talking to anybody about it, chopping and changing my units and just growing increasingly anxious about my studies until yeah basically I reached the point where I realized it was getting uncontrolled and if I carried on (a) fail uni[versity] and (b) something more serious might happen.

Case Study 7

Case Study 7 is in her 20s and is a wife and mother of two. Following the funeral of her three-month-old son who died from sudden infant death syndrome, she was made an involuntary patient and spent 16 days in hospital. Diagnosed with post-partum psychosis, she was given electroshock a week into her stay. She recently lost a pregnancy through miscarriage. At her insistence, she no longer takes medication and seeks support from a self-help group and a psychologist.

Case Study 7 recalled her experiences with emotional acumen in an interview that lasted just over an hour in her home.

My son died on a Wednesday. We had a lot of trouble with the coroner about the autopsy. We didn't want to have an autopsy done. Then we found out that we had to have one done and all the processes that went along with that and he had his funeral nine days after he died ... the day after his funeral I started hearing voices and signs and that next day I was admitted to [Hospital] and that's how I got there as an involuntary patient.

Case Study 8

Inviting me to interview her in a relative's home, Case Study 8 is a mature age university student in her 50s. A single mother of two, she sustained a back injury at work and was hospitalised. During this time she was diagnosed with endogenous depression. That was nearly twenty years ago. She has since been in hospital several times. She continues taking medication.

In an interview that lasted several hours, Case Study 8 shared her experiences as a public patient with me.

I think in part what led to it was the back injury. I know it precipitated this. Because I was a very energetic person and suddenly you are flat on your back. You've got nothing to do. Well you can't do much you know. I think my lifestyle was changing completely. I mean I was a working mother, a single parent. I'd always worked, had a mortgage and you know I had all those worries and all the other stuff.

Protocol

A semi-structured interview format was used to guide the interviews (see Appendix C). Probe questions were asked as and when it was appropriate.

Ethical considerations

Prior to the commencement of the interview, each participant was verbally advised about the nature of the study and given a written explanation (see Appendix D). A list of telephone numbers of agencies and hospitals was made available to participants in the event they required counselling or support after the interview (See Appendix E). Signed consent was obtained from all the participants (See Appendix F).

After signed informed consent had been obtained and before the taping of the interview commenced, to ensure further protection of confidentiality, each participant was asked to provide demographic details which was recorded in a notebook. The details included: marital status, present employment status, the year of their first hospitalisation, the year of their last hospitalisation, the mental health status on admission, the diagnosis on discharge from hospital, the approximate length of stay, and whether or not they were still on medication. At the end of the interview the participant was asked if they would be willing to provide more information should that be necessary.

Interviews

The interviews were conducted during the period 23 July - 11 August 2000. All interviews were audio taped and lasted between 45 minutes to 3.5 hours. The interviews followed the flow of the semi-structured format with probe questions added as, and when it was thought necessary. Although the interviews were

expected to last approximately one hour, due to the sensitive nature of the experiences extra time was allowed to enable the participants to contribute to the study in a time period that was more suitable to their needs.

Six interviews were conducted in the home of the participant; as requested by the participant, one interview was conducted in the home of the researcher and one interview was conducted in a neutral office setting. None of the participants were interviewed more than once for this study.

Analysis

A cross-case analysis approach was used to analyse the data (Miles & Huberman, 1994). Firstly, the researcher transcribed each interview verbatim and the data subjected to a comparative method of analysis with specific points in time being noted, such as the events preceding the hospitalisation, admission, and daily routine. This step produced a time-ordered structure for the participants' explanation of events they thought was important and influential towards the outcome.

Secondly, starting with the first participant, the transcripts were subjected to content analysis and categories were constructed under the categories of Expectations, Experiences, Perceptions and Reflective Comments. Guided by the definitions of these categories, themes and sub-themes were generated. As the experiences of Case Study 5 and 6 were dissimilar to each other and dissimilar from the others, the data were then analysed for similarity and disparity. Following a process of exhaustive analysis for each interview, the data from other respondents were included in the results.

Lastly, themes were combined when they overlapped and adjusted to accommodate new themes. Two academics reviewed the data (see Appendix G) and

categories were agreed upon, and, following minor adjustments so were the final themes.

Results

The analysis was conducted using a three-step process (see Figure 3). Firstly, each interview was transcribed verbatim and the data subjected to a comparative method of analysis with specific points in time being noted such as the events preceding the hospitalisation, admission, daily routine. Secondly, categories were constructed and themes identified. Case Study 5 and 6 were private patients and their experiences were identified as being similar to each other yet dissimilar from the other respondents. Therefore, after all transcripts had been analysed, the transcripts were re-analysed and subjected to content analysis (Miles & Huberman, 1994) to elicit themes of similarity and disparity. Following a process of exhaustive analysis for each interview, the data were included in the results obtained from other respondents. During this process, several ancillary themes emerged.

Lastly, themes were combined when they overlapped and were adjusted to accommodate new themes. Five hundred quotes were assembled under themes and sub-themes. [Abbreviated quotes are used in the Results section and identified by number to correspond with the fuller quotes in Appendix G.] To establish reliability, two academics reviewed the data independently (see Appendix G). Consensus was reached for the categories and after minor adjustments, for the themes.

Exploration of the events that precipitated the first hospitalisation was important to delineate the broad categories of EXPECTATIONS, EXPERIENCES and PERCEPTIONS. The last question in the interview format produced a further category REFLECTIVE COMMENTS. Under each category, several themes and sub-themes

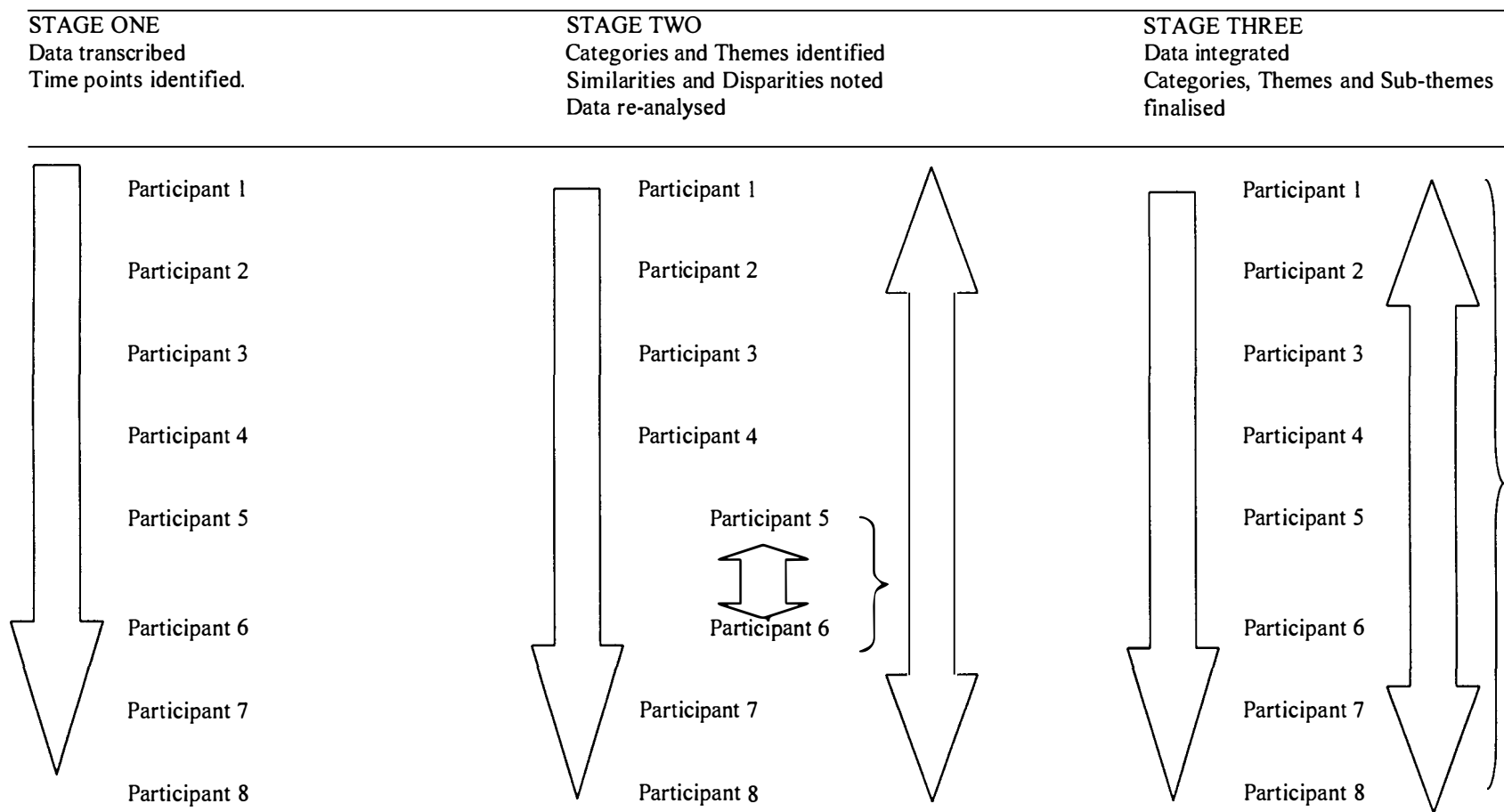


Figure 3. Stages of analysis for qualitative data from Case Study 1-8 using a cross case approach.

were generated. A complete list of the categories, themes and sub-themes are identified in Table 2. As some participants had several episodes of hospitalisation, their expectations were examined in the time frame just prior hospitalisation for the first and where relevant, most recent episode. According to Calnan (1988) expectations about health care can be revised following experiences, therefore experiences prior 1992 were also examined for these individuals.

The first step of the process produced a time-oriented structure to the events leading to the first admission to hospital for each individual. In some cases, the first hospitalisation was prior to 1992. However, this was taken into account as the participants were still accessing mental health services. The data indicated all eight participants experienced social events that triggered the first hospitalisation. For example:

Case Study 2 (Diagnosed with psychosis and later diagnosed with bipolar disorder):

I went up to [country town] to help build a kitchen and I had a disagreement with the guy who owns the property there because he was hitting his child and I witnessed that and that really hurt me because I thought he could be trusted. Anyway, I had a disagreement with him and I ended up on a rock and I was on it for three nights and three days ...

Table 2

List of Categories, Themes and Sub-themes emerging from content analysis of transcripts from Case Study 1-8 exploring expectations and perceptions of mental health services in Western Australia

EXPECTATIONS	EXPERIENCES	PERCEPTIONS	REFLECTIVE COMMENTS
PSYCHOLOGICAL RESPONSE Seeking refuge Need to be heard Fear	PSYCHOLOGICAL RESPONSE Fear/Lack of Control Disbelief Sense of imprisonment Powerlessness Analogy to being a child Lack of safety Fear Escape Impact of diagnosis	PSYCHOLOGICAL RESPONSE Lack of powerlessness Fear Stigma Stereotyped Discounted	MANAGEMENT OF ILLNESS Talking/empathy/ understanding Biopsychosocial approaches to care Environment Interaction with staff Paradoxical staff behaviours
NO EXPECTATIONS	CONFLICTING MODELS OF ILLNESS Medical model of illness Explanatory model of illness	MANAGEMENT OF ILLNESS Lack of confidence in staff Lack of choices Lack of consistency in care Lack of time	INADEQUACY OF SERVICES More services Consumer groups/ self-help groups
	MANAGEMENT OF ILLNESS Over-reliance on medication Lack of appropriate therapeutic approaches Treatments/interventions	STAFF BEHAVIOURS Lack of understanding Lack of empathy/compassion	
	STAFF BEHAVIOURS Lack of understanding Lack of empathy/compassion Lack of appropriate contact Threats/abuse/Ridicule		

Participant 6 (Diagnosed with anxiety/depression):

I had been away and then I came back to uni[versity] for the start of semester and found myself increasingly worried about units that I was choosing, whether I had made the right choices and not really talking to anybody about it, chopping and changing my units and just growing increasingly anxious about my studies until yeah basically I reached the point where I realized it was getting uncontrolled and if I carried on (a) fail uni[versity] and (b) something more serious might happen.

Participant 8 (diagnosed with Endogenous depression):

I think in part what led to it was the back injury. I know it precipitated this. Because I was a very energetic person and suddenly you are flat on your back. You've got nothing to do. Well you can't do much you know. I think my lifestyle was changing completely. I mean I was a working mother, a single parent. I'd always worked, had a mortgage and you know I had all those worries and all the other stuff.

EXPECTATIONS

Examination of the data for the category EXPECTATIONS produced two themes: PSYCHOLOGICAL RESPONSE with sub-themes of SEEKING REFUGE;

NEEDING TIME TO TALK; and FEAR. Other responses came under the theme of NO EXPECTATIONS (see Table 3).

Indications of psychological distress were evident in all the comments including those from individuals who did not have expectations, for example:

Well I didn't know did I? Because when you are in that state you don't know. You've got no preconceived notions. (14)

Table 3
Themes and sub-themes generated by Case Study 1-8 indicating EXPECTATIONS of mental health services, prior to hospital admission

EXPECTATIONS	
THEMES	SUB-THEMES
<u>PSYCHOLOGICAL RESPONSE</u>	SEEKING REFUGE
	NEEDING TIME TO TALK
	FEAR
<u>NO EXPECTATIONS</u>	

Further analysis of the data suggested that individuals in this sample experienced psychological distress, with fear being alluded to by just one participant. The following example combines the psychological subtext of both themes under the heading EXPECTATIONS into a single comment:

Oh, I would want to see somebody I could talk to long enough, to be able to feel safe enough, and not scared enough, and feel safe enough not to feel ashamed of what's really going on in my gut. (9)

EXPERIENCES

Under the category EXPERIENCES, four themes PSYCHOLOGICAL RESPONSE; CONFLICTING MODELS OF ILLNESS; MANAGEMENT OF ILLNESS and STAFF BEHAVIOURS plus several sub-themes emerged (see Table 4). These themes included similarities and disparities. The discrepancies related mainly to the differences in whether or not the participant was a private or public patient and the examples provided, highlight this distinction.

PSYCHOLOGICAL RESPONSE

Under the theme PSYCHOLOGICAL RESPONSE the sub-themes were: FEAR/LACK OF CONTROL; DISBELIEF; SENSE OF IMPRISONMENT; POWERLESSNESS; ANALOGY TO BEING A CHILD; LACK OF SAFETY; FEAR; ESCAPE and IMPACT OF DIAGNOSIS.

The pre-hospitalisation phase was dominated by comments that indicated FEAR/LACK OF CONTROL. A closer examination of the sub-theme suggested the type of fear being experienced differed between individuals given different diagnoses. In addition, the fears under this theme appear to be illness-related distress, whereas the fear expressed under the category EXPECTATIONS appeared to come from secondary sources and were associated to the prospect of hospitalisation. The following examples highlight the differences between these two different sources of fear.

Table 4

Themes and sub-themes generated by Case Study 1-8 indicating EXPERIENCES of psychiatric hospitalisation in Western Australia

EXPERIENCES	
THEMES	SUB-THEMES
<u>PSYCHOLOGICAL RESPONSE</u>	FEAR/LACK OF CONTROL DISBELIEF SENSE OF IMPRISONMENT POWERLESSNESS ANALOGY TO BEING A CHILD LACK OF SAFETY FEAR ESCAPE IMPACT OF DIAGNOSIS
<u>CONFLICTING MODELS OF ILLNESS</u>	MEDICAL MODEL OF ILLNESS EXPLANATORY MODEL OF ILLNESS
<u>MANAGEMENT OF ILLNESS</u>	OVER-RELIANCE ON MEDICATION THERAPEUTIC APPROACHES TREATMENTS/INTERVENTIONS
<u>STAFF BEHAVIOURS</u>	LACK OF UNDERSTANDING LACK OF EMPATHY/COMPASSION LACK OF APPROPRIATE CONTACT THREATS/ABUSE/RIDICULE

EXPECTATIONS

FEAR

Case Study 5 (diagnosed with Anxiety/depression):

*And I was quite scared at first because the other people like the GP ...
said to me, they will knock you out for three days and talk later. (11)*

EXPERIENCES

FEAR/LACK OF CONTROL

Case Study 5 (diagnosed with Anxiety/depression):

First of all I couldn't function in the morning at all. Umm and I felt like I was not in control of things at all in any way, shape or form. So I was terrified if I got any worse I would start thinking of suicide. I didn't feel suicidal at all but I felt so not in control of myself that I didn't know what I would do. (17)

Case Study 4 (diagnosed with Psychosis):

So I thought my family and my friends were these aliens in disguise who could not be trusted. So it was just a nightmare because I just didn't know who to trust. (25)

The theme of DISBELIEF was evident in the comments of the majority of participants regardless of their mental health status. An example of the response from an involuntary patient and voluntary patient is provided below:

Case Study 7 (diagnosed with post-partum psychosis following death of four month old infant) [involuntary public patient]:

That's just unreal. Its like "Why am I here? What did I do so wrong to be put in this situation." (33)

Case Study 6 (diagnosed with anxiety/depression) [voluntary private patient]:

I was pretty calm about it until I realized where I was and that I wasn't at uni[versity] and wasn't in my natural environment and within this place I felt that people were putting all these sort of labels on me and that sort of thing and I suddenly went "Wait a second, I shouldn't be here" and would basically stop anybody who was willing to listen and explain to them why I shouldn't be there. (36)

Nearly all participants except the two who were private patients and neither of who had been in a locked ward, commented negatively about the hospital environment. On the other hand, three of the six public patients had been admitted to a locked ward. These three participants found the environment non-therapeutic and punitive with comments indicating a SENSE OF IMPRISONMENT such as:

A prison. Like a prison. Like a concentration camp. ... I felt ... like a dunce in school ... being punished. I just felt punished. I felt punished. I felt that I had done something so bad ... you go so blank because you think you've done something so bad that you have to be, basically you feel so bad. And then eventually they let me out of there and put me back in [hospital] (55)

Another participant found the atmosphere with the other patients to be prison-like. She recalled, for example:

I had to learn very quickly that you just can't sit at a table when its mealtimes, you had to ask permission of all the people there "Is it okay if I sit here?" ... it's like a prison, they've worked out their pecking order and where you can go and who you are allowed to talk to(47)

In contrast, Participant 6 (private patient) who experienced a sense of DISBELIEF at being in hospital tempered it with the option she was advised that she could exercise:

I don't think I was seriously trying to get out especially since after he told me I was there voluntarily and I realized that I could basically walk out. That took some of the edge off my anxiety about being there. (62)

Although the physical environment created a punitive atmosphere as reported in the comments above, all of the participants who were admitted as public patients experienced a sense of POWERLESSNESS. The following comment by a participant in a locked ward illustrates this:

... I got held by, I can't remember how many of them there was, but they marched me off to my room and gave me a couple of needles in my bum. I was just screaming and screaming trying to get them to understand but no they just held me down and I think that was the worst part about it, that they could do this to me without me, like I could do nothing, just nothing at all. (68)

I don't know. Its crazy isn't it. [referring to not being able to speak out in hospital ward]. (73)

However, a participant who was a private patient provided a different perspective. She expressed her implicit trust in having her needs met in the treatment environment in the following comment:

No. Not at all. Not at all. Because at that stage I wasn't feeling up to making any decisions of what I was going to do and I was fortunate enough to have a structure and being in a situation where people understood exactly what the situation was. (76)

With the exception of the two participants who were private patients, all participants recalled experiences with staff explaining them as an ANALOGY TO BEING A CHILD:

I just felt like a child, I felt like, and I felt like I was throwing a tantrum. That's what I felt like and no one was listening to me(78)

... they treat you like children. They are so patronizing, its unbelievable. They think that you are senseless. (87)

Participants who were public patients experienced a LACK OF SAFETY in the proximity of other more highly disturbed patients.

... there was a man there who used to get very confused ... he used to walk around with an erection and he really scared me because he used to keep walking into people's rooms. (91)

However, one participant recounted staff management of her situation when she felt threatened in the hospital environment.

They threatened me with a needle. If I didn't shut up. Because I was yelling at security ... because in my mind ... I should feel safe in a hospital whether I'm in a psychiatric hospital or in a normal hospital ... I should feel safe and I'm not safe. [referring to an assault by another patient]. (90)

A sub-theme of FEAR emerged relating to the unease being expressed after incidents with staff and fellow patients. The data under this sub-theme was different to that explored under FEAR/LACK OF CONTROL, the latter being generated from illness-related distress. One participant recalled an incident:

And it was like all my fears were challenged in hospital. ... I had been raped by a Japanese man and there was a Japanese man who kept following me and he triggered that. (94)

The implicit fear from interaction with staff is expressed in the following comment:

I would have to feel safe enough to do that [request help from hospital staff]. (97)

The need to ESCAPE from the hospital environment was evident in the comments by some of the participants. Case Study 4 has been in the mental health system for several years and expressed some knowledge of how the system works. She explains:

Case Study 4

It's like a waste of time and I could not wait to get out of there. So I fake it. I actually fake being well you know to get out of there. When I think I'm just able to cope, I fake being well really, really well so I

can get out of there. Anywhere, anything. I do it all the time. I walk in to my doctor. "How are you", "I'm fine". (99)

On the other hand, Case Study 7 had a single episode of hospitalisation. She comments:

Case Study 7

At first I was behaving how I was at home, a psychotic sort of way I suppose, doing things I felt I wanted to do at that time. ... And then I quickly learnt that I can't do this stuff. I've got to, even if I don't think anyone is, but I've got to try and behave myself while they are watching me and then I'll get out quickly. (101)

The data suggested the IMPACT OF DIAGNOSIS on the individual was experienced on a subjective level ranging from a sense of loss to a sense of empathy. For example:

I was very, very disappointed I had the illness. It was like they were going to amputate one of your legs or something, ... because when you're at school, you sort of encouraged to think that people with a mental illness are sort of second rate and hopeless and that they would be losers for their whole life and so that's how I felt. (104)

At the time, it made me psychologically worse but you know you turn your crap into something good and I have that ability to relate to people in that situation. (112)

The theme PSYCHOLOGICAL RESPONSE suggested private and public patients had dissimilar responses to hospitalisation. In particular, public patients, (three out of six) who had been in locked wards, regarded the experience with punitive overtones. In contrast, the private patients appeared to be more trusting and relaxed about having their needs met. All public patients reported feeling powerless and being treated like a child with fears about their safety within the hospital environment. Fears were also implied about their interactions with staff which generated the need to escape. The impact of the diagnosis on the individual differed with some feeling a sense of loss that affected other parts of their social life, to others who worked constructively to redress the negativity associated with the feeling.

CONFLICTING MODELS OF ILLNESS

The divergence between the clinician's approach of diagnostic categorization and the patient's emphasis on the underlying reasons for distress produced the theme CONFLICTING MODELS OF ILLNESS. One participant provided an example, as explained to her by her doctor and framed within the sub-theme, MEDICAL MODEL OF ILLNESS:

... my doctor ... believes that there are these chemical imbalances and people who suffer from anxiety disorders can also have that sort of

disturbance in the brain and clearly medication keeps it under control
(123)

Four public patients had been given diagnoses that changed over time, one of whom provided a wider explanation for psychiatric disorders:

Oh Bipolar. Umm dissociative disorder. Post traumatic stress disorder. Well that would be obvious that would. It comes around when you're in war zones every day ... and sometimes they try to put borderline personality ... (122)

Structured within an EXPLANATORY MODEL OF ILLNESS, participants with two different diagnostic categorisations provided fuller explanations for illness presentation:

Case Study 4 (currently diagnosed with bipolar disorder):

So running away from reality a million miles an hour is what happens when you're hyper and you're running away from grief and loss so you go hyper to avoid it (126)

Case Study 7 (diagnosed with post partum psychosis):

... the pain was so deep that I started to go off to this other place where it wasn't so painful for me. (124)

Analysis of data under the theme of CONFLICTING MODELS OF ILLNESS

indicated although all patients had social antecedents that precipitated their hospitalisation, they were given a psychiatric diagnosis and treated within a ‘medical model’ based on symptom reduction. This differed from patients who provided broader explanations for their illness presentation.

MANAGEMENT OF ILLNESS

The data analysis indicated that the theme MANAGEMENT OF ILLNESS contained three sub-themes: OVER-RELIANCE ON MEDICATION; THERAPEUTIC APPROACHES; and, TREATMENTS/INTERVENTIONS.

All participants reported OVER-RELIANCE ON MEDICATION with some reporting coercion. This is illustrated below with comments from public and private patients:

Public patient:

No. Just pills. All different types of pills. And I didn't know what they were or what they were for and at first I refused to take them because I didn't know anything about them and they just got me to take them. (132)

Private patient:

So yes they did, they drug you to the eyeballs but they need to get you functioning. (136)

The public patients provided a substantial amount of information regarding the THERAPEUTIC APPROACHES and activities. Typically the comments were as follows:

They didn't look. ... But nobody. Not once did ever anyone ever go into any past stuff. No. Never. (137)

... we had occupational therapy a lot and activities to do but they were all like kids, very childish level like we'd sit down and cut out things or colour things in and it wasn't adult occupation(141)

... they stick you in these assertive groups and the self-esteem groups, well, how the hell can you get self-esteem back when you've never even known what self-esteem is. And, how can you get it when you've still got all this underlying stuff there. You can never get it until you've dealt with it and explored it. But they say oh we don't want to explore that

In addition, hospital routine was explored and participants who were private patients alluded to a relaxed atmosphere for example:

Well we would wake up and have breakfast, very nice breakfast and umm get dressed then at some stage a little later in the morning you had group sessions. (161)

This is in contrast to the experience of most of the public patients. As one participant summarised:

Formula! Like five o'clock give them their medication, meal times are this, meal times are that. Oh god when you are mentally ill, that's another thing that has to be revised is having these structured things in a person's life. You are probably in there because your bloody life has been so flaming structured and so ruled, you know and then you go into another rule that victimizes you again. You know they say you can go in for a rest, a break. A rest? Break?! (158)

The sub-theme TREATMENTS AND INTERVENTIONS was positive when referring to cognitive behavior therapy (CBT) and interactions with staff. Both private patients who had been given an intensive two-week post-discharge course in CBT mentioned its long-term benefits. And, as one participant commented:

I would be much more quick to discuss how I was feeling with other people more openly. (166)

In addition, the data suggested that touch played a positive therapeutic role. A public patient describes the impact:

I said just hold my hand X. Just hold my hand. And I could feel, she's very calm, and I could feel her energy counteracting my energy and it automatically started to calm me down you know. (163)

The majority of the negative comments about TREATMENTS/INTERVENTIONS were related to the side effects of medication. However, the dubious merits of other interventions were also mentioned. The following are selected comments to illustrate this point:

No. I was taking up to ten tablets a day and it wasn't helping. I still wanted to die so they didn't help really. (187)

.... I was getting this grief thing. ... And I was also feeling angry. ... anyway the social worker said to me "Well yes I felt angry when my mother lost the negatives to my wedding photos". I felt humiliated. I felt so bad that I had gone in there to try and get some expressions, thoughts or something that was really deep inside me and I thought I shouldn't have said that. ... I felt so bad. Oh my god I felt like a clot. I did. I felt really bad so I just went up to my room and felt so bad. (171)

Especially after having the ECT ... I had short- term memory loss for about three months. Now looking back I cannot remember those three months. At all. Like it feels so strange to me that someone says you came to my birthday party then and you bought me this and they are showing me this thing and normally that would trigger something, you know you would oh yeah that's right, I just. No. It's gone. And the thing that scared me the most about that, ... the thing that bothers

me about it is that what if I didn't lose, what if I lost three months before instead of three months after. That three months before, that was my whole son's life that I would have lost and I wouldn't have been able to forgive anybody for that. (189)

An overview of the data under the theme MANAGEMENT OF ILLNESS indicated restricted options available for public patients with the use of medication being the primary intervention used for both private, and public patients. Positive comments about appropriate interventions were mostly from private patients and referred to cognitive behaviour therapy and the quality of the interaction with staff. Both public and private patients commented favourably about the use of touch as an intervention during their time of distress. All participants reported adverse side effects of medication. Those who underwent other interventions reported iatrogenic side effects and psychological distress related to physical interventions.

STAFF BEHAVIOURS

Under EXPERIENCES the final theme was related to STAFF BEHAVIOURS, and the following sub-themes emerged: LACK OF UNDERSTANDING; LACK OF EMPATHY/COMPASSION; LACK OF APPROPRIATE CONTACT; and THREATS/ABUSE/RIDICULE.

The distinction between understanding and empathy is made by the participants who allude to understanding being embedded in the knowledge of mental illness, and compassion being demonstrated in practice behaviours. This distinction is clearly articulated in the following responses with LACK OF UNDERSTANDING being:

The staff were very cold and non-understanding. Because I wasn't physically sick, what was my problem? ... So I basically felt as though they were looking at me as though I was making any excuse I could to go to hospital. (191)

In contrast, one of the participants, a private patient recalls her experience:

There were people occasionally who just couldn't cope. But they did encourage everybody to their best extent. [referring to nurses] (196)

All participants recalled incidents vividly to clarify their comments. For example, the sub-theme, LACK OF EMPATHY/COMPASSION was described in emphatic and non-emphatic behaviours and are illustrated below:

Case Study 7 (public patient):

That's what I kept telling them. I kept saying. I kept telling them "Don't you know I've just lost my baby" and it just, just, I was really, really amazed that it just didn't seem to affect anybody. They just didn't seem to show any compassion or yeah, it still seems very strange to me. (200)

Case Study 6 (private patient):

There were very nice. Probably the most positive thing was at night like the nurses would come and go through with you what you were thinking about and that sort of thing. That was one thing I found very useful. Because it can be very distressing to be you know away from home. Especially when you are not in a good frame of mind anyways. So it was nice to have them there to sit and chat and they were very sympathetic. (207)

All patients recalled the need to talk and the public patients in particular, highlighted the unavailability of staff. The following scenarios provide examples describing LACK OF APPROPRIATE CONTACT with staff:

They sort of, like when you are having a meal, they stand around the room, or when you are watching television, there's always someone around there. They don't always talk to you but they always stand there and they have a notepad and they're writing. (216)

... the psychologist ... was alright I suppose. And then he tried to come and visit me at home once a week but like it didn't happen like that. He would turn up once and then umm I would be ready for him to come the next week and he couldn't and then I would have to wait

another three, four, five or six weeks before I could see him again.

(212)

... well I had a psychiatrist but I never saw him, I only saw him once when I went in there and then I had a social worker or psych, I'm not sure what his position was(211)

Public patients reported staff behaviours as THREATS/ABUSE/RIDICULE. The threats were predominantly about the use of medication and the abuse of power. A few respondents reported comments about ridicule:

They threatened me with a needle. If I didn't shut up. (224)

There was one nurse who deliberately not give me my medication at eight o'clock because he liked seeing me spinning out and he would wait. On my notes it had that I didn't have to have my medication from 8 o'clock to 9 o'clock. ... I would go up to him and ask for my medication. ... But whenever my family were there he would come and give me my medicine at eight o'clock but if I was on my own at eight o'clock, he would not come near me. And he would not let me get my medication at eight. (225)

When you're ill you don't do rational things, so they may say "Oh here comes that idiot that did this the last time" but you are not rational. (227)

The overall analysis of theme EXPERIENCES suggested that key to the episode of hospitalisation is the interrelated of the psychological response to distress just prior hospitalisation, the conflict in understandings about the distress and the subsequent management of the hospital stay. Fears emerged under two separate sub-themes as emanating from the illness-related distress and those that were related to interactions with staff and fellow patients. The psychological responses to feeling imprisoned, powerless and being treated like a child suggested the inability of the patients to express themselves in the ward. Of particular note are the differences in the experiences of private and public patients. Only public patients reported comments under the sub-themes ANALOGY TO BEING A CHILD, LACK OF SAFETY, FEAR and ESCAPE (see Appendix G), as were negative comments related to POWERLESSNESS.

PERCEPTIONS

The category PERCEPTIONS produced three themes: PSYCHOLOGICAL RESPONSE; MANAGEMENT OF ILLNESS; and STAFF BEHAVIOURS (See Table 5).

PSYCHOLOGICAL RESPONSE

The theme PSYCHOLOGICAL RESPONSE had five sub-themes: LACK OF POWERLESSNESS; FEAR; STIGMA; STEREOTYPED and DISCOUNTED. Most comments in the sub-theme POWERLESSNESS reflected consumers perceptions to 'having a voice' with similarities typically being:

... start forming groups so that I can help them from my own experience to have a voice through art too(228)

... I think we are getting a bit more of a voice (229)

One participant attributed this to the consumer movement, saying:

I think the strength of it at the moment is the consumer representation (231)

Table 5

Themes and sub-themes generated by Case Study 1-8 indicating PERCEPTIONS of mental health services following hospitalisation in Western Australia

<u>PERCEPTIONS</u>	
THEMES	SUB-THEMES
<u>PSYCHOLOGICAL RESPONSE</u>	LACK OF POWERLESSNESS FEAR STIGMA STEREOTYPED DISCOUNTED
<u>MANAGEMENT OF ILLNESS</u>	LACK OF CONFIDENCE IN STAFF LACK OF CHOICES LACK OF CONSISTENCY IN CARE LACK OF TIME
<u>STAFF BEHAVIOURS</u>	LACK OF UNDERSTANDING LACK OF EMPATHY/COMPASSION

In addition, there were limited negative comments. Once again, these comments were related to 'voice'. An example follows:

*Well this feeling of not being in control of yourself actually.
This feeling of not having a voice. The feeling of, like going to
this person, and I reflect back, oh god I was so capable, so
coping, I was so this, they didn't acknowledge that side of it.
(237)*

The second sub-theme was FEAR. The enduring effects of fear are noticeable in a comment from a participant who has had several hospital admissions. She explains:

*... but right now if I was up there ... I would be too scared, even if I
walk in there ... not a patient and I may walk into that ward to see
somebody or whatever I get this feeling in myself. (243)*

Similarly, the prolonged effects of fear is reflected in a comment from a participant who had only one admission:

*And I would also say that tainted the rest of my life because in April I
just had a miscarriage ... I'm just going to be under eagle eyes again.*

I've just got to make sure nobody sees that and that I've got to act as normal as possible because I know where I'll go. (251)

The sub-theme STIGMA was associated with experiences consumers had in the hospital and their interactions with community, family and the mental health system, and included the following:

... you take a risk every time you divulge it you risk. There is a big risk and especially when you've got people in counselling positions that tell you not to tell your supervisor(263)

... they say we've got stigma and discrimination right on the outside but believe you me, the biggest stigma and discrimination actually comes from inside the system itself. They stigmatise us big time compared to the outside. (256)

There were only a few remarks of disparity in this sub-theme with many expressing the experience and understanding of mental illness in contemporary society. A statement from one participant provides an overview:

I mean its amazing how many people will say to you yeah I went through a period of depression when they hear about what has happened to you. ... I never realized until I was sick, how common it

is. And I think that's one thing that probably needs to be brought out in the community generally. (264)

Under the sub-theme of STEREOTYPED participants reported the impact of their illness on friendships as well as staff behaviours in the clinical setting. An example of each is provided below:

... I mean there were only two people who were friends who came to visit me in hospital but I'm sure they are scared because they don't know what could happen, what I might be like. (265)

... I would say after a few visits they have made up their mind about you. So yeah I'd say after a few visits, like you might go in three times and the fourth time they'll treat you like they did the other three times. [referring to nurses] (266)

Analysis of the data indicated most of the comments about being DISCOUNTED were associated with behaviour of staff towards the patients. Few comments referred to the wider community. A participant recounted:

Do you know it took three days for the police to come and if I had been out on the street they would have been there oh within an hour one would think. But it took three days. So for three days I was a mess. [referring to violent incident with fellow patient]. (285)

Another participant who has been in the mental health system for twelve years observes:

This is why we have so much mental illness because we the people who develop a mental illness are the ones ... made to feel that it is our fault. That we are inferior. ... instead of addressing the issues that have brought us to this stage and validating our experience they don't. (295)

MANAGEMENT OF ILLNESS

Under this theme, four sub-themes surfaced and were related to the perception of the quality of care received. These sub-themes were: LACK OF CONFIDENCE IN STAFF; LACK OF CHOICES; LACK OF CONSISTENCY IN CARE, and LACK OF TIME.

Comments under the sub-theme LACK OF CONFIDENCE IN STAFF were concerned with interactions with staff from the multidisciplinary team. Concerns about staff skills and training were almost always negative. These comments came only from public patients. The following statement illustrates the point:

People who were in the field of mental health. They know better but nurses ... are not really trained for mental problems. (318)

Umm let me out. Just talk to me. But I don't even know if they had the skill or training to deal with that anyway. [referring to locked ward situation and nurses]. (319)

Another participant acknowledged the challenges faced by the staff, and stated her opinion from the staff's perspective:

... they are faced with a dilemma as well because they don't know because ... practices they come along with are practices that are archaic you know and they need to chuck that away and start becoming more contemporary and start to rethink it ... (337)

All participants who were hospitalized in public hospitals commented about the LACK OF CHOICES available. Most of the comments highlighted the need to talk, and this was supported by the special emphasis given to the need to have more psychologists. Reported below are insights from two participants:

Very limited and totally inappropriate. (342)

There could have been more alternatives. You know like psychology. Someone to talk to. Umm herbal. Herbal tea available. I mean that's a really basic. Yeah. I mean that's on a very, very minor scale. But it's ; still relevant. I mean normal tea is caffeine. It heightens. (358)

All participants who were public patients reported the disruptive nature of the mental health system due to the LACK OF CONSISTENCY IN CARE. One participant, who despite feeling empowered, sums up the negative aspects of this disruption on the recovery process:

... for people like us where ... in my first year of life I had five houses. It is very disruptive. There is no consistency. And if you are coming from childhood where a child needs consistency and maybe if you've flipped back to being a child and there is no consistency there I mean God! It's dreadful! I can't tolerate that anymore. I couldn't tolerate it. I just went along with the flow of it but now I've become more empowered I can't tolerate that inconsistency. ... it doesn't do anything to really help me. I actually feel worse. (360)

The data indicated most of the comments under the sub-theme LACK OF TIME referred to minimal contact with doctors and with nurses spending insufficient time with the patients. Once again these comments came from public patients only. The observations made by a private and public patient are provided below. Despite the lack of appropriate time given to the client, the public patient participant saw the point from the service provider's perspective:

Public patient:

Well we haven't got time allocated ... I was just getting to the stage when its going to be really beneficial and then "Oh I really don't have any more time". It is difficult for them, That's the logistics of it. They do need addressing obviously if the treatment is not getting to a point where its not getting on to the next step because of the time allocated and you could have five minutes more and you could reach that next step. (379)

Private patient:

I guess the thing that impressed me the most was, the psychologists who ran the programs were unbelievable, but the nursing staff ... were out of this world. They were each assigned 4-5 per session and they would come and find you and say I'm your nurse for this morning or this afternoon and if you've got any problems please come and speak to me. And they would come and see you and check how you were and a couple of times when I was feeling really bad I would go and say, can you come and talk to me and they would come and sit, sit and talk, and discuss whatever was worrying me. They were unbelievable. (380)

The sub-themes under the theme MANAGEMENT OF ILLNESS emphasized the benefits of talking therapies, availability of choices, continuity of care and staff that are skilled and empathic in their care of people diagnosed with a psychiatric disorder.

STAFF BEHAVIOURS

All participants explained their episode of illness within a broader biopsychosocial framework. Participants reported their perceptions of STAFF BEHAVIOURS framed within their own understanding of illness and the staff's response to their needs. LACK OF UNDERSTANDING was expressed when staff failed to understand the underlying problems to the symptoms of distress. A participant reflects:

Because it was always what I was going to do about the problem. Not about what the problem caused me to be like and how and acknowledging that outside my problem there were these other problems that really do need addressing in society. I was it. It was always ... it was back on me. I acknowledge that I am the only person that can actually jump ahead. But I think my jumping ahead would have been a lot quicker if they acknowledged my pain and my feeling about that social stuff that ... initiated all this. (387)

Where there was a disparity to this viewpoint, the participants alluded to staff having prior knowledge about mental illness and responding to it appropriately. For example:

My doctor was okay. He was fairly sympathetic towards it because from what I heard his mother had severe depression and he grew up with it so he was really understanding about it. (391)

References to work practices of mental health professionals generated the sub-theme LACK OF EMPATHY/COMPASSION. A participant who was a public patient elaborates sharing her views after several episodes of hospital care, the last being eight months ago:

Well they seem to work to a pattern. You know ... it's a pattern, it's not real, and it's not genuine. They are not genuine. I mean I'm not saying they have to be genuine but I think if you are dealing with people who have emotional problems you have to be genuine. It can't be run by the book. Its like they picked up a book, oh we are going to do this first, oh yes we'll treat this first like this because it says so in the book. Oh god! (404)

A further comment from a participant who was a private patient supports this following a single episode of hospital care:

The doctors? [laughter] Interesting. My doctor, he, he didn't show his emotions very well and I thought gee I must be ill because I cannot see emotions in other people. (400)

On the other hand, the data indicated the perception of empathy reported by a participant incorporates understanding of mental illness and the work practices employed by the staff.

They are kindly and understanding to an amazing extent. They are also gently, gently firm. They will not, if they think you are lying around feeling sorry for yourself, they will try very hard [referring to nurses in private hospital]. (411)

An examination of the data related to the sub-themes under STAFF BEHAVIOURS reflected those under the category EXPERIENCES. The comments were framed within the perception of knowledge, practice and care demonstrated towards the participant in the clinical setting. On many levels, the differences between private and public patients were distinct by their dissimilarity.

The themes and sub-themes under the category PERCEPTIONS is remarkably similar to that under EXPERIENCES. However, the episode of hospitalisation is notable for the lasting perceptions and psychological responses to it (see Figure 4). In particular, once again, most of the positive comments came from private patients and focused on the quality of interaction they received from staff. On the other hand, the public patients shared perceptions that were similar and focused on what they perceived to be mismanagement of their illness.

REFLECTIVE COMMENTS

The last question in the interview schedule elicited responses that covered a wide spectrum of expectations and perceptions based on the experience of mental health services in Western Australia. Two themes MANAGEMENT OF ILLNESS and INADEQUACY OF SERVICES and several sub-themes were generated under this category (see Table 6).

EXPECTATIONS	EXPERIENCES Psychological responses	PERCEPTIONS
Case Study 4: Public patient in public hospitals with first hospitalisation 14 years ago and most recent, 8 months ago	Somewhere where I can get away from the environment and be there with somebody who understands	I just wanted to get off this earth basically
		... you feel like a child ... like you're going up asking for something you shouldn't have. You feel like a child. You're scared.
		... my whole experience in psychiatric hospitals is exactly the same mirroring experiences of what I experienced as a child. And it is still like that for me. That's why I won't even contact them now because I'm having some difficulties ... I don't want to be re-abused.
Case Study 5: Private patient in private hospital with first and only hospitalization 3 years ago	And I was quite scared at first because the other people like the GP ... said to me, they will knock you out for three days and talk later.	I just felt like I didn't know what was going to happen next.
		... so I went in ... it was the most enormous relief ... about ten days prior to that were easily the worst ten days of my life ...
		... the two most valuable lessons I had learnt were ... I would never let myself get to the bottom of that pit again ... I would never be nervous again about going back into that sort of situation ...
Case Study 7: Public patient in public hospital with first and only hospitalisation: 18 months ago	... at first I thought okay I'll just see what its like, well they're just giving me a rest.	I think when I started to be left alone after the funeral, that's when things started to change because all of a sudden I was by myself
		At first I was behaving how I was at home, a psychotic sort of way, ... then I quickly learnt that I can't do this stuff. ... I've got to try and behave myself while they are watching me and then I'll get out quickly.
		And I would also say that tainted the rest of my life ... I just had a miscarriage ... I've got to act as normal as possible because I know where I'll go.

Figure 4. Comparison of the expectations, psychological responses to, and perceptions of pre- and post-hospitalisation between Case Study 4, 5 and 7 depicting differing psychological responses to the experience of hospitalisation in Western Australia.

Note: Selected quotes are in abbreviated form. Fuller quotes are listed in Appendix G.

Several sub-themes were nested under the theme MANAGEMENT OF ILLNESS:
TALKING/EMPATHY/UNDERTANDING; BIOPSYCHOSOCIAL APPROACHES TO CARE;
ENVIRONMENT; INTERACTION WITH STAFF; and PARADOXICAL STAFF BEHAVIOURS.

Table 6

Themes and sub-themes generated by Case Study 1-8 indicating REFLECTIVE
COMMENTS about mental health services in Western Australia

<u>REFLECTIVE COMMENTS</u>	
THEMES	SUB-THEMES
<u>MANAGEMENT OF ILLNESS</u>	TALKING/EMPATHY/UNDERSTANDING BIOPSYCHOSOCIAL APPROACHES TO ENVIRONMENT INTERACTION WITH STAFF PARADOXICAL STAFF BEHAVIOURS
<u>CARE</u>	
<u>INADEQUACY OF SERVICES</u>	MORE SERVICES CONSUMER GROUPS/SELF-HELP GROUPS

All participants referred to the need for TALKING/EMPATHY/UNDERTANDING from mental health professionals. The comments from two mental health consumers are provided below. The first participant has been in the mental health system for several years and notes:

*I think heaven for me would be a hospital where people who really
wanted to be there and are caring ... and its sort of a place where you*

can come together quite quickly instead of being jam packed in somewhere and ... everything is like it was in the seventies ...(424)

Another participant observed after a single episode of hospitalisation:

Yeah the biggest gaps I would say are they are too reliant on medication to fix everything when they could use psychology for psychological problems. (427)

All participants provided a wider explanation for their episode of illness and suggested BIOPSYCHOSOCIAL APPROACHES TO CARE. One participant summed the comments under this theme saying:

I think to address mental illness you have to address the emotional aspect, the intellectual aspect, the physical aspect and spiritual aspect. And the sexual. You cant, just, it cannot just be on the mental level because the human being is made up of different, its not one part you know. You have to address the whole person. (431)

Under the sub-theme ENVIRONMENT comments referring to the tangible and intangible elements of the psychiatric setting revealed the importance of a nice environment. However, the perception of a public patient who spent some days in a locked ward makes a discerning observation. For example:

Private patient:

Yeah it was nice. It was nice, ... just sitting outside and there was a little garden out the back so that was fairly quiet and tranquil. (438)

I just thought that it was the utmost wonderful place on the planet. (447)

Public patient:

... there was a lovely garden, had a gazebo in it but they had it locked. (450)

Public patient:

Totally bloody worthless, well I felt like I was going mad. I felt as if I was actually going mad(453)

All participants referred to their INTERACTION WITH STAFF. A long-term mental health consumer observes the importance of individuals within the system:

But I can't say there was anything good about the system as such. I can only say there was something good about that particular individual at that time of my need. (458)

I find that 'consumer' a strange word but I had no intention of being there and I don't know why I was in there anyway. And I wasn't treated very well while I was there and it was just a balls-up. (464)

Participants reflected on their previous experiences as a general patient in a hospital and as a patient with a psychiatric diagnosis and noted PARADOXICAL STAFF BEHAVIOURS. With the exception of one participant (a private patient), all participants who had experienced a previous hospitalisation as a general patient, reported differences in care they received. An example is provided to contrast the comments between two participants, the first being a long-time mental health consumer (public). The second was a private patient in a private psychiatric hospital for a single episode of hospitalisation. She was also hospitalisation as a general patient in a general private hospital and her comments are related to the two experiences. The statements highlight the perception of service delivery under different circumstances.

General hospitalisation versus psychiatric hospitalisation – Public patient (Negative)

Oh like they can look busy when they are hovering around you, checking your stitches and doing this and doing that with the baby or you. But when you are in there because of a mental problem, there's nothing for them to do. (467)

General hospitalisation versus psychiatric hospitalisation – Private patient (Negative)

They are very, very different. The nursing staff at the [general hospital] are also very nice but it's not the same. There is an element that applies at the [psychiatric hospital] of genuine, real concern about how you are. The [general hospital] is excellent and I'm not knocking it in any way and I'm simply saying ... that they check you and you might get a nurse who will have a little chat with you if you have established a rapport but basically they've got all these duties to do and they are going to come in and do all those duties. (478)

All participants framed their episode/s of illness within a biopsychosocial context and tailored their reflective comments accordingly. In addition, the overview of the theme MANAGEMENT OF ILLNESS indicates inflexibility of the service delivery system. The need to talk and engage in a therapeutic environment was articulated by all participants. The lack of contemporary perspectives into managing mental illness is noted by consumers in terms of appropriate interaction with staff, the environment and staff behaviours.

INADEQUACY OF SERVICES

Some comments were identified under the theme of INADEQUACY OF SERVICES, and one participant who has been with the mental health system for twelve years notes the lack thereof. She articulates her frustration saying:

*... we need somewhere, when you have had forty odd years
[participant distressed]. ... Yes very difficult. When you've had a*

lifetime basically things like this and yet you can still function but you can't form relationships not even with your own children and you go to mental health places and they say "See you in six weeks". Six weeks! Hang on, it's taken forty odd years to get here(483)

The last sub-theme was related to CONSUMER GROUPS/SELF HELP GROUPS.

Other than one mental health consumer who was involved in the consumer movement, none of the other participants were aware of the National Mental Health Strategy or knew how to convey their needs to the relevant authorities and/or consumer/advocacy groups. However, some had accessed self-help groups and there were varying responses to the benefits or otherwise of these groups.

Private patient – comment refers to private psychologist following hospital-based CBT:

... this came out in the individual therapy sessions, there were a lot of long term beliefs that I had about myself and things that had happened to me that that really needed that individual attention because they were so deep and in groups you can get to surface things but you cant really always get to the things that are the root of your self-perception. (498)

Public patient – comment refers to self-help group for people diagnosed with depression:

Well, I'm in a support group at the moment but I wouldn't like to do it for that long but its just people have a lot of problems and you end up finding out too many problems. (494)

Of note, under the category REFLECTIVE COMMENTS is the emphasis placed on the need for talking therapies and choices that are perceived to be absent in the public mental health system in Western Australia. The data in the themes, MANAGEMENT OF ILLNESS and INADEQUACY OF SERVICES suggest consumers of mental health services perceive their needs are not being met adequately and appropriately.

Finally, the following comment encapsulates the various themes and sub-themes under the categories EXPECTATIONS, EXPERIENCES and PERCEPTIONS.

Proper help, respect and care. And being believed. Sometimes we are in great distress and that's all it is sometimes. And we are human beings. (276)

Summary of Results

The salient feature of the data analysis related to the sub-theme of PSYCHOLOGICAL RESPONSE under the categories EXPECTATIONS, EXPERIENCES and PERCEPTIONS. The experiences of private patients were different to those of public patients and generated differing psychological responses

to the experiences. These responses produced two new conceptual frameworks (see Figures 5 and 6) that differ from the conceptual framework depicted in Figure 1.

The analysis suggests that participants entered the mental health system with no expectations of the services but rather in a state of psychological distress seeking refuge from events in their lives. Once hospitalized, the interactions of staff and management of their distress influenced their experiences. The incongruence between the patients and the clinicians produced a conflict where illness was treated within a medical model whereas the patient provided a broader understanding for their illness presentation.

The lack of appropriate choices and the quality of staff interaction reported by public patients created lasting perceptions. These experiences either generated various negative responses during hospitalisation and a feeling of fear that accompanied subsequent hospitalisations, a reluctance to seek help at the appropriate time or suppressing emotions that have the potential to precipitate another episode of hospitalisation (see Figure 4).

Participants, other than one individual who was actively involved with the consumer movement and one who was disinterested in it, were either unaware of avenues to convey their needs, or redress problems they may have encountered. However, those who were aware of the consumer movement articulated a sense of empowerment. The trend towards LACK OF POWERLESSNESS also came from public patients who empathised with the obstacles encountered by staff working within the mental health system, for example, limited time.

NATIONAL MENTAL HEALTH STRATEGY

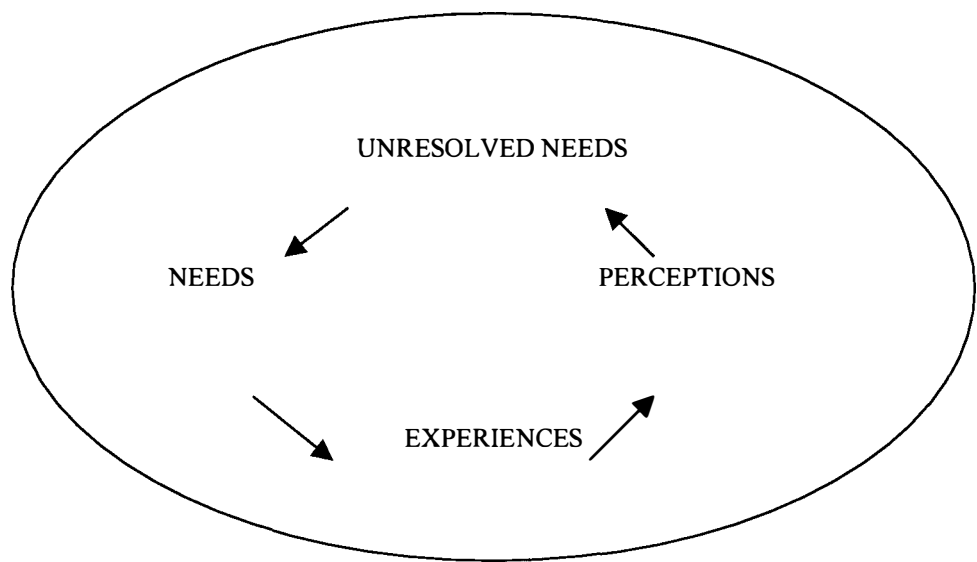


Figure 5. A conceptual framework indicating a ‘revolving door’ for public mental health consumers, following the experience of mental health services in Western Australia.

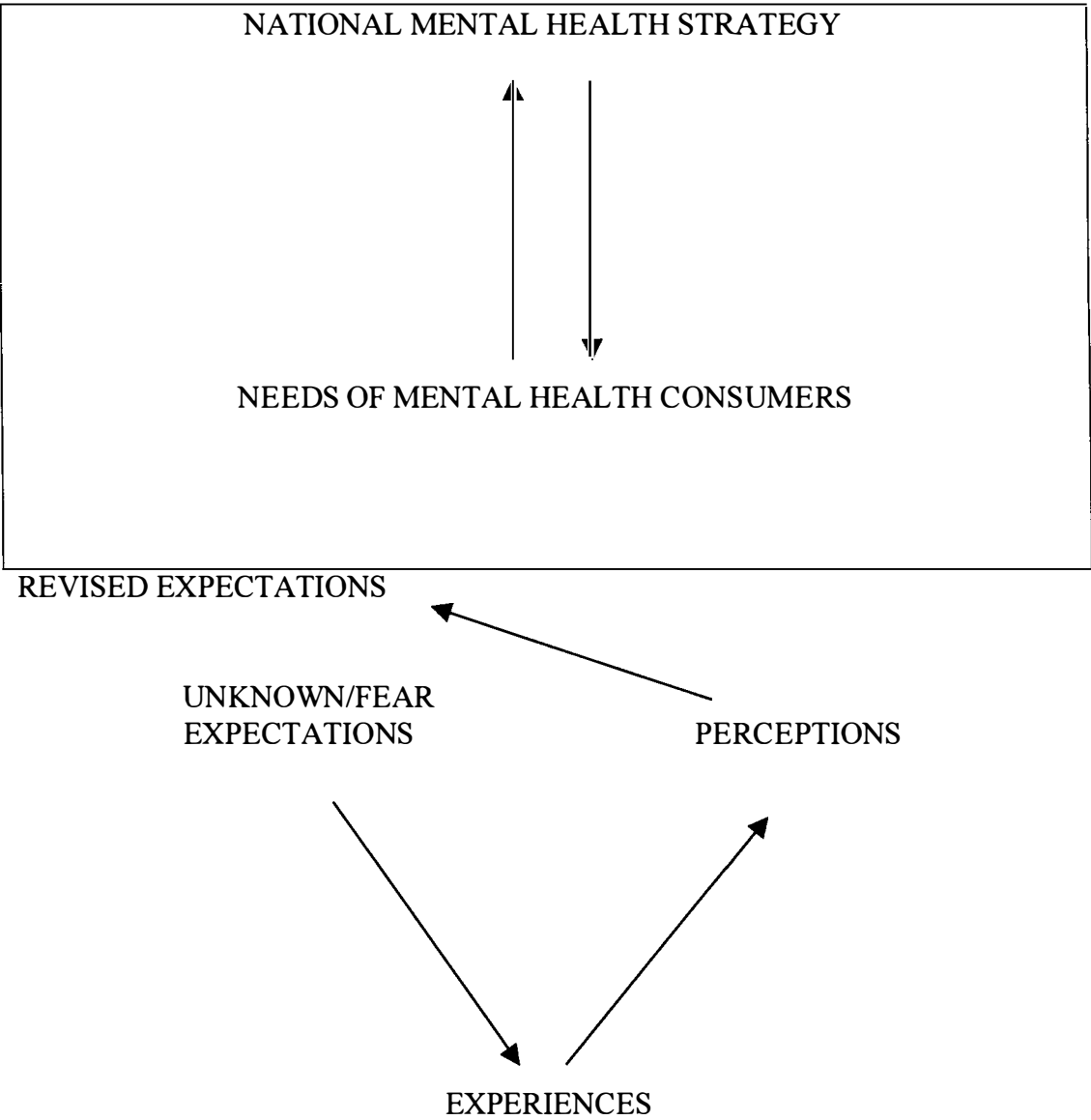


Figure 6. A conceptual framework indicating a revision in expectations for private mental health consumers, following the experience of mental health services in Western Australia.

The data suggests a differing conceptual framework for private patients (see Figure 6). Only one participant reported fearful expectations. Generally, the experiences of illness management and staff interactions were positive. Despite being treated within a medical model, choices of other appropriate interventions were available. The data indicate a revision of expectations for these patients. This is reflected in their comments about the therapeutic encounter which are predominantly positive.

Lastly, the needs of individuals entering acute settings are complex. The mechanism that advises policy makers and service providers of these needs is obscure.

The results of this study are discussed in the next section.

Discussion

Framed within the expectations and perceptions of mental health services, a semi-structured interview format facilitated exploration of the experiences of mental health consumers in Western Australia. The cross case qualitative methodology indicated differences between cases were largely related to whether or not the patient was treated in a public or private hospital. Experiences were predominantly structured around management of illness and staff interactions. For those consumers who had their first hospitalisation prior to 1992, some positive changes are identifiable. However, remarkably, the themes and sub-themes in the qualitative data suggest trends are similar to those reported elsewhere in international and Western Australian qualitative studies (Goffman, 1961; Goodwin et al. 1999; Letendre, 1997; Martin, 1998; Rogers et al. 1990).

EXPECTATIONS

Previous research on the views of mental health consumers has focused on the construct of satisfaction of services (Lebow, 1982). The limitations of this are inherent in examining expectations of consumers from a service providers' perspective (Carr-Hill et al., 1989) and restricts the exploration of the time period to the hospital stay (Parkman et al., 1997; Shields et al., 1988). This study elicited expectations of mental health consumers with the focus being the experience of hospitalisation. Therefore, this study extended the time to the period just prior hospitalisation and examined perceptions following hospitalisation.

Psychiatric epidemiology has established social stressors like poverty is strongly associated with mental illness (Belle, 1990). Also, the impact of social events and stressors on mental health has been reported (McBride, 1990). By exploring the

expectations of psychiatric care before hospitalisation, the study found individuals experienced social antecedents to their emotional distress before admission to hospital. These events influenced their psychological wellbeing resulting in expectations that were either embedded in psychological needs or subsumed by them. Calnan (1988) asserted individuals seek help to alleviate physical, psychological or emotional needs. The findings of this study suggested fear of hospitalisation was minimal and when expressed, it related to secondary sources. Having accessed specialist services in a state of illness-related distress, all patients were treated within a medical model of diagnosis and symptom reduction. The choices of interventions were limited for public patients. In particular, there was an absence of 'talking therapies' either through formal or informal channels; leading to unresolved needs added to existing needs.

The value of patient-centred care has been promoted in clinical literature (Campbell et al, 1990; Opie, 1998; Toop, 1998; Wallace et al., 1999). The current study supports these views, as the experiences of the two private patients were different to that of the public patients. Having had their needs met, in what they perceived to be an appropriate manner, led to them revise their expectations from unknown and/or fear, to expectations of implicit trust in the private mental health system to meet those needs.

EXPERIENCES

Relying on recall of memories has strengths and limitations according to Breakwell et al. (1995) as it offers "... the individual's unique perspective ..." and it also provides "... commonality and, ... shared identity ..." (p. 322). They further claim, although experiences are not individually stored, information relying on

autobiographical memory is hierarchically structured and, "... is useful when ... one needs to distinguish between memory effects and conscious self-representation or when the veridicality of a memory is at issue" (p. 322). The latter is an important consideration when eliciting the views of mental health consumers due to potential bias or their presumed mental (in)capacity (Wong, Clare, Gunn & Holland, 1999). However, the veracity of the comments reported in this study is supported by the small sample where most of the participants were not only inpatients of the same hospitals, but were patients at different periods of time. Participants were also interviewed independently using a semi-structured format and identified areas that were of importance to their experiences.

Although consumers did not express specific expectations about psychiatric care, they judged their experiences in the hospital against the social antecedents that precipitated their hospitalisation, their psychological needs at the time of admission and the subsequent interactions with staff. The psychological vulnerability of the individuals at admission is evident from fear and a sense of lack of control experienced from the illness-related distress. All patients experienced a sense of disbelief at being in the hospital environment, however, the experiences of private patients differed from those of public patients.

The nature of the psychiatric setting imposed psychological duress making the experience of hospital for public patients in this study, an unpleasant one. This was not the case for private patients who reported mostly positive experiences. The negative psychological responses for public patients included feeling powerless, being treated like a child, fearful of staff and fellow patients, being imprisoned and for some a need to escape. The impact of the diagnosis too, produced a range of

responses from feeling despondent and experiencing losses in personal relationships and social activities to disregard for psychiatric labelling.

Rogers, et al. (1990) in a study of consumers and ex-consumers in the UK reported that participants provided an understanding of mental illness that included wider explanations. Nonetheless, they were treated within a medical model of symptom reduction through biopsychiatric approaches. The conflict between the consumers' explanatory model of illness and the medical model of illness is an important observation. Bhugra (1997) stated that at the heart of help-seeking is the distinction made between disease and illness. Chrisman (1980) asserted illness is the perception and/or worldview of the problem considered from a socio-cultural angle whereas disease is a biomedical understanding of the presenting problem. Therefore, he claimed eliciting the client's explanatory model of illness is crucial to the process of the client's perception of being heard. It is an important dynamic in the clinical encounter where elements are symptom definition, treatment action and adherence; the interrelatedness of which is crucial for successful outcomes (Campbell et al., 1990; Camphina-Bacote, 1994; Lopez & Guarnaccia, 2000; Opie, 1998; Toop, 1998). This is evidenced in a study by Callan and Littlewood (1998), which examined ethnicity and explanatory models of illness of patients diagnosed with a psychiatric disorder. The authors reported that satisfaction of inpatient psychiatric care was strongly associated when there was a concordance between clinician and patient of an explanatory model of illness. Ethnicity match between clinician and client nor mental status (i.e. voluntary or involuntary admission) was influential to the outcome.

In a study of clients from CALD backgrounds carried out in Western Australia, Martin (1998) highlighted the linguistic and cultural barriers to optimum culturally sensitive care. In some instances, the clients felt their condition had deteriorated due to inadequacies in the management of illness and inappropriate staff behaviours.

Goffman (1962) sees this as "... applying a single technical-psychiatric view. That one person differs from another in sex, age, race grouping ... is merely an item ... to be corrected for, ... so that general psychiatric theory can be applied ... (p. 306)."

Although observed by Goffman (1961) nearly forty years ago, it is a scenario repeated in the current study where all patients provided explanations for their distress within the context of social events. Despite this, they were treated within the framework of the dominant culture of the institution.

The findings of this project reflect 'medico-centricity' similar to that reported by Rogers et al. (1990). Once diagnosed, management of illness of participants was conducted using biopsychiatric interventions ranging from medication to electroshock. The use of medication was widespread for all participants. With the exception of the two participants who were private patients in a private hospital, exploration of the events that preceded the patient's distress was not investigated. More alarmingly are the reports of incorrect medication being administered, gaps in clinical histories, and the use of medication as threat to manage patient behaviours. These practices fail to comply with several standards outlined in the National Standards for Mental Health Services (AGPS, 1996), and infringe on basic human rights (see Appendix H). This was not the case for private patients who perceived the services they received to be caring and humane.

Another salient observation is the absence of 'talking therapies'. All public patients reported negative accounts of their encounters with staff and members of multidisciplinary teams. Camphina-Bacote (1994) makes the distinction between understanding and empathy with understanding being demonstrated in knowledge of illness whereas empathy is related to practice. Public patients reported limited contact with hospital staff and the quality of the contact was poor and in some case unfavourable. Virtually no avenues were available for counselling other than group therapy which most found ineffectual and in some cases, detrimental. The two private patients were the exception; they were given an intensive course of cognitive-behaviour therapy for two weeks after discharge. Both respondents reported positively to this approach.

PERCEPTIONS

Letendre (1997) stated that one of the processes involved in psychiatric hospitalisation concerns the patient's interaction with staff. Fifty percent of the participants of his study had entered the hospital system in the hope of escaping a distressing situation. Miedema & Stoppard (1994) reported a similar trend, as did this study. Seeking out alleviation for their distress was the basis of the help seeking behaviour for the majority of participants. Interaction with staff therefore formed, as Letendre (1997) put it, '... the background for the course of the hospitalisation experience ...' (p. 298).

Anderson (1995) states perception is an inferred process. The experiences of mental health consumers reported in this study supports that view. There was concordance between the themes and sub-themes under PERCEPTIONS and EXPERIENCES especially those related to interactions with staff. Of note the

experiences of public patients with staff which generated perceptions that were lasting. These perceptions reported the lack of confidence in trained staff, limited treatment options and the inadequacies of the therapeutic environment. The management of illness and staff behaviours generated new sub-themes under psychological distress for these consumers, all of which suggested negative experiences.

Letendre reported (1997) causal factors generated "... an identity based on a sense of deficiency ..." (p. 298). Similarly, public patients of this study perceived stigma, being stereotyped, and being discounted within the mental health system and to a lesser degree by family and community. Once again, the perceptions of private patients were different. They were positive about the experience of hospitalisation and the interactions with the therapeutic community. Unlike public patients, private patients did not report fear of re-hospitalisation should that be an option in the future. On the other hand, public patients reported unresolved needs that become amplified due to their reluctance to seek help at the appropriate time.

Caslyn et al. (2000) reported that perceived choice is an important element in empowerment. A notable finding under PERCEPTIONS refers to the sub-theme POWERLESSNESS. This demonstrated a change in trend from EXPERIENCES with an inverse direction in similarities and disparities which lead to a sub-theme LACK OF POWERLESSNESS. The comments under this sub-theme were mainly from a consumer who was involved with consumer activities. Despite comments about her inability to speak within the mental health system, her activities may have led to a perception of having her voice heard. However, other public patients expressed empathy for the staff implying they, (the staff), were in a position of 'powerlessness'

with emphasis being made on the organisational structure of the mental health system.

To a lesser degree, observations were made about the lack of the active presence of consumer bodies/advocates in the hospital setting. Paulson et al. (1999) reported on a study that compared the work practices of consumers and non-consumers in a mental health setting. The authors reported although both groups had equivalent work loads the group with consumers demonstrated an empathic approach to their task whereas the non-consumers were focused on task completion. The use of consumers in mental health settings is prevalent in New South Wales and Victoria (Mental Health Association, 1998). Given that several themes and sub-themes report observations made by consumers about staff interactions (or lack thereof), the use of consumers in mental health settings is a worthwhile area for consideration. It is notable that all participants framed their experiences within the context of their interactions with staff. Understanding, warmth, caring and empathic approaches were at the core of their experiences and perceptions. These experiences and perceptions are similar to those reported by Goodwin, et al., 1999; Letendre, 1997; and Rogers et al., 1990.

The EXPERIENCES and PERCEPTIONS of hospital care generated the theme REFLECTIVE COMMENTS. This theme covered comments from a post-hospitalisation perspective and highlighted those needs consumers believed to be unmet by the mental health services in Western Australia.

The illumination of needs is a pertinent finding. All participants shared their experiences by placing them within the broader context of their lives. Seeking refuge from outside stressors were dominant reasons for their help seeking

behaviour. Those who received appropriate care within a therapeutic environment that was supportive and empathic reported positive experiences. Those who were unable to receive a similar standard of care were distressed and fearful of future episodes of hospitalisation.

In the main, most of the needs identified by consumers related to the lack of appropriately trained staff and lack of counsellors and/or psychologists. This study found individuals entered the mental health system with complex psychological and social histories. The resources within the system were unable to cope with the presenting complexity. The current scenario is disconcerting, given the recommendations from the Inquiry several years ago, which urged the use of 'psychotherapies' (Burdekin, 1993) and is a practice endorsed in the National Standards for Mental Health Services (1996)..

Another notable finding was the widespread use of medication and the range of side-effects experienced by the individuals. The lack of flexibility exacerbated the physical condition of individuals who struggled to cope with the rigours of hospital routine and the debilitating effects of medication. This, once again, was a contrast to those experiences reported by private patients. Public patients, disgruntled about their experiences have lasting perceptions of what they perceive to be staff incompetence and lack of expertise.

The National Standards for Mental Health Services (1996) makes provision for Standards to be subjected to monitoring in an endeavour to improve performance and service delivery yet none of the consumers were aware of this process. Although consumers may not be aware of the operation of these Standards, the staff within the

mental health system is made aware of them through staff training and development activities, namely:

9.17 The MHS regularly identifies training and development needs of its staff.

9.18 The MHS ensures that staff participate in education and professional development programs.

9.19 New staff are provided with an orientation program to the MHS.
(AGPS, 1996).

The lasting perceptions of mental health consumers about the inadequacies of mental health services lead them to either delay seeking help or seeking help until a crisis developed. The implications of this are important for economic, social and humanitarian reasons. This highlights the urgency to promote, undertake and maintain contemporary standards for mental health care in Australia which include the principles inherent in patient-centred care as espoused by Toop (1998).

The definition for mental illness provided by the Taskforce on Mental Health in Western Australia makes the distinction between mental disorder and illness and prefers the use of the term 'mental disorder' because it accommodates a range of interventions. Despite all consumers being given a psychiatric diagnosis that falls within this definition, public patients were limited to a narrow range of options. Being treated within a medical model that overlooked their psychosocial needs left public patients articulating the need for more counsellors and appropriately trained staff. The perception of not being heard was extended into their interactions and

involvement with self-help groups. Most consumers were dissatisfied or disinterested in the support groups associated with the diagnosis. An explanation for this could lie in the need to have their needs met on an individual basis and in the privacy of a therapeutic dyadic encounter. On the other hand, those consumers who were members of support groups who understood their needs within a psychosocial framework were more inclined to report their involvement in positive terms. As the experiences in the hospital demonstrate even though all patients were treated within a medical model, the private patients did experience some degree of psycho-social approaches to management of illness. Both of these consumers reported positive experiences.

This study suggests that the quality of care received by public patients is perceived to be inadequate. More importantly, the psychological response to hospitalisation changed from seeking refuge before entering hospital, to escaping from the hospital (see Figure 4). The detrimental effects of this are evident in comments of consumers who voice their reluctance to seek help when they need it, or else, leaving contact with the relevant authorities until a crisis develops. This generates the 'revolving door' syndrome (see Figure 5) and to what one long term participant refers to as "... a career in mental health ... (209)." Goffman (1961) asserted this is a process where there is one internal identity and another which is accessed by the public. For a person diagnosed with a psychiatric disorder, the internal self becomes largely determined by the labeling process and impacts on the individual's life in significant ways. These views were alluded to by the public patients, most of whom, remain within the mental health system.

Adapting a general style that meets the individual's needs is time consuming and suits the needs of the service provider rather than the needs of the consumer (Campbell, et al., 1990). Since 1992, the Australian government has promoted the National Mental Health Strategy as a responsive policy, driven by the needs of the consumer. Although some positive changes are noted, for example, consumer representation at committee levels and the perception of feeling 'empowered' within the system by public patients, the translation of this dialogue at the provider-consumer level remains a concern. A long-term mental health consumer who is also a consumer representative articulates this:

... if they announced that somebody was going to knock Broome off the side of the earth with a war, how long do you think it would take them to take a whole pile of stuff up there, ten minutes? Exactly. And it's going to take ten years for one little simple thing. Why? If they can get the forces in a matter of minutes to go and kill a load of people off instead of getting the resources to help somebody live then you really have to start questioning the system and values. You know what does all that come down to. Money. ... But I didn't tell them that because then they would really think I've gone mad.

These comments touch on some of the issues raised in this study. In particular, this consumer's inability to speak in a forum where her voice *can* be heard is a sensitive reminder of what remains to be achieved in the area of mental health reform.

As communication is key to the clinical encounter, exploration of the dialogue between service provider and consumer at the service level is an important research area identified by Wadsworth and Epstein (1999). The ramifications are universal in a multicultural society like Australia. As needs are elicited by policy makers and service providers alike, the mechanism that responds to these needs appears to be obscure (see Figure 4). Further exploration of this pathway is warranted.

Strengths and Limitations of the Study

This study did not seek evaluation of the services in Western Australia, rather, it focused on the experience of being a mental health consumer. The major strength to this study is the methodology. A case study approach employing a semi-structured format to the interviews provided a time-oriented structure to the experiences, which was beneficial in the analysis of the data. Transcripts were examined sequentially to create the categories. Within these categories the themes and sub-themes emerged by remaining close to the narrative. The narrative facilitated the exploration of issues important to the participants and accommodated a closer examination of the psychological response to psychiatric hospitalisation through the consumer's narratives of the experience. This methodology was a particular strength because according to Susko (1994) '... caseness ... in an intellectual construct that facilitates the objectification of a person in the medical system ...' (p. 87). This 'intellectual' construct is conducive to the medical model. However, narratives of individuals who have undergone psychiatric intervention provide an "... inside out ... [perspective] ... that ... helps find meaning with the flow and context of a life story ..." (p. 96).

Although generalizability is not the aim of qualitative research, a cross case approach enables the examination of phenomena by linking strands across cases. Despite the small sample the strength inherent in a cross case analysis is that both consumers covered by private health insurance were patients at the same hospital, albeit at different time period. In addition, three of the six consumers who were not privately covered were patients at the same public hospitals in metropolitan Perth. Once again, these consumers were patients at different time periods. The findings are therefore, a cogent account of the experiences.

A project such as this is dictated by a time frame that favours feasibility rather than scope. Despite this limitation, as an exploratory study the findings produced a rich data set of the experiences of mental health consumers who accessed specialist services across metropolitan Perth and one from rural Western Australia. The data highlighted the differences in the psychological response to hospitalisation which was largely influenced by the management of illness and interactions with staff. The differences between private and public mental health consumers are a notable finding. An extension of this study to include gender balance and further exploration of the differences between private and public mental health consumers would advance understanding in this area. It is also noted that consumers who were admitted to public hospitals had diagnoses that were more severely incapacitating (for example, schizophrenia) than those in the private health care system who were diagnosed with affective disorders. A study that included a wider range of diagnoses in private patients may serve to redress this imbalance.

Respondent and researcher bias can affect the quality of data, according to Miles and Huberman (1994) which can be minimized by ensuring representativeness, being

alert to researcher effects and triangulation. However, bias in this study was minimised through the cross case approach by checking for outliers (divergent views) and eliciting negative and positive accounts. In addition, the researcher was not involved in the care of the patients and the interviews were conducted in an environment, the participant felt secure in. Choice was not an option in selecting participants; the first eight to respond were interviewed. However, it is acknowledged that those who responded may have felt more strongly about their experiences than those who did not. Despite this acknowledgement the findings remain valid as the issues identified as negative by some respondents, were identified as positive by others (see Quote Nos. 130 and 205 in Appendix G).

The inherent imbalance in the power relationship between researcher and participant has been acknowledged as an area of potential bias in qualitative research (Breakwell et al., 1995). In qualitative studies of mental health consumers, this imbalance is particularly delicate as according to Letendre (1997) "...the subject speaks from a position of powerlessness ... (p. 296). However, the strength of this study is supported by the following points: Firstly, the researcher was not a staff member of the hospitals referred to by the participants nor had been involved in the clinical care of patients diagnosed with a psychiatric disorder. This facilitated detailed and informative data collection with the interviews being directed by those issues the participants felt was relevant and important to them.

Secondly, the researcher conducted the interviews, transcribed the tapes and carried out the analyses. This approach enabled the researcher to remain 'close' to the data and '... enter the landscapes of human suffering' as Gregory et al. (1997) observed about the repetitive nature of transcription. This process facilitated a sense

of immediacy in the process of interpretation. Eliminating a third element to the interpretation where a 'best fit' is generated from the combination of the views of interviewers-participants-researchers identified by Goodwin et al. (1999) was minimized. In addition, congruence of themes was validated by two academics that were not involved with the study. Lastly, most of the participants had been inpatients of the same hospitals, albeit, at different time periods. Although subjective views are reported in the current study, the last point adds credence to the reports of the participants, particularly in the area of service delivery.

Lastly the study highlights individuals entered the mental health system having suffered major stresses in their personal lives. But, having experienced what Campbell et al. (1990) refer to as 'the assembly line', mental health consumers in this study have afforded a glimpse into the complexity of needs of individuals in acute settings. The needs expressed in this study are echoed in international studies and underscore the importance of understanding, caring and empathic approaches in mental health care. This glimpse provides a window of opportunity to meet those needs more appropriately in the future.

Concluding Remarks

This qualitative study has been inspired by the words of Kate Millett who writes in *The Politics of Cruelty*:

The French, who have a word for this kind of writing, call it *témoignage*, the literature of the witness; the one who has been there, seen it, knows. It crosses genres, can be autobiography, reportage, even narrative fiction. But its basis is factual, fact passionately lived and put into writing by a moral imperative rooted like a flower amid carnage with an imperishable optimism, a hope that those who will hear will care, will even take action. (p. 15)

There are relatively few qualitative studies examining the experiences of mental health consumers, and, these studies have invariably come under multiple criticisms. The most enduring of these criticisms question the mental capacity of the recipients of mental health services to provide an unbiased account. Nonetheless, views of mental health consumers are elicited more frequently through quantitative methods and examine satisfaction of services provided. The inherent summative quality of this methodology generally indicates positive reports of service delivery. A thorough search of the literature databases failed to produce a similar qualitative study of inpatient experiences of mental health consumers in Australia. Given the Australian government's commitment articulated through legislation, resources, and

on-going collaborative policy-making practices, the time to 'hear' the voice of mental health consumers seemed timely and apposite.

As a novice researcher, I made several personal observations. Having not worked with patients diagnosed with a psychiatric disorder at the time of the interviews, one of the strengths of this study was the opportunity to ask questions and elicit answers that were informative and detailed. I was there to hear the narratives of the participants, with their experiences framed within their expectations and perceptions. I was accepting of them. I believe this engendered a degree of trust in the participant-researcher relationship. With the exception of one (Case Study 7 whom I had met on one previous occasion), it was my first meeting with all other participants. The limitations of my lack of clinical skills related to my own sense of restraint during those times when the participants were distressed. By not exploring the social antecedents in finer detail, there may have been some loss of important data. It also made some of the interviews longer than others. However, I felt it was important for the participants to work within an environment that suited their emotional needs. Although positive, from a pragmatic perspective, this is a time-consuming and intensive research exercise.

This qualitative study facilitated exploration of the experiences of mental health consumers in Western Australia with a particular focus on the time period after the launch of the National Mental Health Strategy in 1992. The small sample studied facilitated a deeper understanding of the experiences of mental health consumers through the generation of numerous themes and sub-themes. The strength of this approach has highlighted the vulnerability of individuals as they enter the mental health system with a range of fears associated with illness-related distress. The key

findings in this study suggest consumers frame their illness presentation, regardless of diagnosis, within a context that is largely attributable to psychological and social factors. However, once hospitalised, their condition is treated within a medical model and dictated by diagnostic criteria. Of particular note are the (positive and negative) themes of psychological response to hospital care; the management of illness and staff behaviours: these themes indicate experiences encountered, influence and/or remain, perceptions.

Surprisingly, consumers of mental health services did not have specific expectations upon admission. In particular, fear was absent in nearly all participants. However, this scenario changed for those who had subsequent admissions. With the exception of the two private patients, the experiences within the system generated fear in consumers that have persisted despite the intervening years. Most comments about experiences related to staff interactions and management of illness, with doubts being expressed about staff expertise. Of note are the experiences of the two private patients who were in the same private hospital, albeit two years apart. Their positive experiences about staff and the range of available therapeutic interventions highlight the inadequacies of other systems that have limited options to offer.

A recent qualitative study in Western Australia examined the needs of clients from CALD backgrounds and reported cultural and linguistic barriers to getting appropriate and culture sensitive care. This study attempted to explore the needs and experiences of non-CALD clients. Remarkably both studies are similar in their findings. Clients who access mental health services are treated within a culture that is dissimilar to their own. The overriding theme of both studies is the dominance of 'medical centrism'. Advocates for CALD clients lobby for more culturally

sensitive and culturally appropriate mental health care. The major thrust being the understanding of illness presentation within the cultural context of the client.

Sensitivity towards this model of care promotes understanding, awareness and ultimately negotiation between client and clinician. Adopting this model of care, indicated in evidence-based literature, leads to positive outcomes.

This study highlights, the needs of non-CALD clients, on many levels, are similar to CALD clients. Eliciting and addressing *their* needs within *their* socio-cultural context would be an appropriate and sensitive standard of care. It is the essence of addressing diversity in a multicultural society.

Eight years after the launch of the National Mental Health Strategy, policy that purports to address the needs of Australian people who are affected by mental illness is in danger of sounding rhetoric. Seven years after the National Inquiry into the Human Rights of People with a Mental Illness, concerns remain about reported covert, and in some cases, overt coercion. The lack of choices is a strident echo of findings reported elsewhere in the world. Until needs of mental health consumers are appropriately addressed at the consumer-provider interface, future directions remain guided by the poignant question of one of the participants:

“A consumer? Doesn’t consumer imply choice?”

References

- Anderson, J. R. (1995). *Cognitive psychology and its implications* (4th ed.). New York: W. H. Freeman
- Australian Bureau of Statistics (1998). *Mental Health and Wellbeing Profile of Adults, Australia 1997*. Canberra: Australian Government Publishing Service.
- Australian Health Ministers Conference (1996). *National Standards for Mental Health Services*. Canberra: Australian Government Publishing Service.
- Australian Little Oxford Dictionary* (2nd ed.). 1995, Melbourne: Oxford University Press.
- Australian Psychological Society, Ltd. (1999). *Code of Ethics*. Melbourne: Author.
- Baldwin, S. (ed.). (1998). *Needs assessment and community care. Clinical Practice and Policy Making*. UK: Butterworth-Heinemann.
- Belle, D. (1990). Poverty and women's mental health. *American Psychologist*, 3, 385-389.
- Bhugra, D. (1997). Setting up psychiatric services: Cross-cultural issues in planning and delivery. *International Journal of Social Psychiatry*, 43(1), 16-28.
- Brandon, D. (1991). *Innovation without change? Consumer power in psychiatric services*. UK: Macmillan.
- Breakwell, G. M., Hammond, S., Fife-Schaw, C. (1995). *Research methods in psychology*. UK: Sage.
- Breggin, P. R. (1991). *Toxic psychiatry*. New York. St Martin's Press.

- Burdekin, B. (1993). *Human rights and mental illness: Report of the national inquiry into the human rights of people with mental illness*. Canberra: Australian Government Publishing Service.
- Callan, A. & Littlewood, R. (1998). Patient satisfaction: Ethnic origin or explanatory model? *International Journal of Social Psychiatry*, 44(1), 1-11.
- Calnan, M. (1988). Towards a conceptual framework of lay evaluation of health care. *Social Science and Medicine*, 27(9), 927-933.
- Campbell, J. D., Mauksch, H. O., Neikirk, H. J., & Hosokawa, M. C. (1990). Collaborative practice and provider styles of providing health care. *Social Science and Medicine*, 30(12), 1359-1365.
- Campinha-Bacote, J. (1994). Cultural competence in psychiatric mental health nursing. A conceptual model. *Nursing Clinics of North America*, 29(1), 1-8.
- Cang, S. (1989). Open to criticism. *Health Service Journal*, 99, 886.
- Caplan, P. J. (1995). *They say you're crazy. How the world's most powerful psychiatrists decide who's normal*. Massachusetts: Addison-Wesley Publishing Company.
- Carr-Hill, R., Dixon, P., & Thompson, A. (1989). Too simple for words. *Health Service Journal*, 99, 728-729.
- Caslyn, R. J., Winter, J. P. & Morse, G. A. (2000). Do consumers who have a choice of treatment have better outcomes? *Community Mental Health Journal*, 36(2), 149-160.
- Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. *Journal of Mind and Behavior*, 11(3/4), 323-336.

- Chrisman, N. J. (1991). Cultural systems. In Susan Baird, Ruth McCorkle, and Marcia Grant (Eds.), *Cancer Nursing: A Comprehensive Textbook* (pp. 45-54). USA: W. B. Saunders Co.
- Chu, C. (1998). Cross-cultural health issues in contemporary Australia. *Ethnicity and Health*, 3(1/2), 125-134.
- Crawford, M. J., & Kessel, A. S. (1999). Not listening to patients – the use and misuse of patient satisfaction studies. *International Journal of Social Psychiatry*, 45(1), 1-6.
- Dalgard, O. S., Bjrk, S., Tambs, K. (1995). Social support, negative life events and mental health. *British Journal of Psychiatry*, 166(1), 29-34.
- Ferry, L. (1996). Ensuring consumer satisfaction. *Behavioral Health Management*, 16(6), 15-17.
- Gray, J. (1997). 'Scientific storytelling': *Narrative as a methodology*. Paper presented at the Annual Conference of the West Australian Institute of Educational Research, Perth, Western Australia.
- Gregory, D., Russell, C. K. & Phillips, L. R. (1997). Beyond textual perfection: Transcribers as vulnerable persons. *Qualitative Health Research*, 7(2), 294-300.
- Goffman, E. (1961). *Asylums*. London: Penguin.
- Goodwin, I., Holmes, G., Newnes, C., & Waltho, D. (1999). A qualitative analysis of the views of in-patients mental health users. *Journal of Mental Health*, 8(1), 43-54.
- Hall, J. A., & Dornan, M. C. (1988). What patients like about their medical care and how often they are asked: A meta-analysis of the satisfaction literature. *Social Science and Medicine*, 27(9), 935-939.

- Health Department of Western Australia (1999). In *National Directions in Mental Health*. http://www.health.wa.gov.au/southwest/ND_MH.htm
- Henderson, S., Andrews, G., & Hall, W. (2000). Australia's mental health: An overview of the general population survey (Abstract). *Australian and New Zealand Journal of Psychiatry*, 34(2), 197-205.
- Kavanagh, S. (1997). Purchasers, providers and managed care: Developments in the mental health market place. *Current Opinion in Psychiatry*, 10(2), 153-159.
- Kent, H. & Read, J. (1998). Measuring consumer participation in mental health services: Are attitudes related to professional orientation? *Journal of Social Psychiatry*, 44(4), 295-310.
- Leavy, G., King, M., Cole, E., Hoar, A. & Johnson-Sabine, E. (1997). First-onset psychotic illness: Patients' and relatives satisfaction with services. *British Journal of Psychiatry*, 170(1), 53-57.
- Lebow, J. (1982). Consumer satisfaction with mental health treatment. *Psychological Bulletin*, 91(2), 244-259.
- Leese, M., Johnson, S., Slade, M., Parkman, S., Kelly, F., Phelan, M. & Thornicroft, G. (1998). User perspective on needs and satisfaction with mental health services. PriSM Psychosis Study 8. *British Journal of Psychiatry*, 173(11), 409-415.
- Letendre, R. (1997). The everyday experience of psychiatric hospitalization: The users' viewpoint. *International Journal of Social Psychiatry*, 43(4), 285-297.
- Lopez, S. R. (2000). Cultural psychopathology: Uncovering the social world of mental illness. *Annual Review of Psychology*, Annual 2000, 571-596.
- MacDonald, R., & Steel, Z. (1997). *Immigrants and mental health: An epidemiological analysis*. Sydney: Transcultural Mental Health Centre.

- McBride, A. B. (1990). Mental health effects of women's multiple roles. *American Psychologist*, 3, 381-384.
- Martin, J. (1998). *In their own words: The experiences of people from non-English speaking backgrounds with Western Australian mental health services*. Perth: Association of Services for Torture and Trauma Survivors.
- Mead, S. & Copeland, M. E. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal*, 36(3), 315-328.
- Mental Health Act of 1996. 1996. Western Australia.
- Mental Health Taskforce (1996). Report of the Ministerial Taskforce on Mental Health*. Perth: Australian Government Publishing Service.
- Miedema, B. & Stoppard, J. M. (1994). 'I just needed a rest': Women's experiences of psychiatric hospitalization. *Feminism and Psychology*, 4(2), 251-260.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis*. (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Millett, K. (1994). *The Politics of Cruelty*. USA: W. W. Norton.
- National Mental Health Policy*. (1992). Canberra: Australian Government Publishing Service.
- Opie, A. (1998). "Nobody's asked me for my view": Users' empowerment by multidisciplinary health teams. *Qualitative Health Research*, 8(2), 188-206.
- Parkman, S., Davies, S., Leese, M., Phelan, M., & Thornicroft, G. (1997). Ethnic differences in satisfaction with mental health services among representative people with psychosis in South London: PriSM Study 4. *British Journal of Psychiatry*, 171(9), 260-264.

- Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutler, D., & Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental health service providers. *Community Mental Health Journal*, 35(3), 251-269.
- Ragg, M. (1994). Health funding in Australia. *The Lancet*, 343(8908), 1279.
- Riessman, C. H. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine*, 30(11), 1195-1200.
- Rogers, A., Pilgrim, D., & Lacey, R. (1981). *Experiencing psychiatry: Users' views of services*. Basingstoke: Macmillan Press.
- Susko, M. A. (1994). Caseness and Narrative: Contrasting approaches to people who are psychiatrically labeled. *Journal of Mind and Behavior*, 15(1/2), 87-112.
- Szasz, T. (1990). Law and psychiatry: the problems that will not go away. *Journal of Mind and Behavior*, 11(3&4), 557-564.
- Shields, P. J., Morrison, P., & Hard, D. (1988). Consumer satisfaction on a psychiatric ward. *Journal of Advanced Nursing*, 13, 396-400.
- Shoop, L. & Wright, D. (2000). *Classroom Warm-ups*. Melbourne: Resource Publications.
- Sobel, D. S. (1995). Rethinking medicine: Improving health outcomes with cost-effective psychosocial interventions. *Psychosomatic Medicine*, 57(3), 234-244.
- Toop, L. (1998). Primary care: core values: Patient centred primary care. *British Medical Journal*, 316(7148), 1882-1883.
- Viney, L. L. & Bousfield, L. (1991). Narrative analysis: A method of psychosocial research for AIDS-affected people. *Social Science and Medicine*, 32(7), 757-765.
- Wadsworth, Y. & Epstein, M. (1998). Building in dialogue between consumers and staff in acute mental health services. *Systemic Practice and Action Research*, 11(4), 353-379.

- Wallace, T., Robertson, E., Millar, C., & Frisch, S. (1999). Perceptions of care and services by the clients and families: A personal experience. *Journal of Advanced Nursing*, 29(5), 1144-1153.
- Wallcraft, J. (1998). Survivor-led research in human services: Challenging the dominant medical paradigm. In S. Baldwin (Ed.) *Needs assessment and community care: Clinical practice and policy making* (pp. 186-208). UK: Butterworth/Heinemann.
- West Australian Association for Mental Health. (September, 1998). *Improving consumer and carer satisfaction. Mental health nursing in Western Australia*. Perth: WA Association for Mental Health.
- Whiteford, H. (1992). Future directions for mental health services in Australia. *Australian Journal of Public Health*, 16(4), 350-353.
- Williams, B., & Wilkinson, G. (1995). Patient satisfaction in mental health care: Evaluating an evaluative method. *British Journal of Psychiatry*, 166(5), 559-563.
- Wong, J. G., Clare, I. C. H., Gunn, M. J., Holland, A. J. (1999). Capacity to make health care decisions: Its importance in clinical practice. *Psychological Medicine*, 29(2), 437-466.

Appendix A: Correspondence to mental health consumer agencies

Date

Address

Dear

Further to our telephone conversation this morning, enclosed please find an advertisement for my research project towards an honours degree in psychology.

My project is as follows:

Experiences of mental health consumers: A qualitative study of expectations and perceptions of mental health services in Western Australia
(Supervisor: Dr Lynne Cohen, School of Psychology, Joondalup Campus, Edith Cowan University)

Abstract

Determined by policy and reform, consumer-provider collaboration is an integral part of mental health service delivery in Australia since 1992. In Western Australia, studies into the consumer needs of minority groups have identified cultural and linguistic barriers to optimum mental health care. Conversely, the experiences of mental health consumers who do not meet the criteria of minority status remain largely unexplored. Rather than being an evaluative study of existing services, this qualitative project aims to explore the *experience* of being a mental health *consumer* within the framework of the consumer's expectations and perceptions of service delivery. It is envisaged the findings of this pilot study will initiate a larger scale study.

Once again thank you for your support and help.

Yours sincerely

DAWN A BARRETT

Encls.

Appendix B: Advertisement for study

My name is Dawn Barrett and I am a fourth year Honours student in Psychology at Edith Cowan University. I am interested in people's opinions about the provision of mental health services in Western Australia.

To this end, I would like to speak to individuals who have been through the mental health system in Western Australia. Of particular interest to my study are the expectations of the individual prior to hospitalization and perceptions of mental health service delivery after discharge. This is not an evaluative study but rather one that focuses on the experience of the individual as a consumer of mental health service delivery in Western Australia.

I would like to interview you about your experiences. The interviews will be approximately one hour long and will be taped on a cassette recorder. I will transcribe the cassette tapes. Your name will not be identified on any of the transcripts, nor will there be any way of linking your name to any of the transcripts.

The project meets the standards and requirements of the Ethics Committee of the School of Psychology, Edith Cowan University. My supervisor is Dr Lynne Cohen.

I would like to hear from you if you are:

- 18 years old and older; and
- have been an in-patient of a psychiatric setting in the last ten years.

If you have any queries at all about this project, please feel free to contact me (via the School Secretary) on 9400 5551 or my supervisor, Dr Lynne Cohen on 9400 5575.

Thanking you,

Dawn A Barrett

Appendix C: Interview schedule and (probe questions)

1. Can you tell me about the events that precipitated your hospitalisation?
2. What were your expectations of the staff/hospital/services?
 - What are your expectations now before you go into hospital.
3. Can you tell me about your experiences with the staff/hospital/services? Can you identify the positive aspects of the experiences?
 - Can you give me an example?
 - What did that feel like?
 - Have you ever been in hospital as a general patient? Did you notice any differences in the two experiences? Can you explain them to me.
4. Were there any negative aspects?
 - Can you give me an example?
 - What did that feel like?
5. What was the ward like? Can you tell me about the positive aspects of the environment?
 - What did that feel like?
 - Did you notice any differences in the experience of being a general patient and a patient in a psychiatric setting? Can you explain them to me?
6. Were there any negative aspects to the environment?
 - What did that feel like?
7. Having accessed mental health services, what are your perceptions about the experience?
8. What advice would you offer to mental health professionals about what you consider was helpful in your recovery and what was not helpful?
9. Is there anything else you would like to add?

Appendix D: Letter of introduction

My name is Dawn Barrett and I am a fourth year Honours student in Psychology at Edith Cowan University. I am interested in people's opinions about the provision of mental health services in Western Australia. My study is not an evaluative study but rather one that focuses on the experience of the individual as a consumer of mental health service delivery.

I would like to interview you about your experiences with a special focus on your expectations prior to hospitalization and your perceptions of psychiatric care following discharge. The interviews will be approximately one hour long and will be taped on a cassette recorder. I will transcribe the cassette tapes. Your name will not be identified on any of the transcripts, nor will there be any way of linking your name to any of the transcripts.

The project meets the standards and requirements of the Ethics Committee of the School of Psychology, Edith Cowan University. My supervisor is Dr Lynne Cohen.

You may terminate the interview at any time and withdraw from the study. You have the right not to answer any question you feel is inappropriate.

If you have any queries at all about this project, please feel free to contact me (via the School Secretary) on 9400 5551 or my supervisor, Dr Lynne Cohen on 9400 5575.

Thanking you,

Dawn A Barrett

Appendix E: Mental Health Resources

24 HOUR EMERGENCY TELEPHONE SUPPORT

Samaritans	9381 5555
Lifeline	13 1114
Psychiatric Emergency Team	9224 8888

HOSPITALS

Fremantle Hospital	9431 3333
Graylands Hospital	9347 6600
Sir Charles Gairdner Hospital	9346 3333
Royal Perth Hospital	9224 2244
King Edward Memorial Hospital (for Women)	9340 2222
Joondalup	9400 9400

METROPOLITAN HEALTH DEPARTMENT MENTAL HEALTH SERVICES

Armadale	9391 2400
Perth City	9224 1720

Appendix F: Consent Form

‘Experiences of mental health consumers: A qualitative study of expectations and perceptions of mental health services in Western Australia’

I, _____,
have read and understood the information sheet given to me.

I understand and give consent to the interview being taped and transcribed by Dawn Barrett and I agree to participate in her study.

I understand the information provided by me and related to me, will be held in a secure environment and will be destroyed appropriately.

I understand my right to withdraw from this project, without prejudice, at any time during the course of the interview.

Date: _____ Participant: _____

Appendix G: Qualitative data from transcripts

EXPECTATIONS

PSYCHOLOGICAL RESPONSESEEKING REFUGE

1. ... at first I thought okay I'll just see what its like, well they're just giving me a rest.
2. ... I just wanted, basically to just have time out ... because I had been under stress situations I just needed that time out in space that I could direct
3. Just to be able to go in there and hide away in a room and take myself out of this world and keep away from everybody
4. ... time to be in that bubble. Well for me it works being in that bubble. I think you have to have that time in the bubble.
5. Somewhere where I can get away from the environment and be there with somebody who understands
6. I think to feel a bit more in control. ... I guess what I wanted was to really to know how to prevent myself from getting in that state again.
7. I needed to feel secure. I needed to feel secure.

NEEDING SUFFICIENT TIME TO TALK

8. ... I would have expected her at best to talk to me a little bit longer, not to take other phone calls, ... to just gently say to me, I think this is what's going on But it was all very business like, cut and dried and I thought for this hallowed woman, ... it was appalling. ... First of all she had some underling who interviewed me ... I have to tell you that was not on because if you are seeing a doctor I want to see the doctor. I don't want to tell some under qualified person who will then translate what I've said for the doctor.
9. Oh, I would want to see somebody I could talk to long enough to be able to feel safe enough and not scared enough and feel safe enough not to feel ashamed of what's really going on in my gut.
10. I guess just the chance to vent out what was really going on. Being able to piece things together.

FEAR

11. And I was quite scared at first because the other people like the GP ... said to me, they will knock you out for three days and talk later.

NO EXPECTATIONS

12. I don't really think I was expecting anything at that moment because I was so wound up that ... I don't think I really thought about where I was going apart from the fact that I was getting out of a situation that was giving me stress.
13. Hmm. I don't know.
14. Well I didn't know did I? Because when you are in that state you don't know. You've got no preconceived notions.
15. Oh it was the same bloody thing I felt after I went in there after a few years and I thought 'God, nothing much has changed except the décor'.
16. No. No. I didn't expect anything. I actually wanted to die. I just wanted to die.

Appendix G:2

EXPERIENCES

PSYCHOLOGICAL RESPONSEFEAR/LACK OF CONTROL

17. First of all I couldn't function in the morning at all. ... I felt like I was not in control of things at all in any way, shape or form. So I was terrified if I got any worse I would start thinking of suicide. I didn't feel suicidal at all but I felt so not in control of myself that I didn't know what I would do.
18. I had one terrible night where I couldn't sleep ... I think that after lying awake for three hours ... I was so frightened that I suddenly sort of said to myself ... you know you are going to end up committing suicide don't you ... that was my big fear, that I would be out of control and that I would do something I didn't intend to do.
19. He was the only one I felt safe with. [referring to husband]
20. I think because you are out of control and you don't know where your mind is taking you ... and what you might do. Are you going to harm yourself or are you going to go completely mad.
21. I think if you haven't been in that situation it is quite difficult to explain to somebody that ... you just don't recognize yourself. Who is this person? Am I going to suddenly become a raving loony and go streaking down the street naked or am I going to take an axe to somebody else or to myself or am I going to start throwing plates around, I just felt like I didn't know what was going to happen next.
22. ... it was very frightening ...
23. ... You just don't want to be there. Its like because you are so suicidal, while you can keep yourself in that cloud that's over you and wrapping you like a bubble from the world then its not there.
24. ... you know I don't feel safe even in my own bed. Nothing. The only place I feel safe is brain dead. In other words, I know it is the next thing to death. I don't want to be dead. But that would be the ultimate, being dead. But I don't want to be dead. But the ultimate is being dead. That's the space I feel like being in.
25. So I thought my family and my friends were these aliens in disguise who could not be trusted. ... it was just a nightmare because I just didn't know who to trust.... That was very real. That was the most realest thing.
26. I just wanted to get off this earth basically
27. I think when I started to be left alone after the funeral, that's when things started to change because all of a sudden I was by myself

DISBELIEF

28. ... but then when I found myself in [Hospital] of all places it was like, "Oh no".
29. ... I woke up and I looked at my wrists and thought "oh they've got me. The aliens have got me"
30. I remember being very surprised to find myself where I was ...
31. ... I remember being in my room ... it was very confusing ... "what am I doing here? Where am I?"

Appendix G:3

32. Yeah took a while for that to be made known to me that I was there.
33. That's just unreal. Its like "Why am I here? What did I do so wrong to be put in this situation?"
34. ... it felt so wrong for me to even be in there in that place. I just didn't get it.
35. ... once I got there that I realized "Oh my God I'm in hospital"
36. I was pretty calm about it until I realized where I was and that I wasn't at uni[versity] and wasn't in my natural environment and within this place I felt that people were putting all these sort of labels on me and that sort of thing and I suddenly went "Wait a second, I shouldn't be here" and would basically stop anybody who was willing to listen and explain to them why I shouldn't be there.
37. ... she said something about the mental state and I said "Oh, am I"?
38. Just like everything was unreal.
39. I don't know what I felt. It was weird. Like it wasn't happening. It was like the weirdest thing.

SENSE OF IMPRISONMENT

Similarities

40. ... you would be in a locked ward which is really terrible, its like being put in prison because you couldn't go out where you want, you couldn't go outside where you want, all your freedoms were gone.
41. ... I felt like I was in jail. You know like I was a criminal you know.
42. ... if you are a bad boy and you chuck a wobbly, ... lose your temper you get put in a cell which is padded, its an isolation cell and they can leave you in there for up to nine hours. I've been in there for a very long time
43. They lock you in and it is physically locked ... so like you can't go outside when you want to, you can't stay up if you want to, everything is locked. Everywhere you want to go. Like they might just put you in the lounge room with just a TV for like three hours and you don't want to watch TV so what do you do?
44. I was not allowed to go home and I remember banging on the door to get home and waiting at the door for someone to open it. It was all locked. It was a locked ward and you couldn't leave
45. Yeah the whole locked situation. I felt I didn't need to be locked in this sort of situation where ... obviously ... they put suicidal people I wasn't suicidal although I couldn't convince them of that and being treated like you can't have a lock on your bedroom door ...
46. A bit like a prison. Just like prison.
47. I had to learn very quickly that you just can't sit at a table when its mealtimes, you had to ask permission of all the people there "Is it okay if I sit here?" ... its like a prison, they've worked out their pecking order and where you can go and who you are allowed to talk to
48. ... past the lounge room there's a caged area. ... A gate to that area ... that got locked as well. Each door got locked as you went through.

Appendix G:4

49. ... I mean I'm supposed to be an adult but I don't feel like an adult. I feel like I'm three. And somebody else is saying "No you can't go there." And I'm thinking "Why?" ... there was a lovely garden, had a gazebo in it but they had it locked.
50. No. [Freedom to sit in the garden].
51. I had to look at the files was right next to the psychiatric ward ... I could see those locked doors and I hadn't been there for a year and it just, just bringing back those memories of me staying in there and trying to get out.
52. ... my ex-husband's friend tried to rape me. ... a week later I was lying on this floor, suicidal in this room and they put me in the lock up and I've never forgotten then. That was really traumatizing and no one talked to me. That was dreadful.
53. Well the lock up is a secure ward that you can't get out of.
54. ... in the morning without me knowing two nurses, got me by my elbows, and started to walk me and ... I really didn't know where I was going. ... I didn't know what was happening. Didn't know what was happening. And I walked towards this thing and I saw this blue door and I sort of recognized it, because it had a lock on it ... I can remember padding around this. ... it was like a square of grass with a big high fence ... we had to be let out of this door and that had to be locked and we just had to plod around this fence and I never spoke to a nurse or a doctor or anyone while I was in there.
55. A prison. Like a prison. Like a concentration camp. ... I felt, ... like a dunce in school ... being punished. I just felt punished. I felt punished. I felt that I had done something so bad ... you go so blank because you think you've done something so bad ... basically you feel so bad. And then eventually they let me out of there and put me back in [hospital]
56. ... and then four of them pinned me down at [Hospital]. And because I had been raped when they were pinning me down I felt like it was going to happen again but this time it was four of them and so I was trying to stop them
57. ... I was in the locked ward for about seven days. And when you are in the locked ward it is very limited what you can do
58. Shocking. The locked ward was terrible.
59. Well like an asylum. It was so cold and sterile.
60. Well in the locked ward, ...you could have a shower whenever you wanted one really. But they would lock your door.

Disparities

61. That was an open ward. That was a lot better.
62. I don't think I was seriously trying to get out especially since after he told me I was there voluntarily and I realized that I could basically walk out. That took some of the edge off my anxiety about being there.
63. ... and no I wasn't in a locked ward. ... they would keep watch over me at times to make sure I didn't go anywhere or something like that and there were weekends I wasn't allowed to go out ... but no I've never been in a locked ward. I was fortunate. Very fortunate.

Appendix G:5

POWERLESSNESS

Similarities

64. And on my door it had a glass thing at the top of my door so the nurses could see in but every other door had a curtain. But mine didn't ... I felt very exposed ...
65. if you are a bad boy and you chuck a wobbly ... lose your temper you get put in a cell which is padded, its an isolation cell and they can leave you in there for up to nine hours. I've been in there for a very long time ... you have no interaction with anyone ... you feel like you're going to be in there forever so its an absolute nightmare
66. They lock you in and it is physically locked and so like you can't go outside when you want to, you can't stay up if you want to, everything is locked. Everywhere you want to go. Like they might just put you in the lounge room with just a TV for like three hours and you don't want to watch TV so what do you do?
67. ... there are all these other people in there and you are locked in with them and they are all really ill too.
68. ... I got held ... they marched me off to my room and gave me a couple of needles in my bum. I was just screaming and screaming trying to get them to understand but no they just held me down and I think that was the worst part about it, that they could do this to me without me, like I could do nothing, just nothing at all.
69. They didn't talk to me about it. They talked to my family about it because I had become an involuntary patient. [referring to ECT].
70. So I went away meek and mild.
71. In any case I went to get up and go and they stopped me, physically stopped and put me back in hospital.
72. No. No. Too scared. Too disempowered.
73. I don't know. Its crazy isn't it. [referring to not being able to speak out in hospital ward].
74. ... some of the nurses sometimes didn't give you very good reports ... if you thought you were well and you'd been told you are well by your family but the nurses didn't give you a well report so you'd be in hospital a lot longer.
75. Well, if you don't, you stay there a lot longer ... [recalling participation in ward activities]

Disparities

76. No. Not at all. Not at all. Because at that stage I wasn't feeling up to making any decisions of what I was going to do and I was fortunate enough to have a structure and being in a situation where people understood exactly what the situation was.

ANALOGY TO BEING A CHILD

77. ... if you are a bad boy
78. I just felt like a child, I felt like, and I felt like I was throwing a tantrum. That's what I felt like and no one was listening to me

Appendix G:6

79. They didn't talk to me about it. They talked to my family about it ...
[referring to ECT]
80. I had a hard time, I mean I'm supposed to be an adult but I don't feel like an adult. I feel like I'm three. And somebody else is saying "No you can't go there." And I'm thinking Why?
81. So I went away meek and mild.
82. Like I felt, like when they used to sit me in a classroom like a dunce in school, when you sit with your hands folded and exposed to everyone, with your hands on your head, being punished
83. ... I saw these brochures and there was one about sexual abuse ... I started ripping up all these brochures. ... one of the nurses just stood there and said "You'll be going back to the lock up at thingy if you don't control yourself". So I knew then I had to restrain myself like hell, pull myself in back into me again, like that and better be a good child, a good person, pull it all back in again, pull the anger down ...
84. You just do everything like a good little person ...
85. You feel like a bad child not taking your medicine. You feel like a bad child. You feel like a child.
86. You are so, its like, like a child who can't speak and you don't know. You don't know. Its like you've lost your language. Its actually like you've lost your language.
87. ... they treat you like children. They are so patronizing, it's unbelievable. They think that you are senseless.

LACK OF SAFETY

88. The other people that I was with, it was very scary. Because I didn't know what they were capable of and if they are in there then I don't know why I am in here. So if they are in there, they are obviously suicidal or have ... really bad problems and some of the looks ... some of the statements were made to me were very scary. And threatening. ... Threatening, some of those patients.
89. Because they thought it was a drug induced psychosis ... one of the reasons why it kept happening was because just after I got admitted into hospital I got beaten up by another patient So that just worsened my psychosis of feeling that everyone was out to get me.
90. They threatened me with a needle. If I didn't shut up. Because I was yelling at security ... because in my mind ... I should feel safe in a hospital whether I'm in a psychiatric hospital or in a normal hospital ... I should feel safe and I'm not safe.
91. ... there was a man ... who used to get very confused ... he used to walk around with an erection and he really scared me because he used to keep walking into people's rooms.

Appendix G:7

FEAR

92. I don't want to make a fuss ...
93. They gave me the wrong medication. A man died in front of me, had a heart attack in front of me. And that just made me think oh shit they are just using this man as a guinea pig. ... they are just playing games ..., that was my fear.
94. And it was like all my fears were challenged in hospital. ... I had been raped by a Japanese man and there was a Japanese man who kept following me and he triggered that.
95. I just thought every person, every new admittance, every new patient who had been admitted was a possible person who was going to get me. ... I thought everyone was out to get me and I had already been got ...[referring to violent incident in locked ward].
96. She said X if you don't have it, security will be in here to give you a needle. And I knew I didn't want another needle
97. I would have feel safe enough to do that [request help from hospital staff].
98. I think I was under their control for about sixteen days. On that eighth day they let me come out for half a day and I got to go home. I wasn't allowed to come home, I had to go to my parents' home which I thought So what! I want to go home. ... they had this big discussion about how did I go. Was I alright. Its like I really had to control my emotions. Otherwise if I did have a big outburst I don't know what would have happened to me again. I just had to control myself and do things in private where any one else couldn't see it.

ESCAPE

99. It's like a waste of time and I could not wait to get out of there. So I fake it. I actually fake being well ... to get out of there. When I think I'm just able to cope, I fake being well really, really well so I can get out of there. Anywhere, anything. I do it all the time. I walk in to my doctor. "How are you", "I'm fine".
100. Well for me I don't want to stay there! ... Because if I was staying there longer, I was genuinely ill, you know what I mean, I was really unwell to have to stay there. ... but I played the ones to get out. So that's the ones I do play.
101. At first I was behaving how I was at home, a psychotic sort of way I suppose, doing things I felt I wanted to do at that time. ... And then I quickly learnt that I can't do this stuff. I've got to, even if I don't think anyone is, but I've got to try and behave myself while they are watching me and then I'll get out quickly.
102. And then another patient came in another young girl who developed mental illness, ... she had grown up with a mother who had mental illness and ... she sat beside me talking about this and I was gradually getting traumatized by her trauma. And I knew by that stage that I had to get out of there

Appendix G:8

IMPACT OF DIAGNOSIS

Similarities

103. And I said oh well, bipolar, that makes me understand why I've had relationships with both sexes. I didn't know. And then I wanted to kill myself after.
104. I was very, very disappointed I had the illness. It was like they were going to amputate one of your legs or something, ... because when you're at school, you sort of encouraged to think that people with a mental illness are sort of second rate and hopeless and that they would be losers for their whole life and so that's how I felt.
105. Yes. I read up. While I was sick I read up on a lot of stuff. I knew what it meant but I was pretty horrified.
106. Well it does have an impact on your life ... because you get embarrassed about it.
107. I challenged a doctor about some labeling put on to me and he said well that's because of your childhood and I was a bit pissed off with that
108. ... its really killed my work life like its very hard to get a job and social life is hard too ...
109. You feel I don't know, very unhappy because you feel, its just not a nice place to be and its, its, you feel very despondent and hopeless. You feel hopeless.
110. [Laughter]. Well if I didn't make myself have my own hope probably no hope. Umm what did they give me for my future? Well they don't because of my age I suppose they don't when you get to a certain age.

Disparities

111. ... I think in a way it was it was good because it made me realize that it just wasn't me, just me being sort of being worried beyond reason and they explained to me the link ... it took me a while to be able to accept it even after I was told, I thought no, not really, I just got overstressed and it took a while learning and reading about it because they provided me with information.
112. At the time, it made me psychologically worse but you know you turn your crap into something good and I have that ability to relate to people in that situation.
113. Yeah. But it doesn't mean much to me. It's one of their terms. [referring to diagnosis of post-partum psychosis].
114. I said oh well just keep sticking the labels and stick as many as you like I don't care about your labels. You know I just don't even consider them. All I know is that I get symptoms and whatever they want to call them then they can call them what they like. I'm past, just past all the labels.

CONFLICTING MODELS OF ILLNESS

MEDICAL MODEL OF ILLNESS

115. ... they thought it was a drug induced psychosis ... but it kept happening ... one of the reasons why it kept happening was because just after I got admitted into hospital I got beaten up by another patient So that just worsened my psychosis of feeling that everyone was out to get me.

Appendix G:9

- 116. ... they first diagnosed me as being schizophrenic which turned out I'm not schizophrenic, I've got bipolar disorder
- 117. Well, firstly they said I had schizophrenia which is, umm the doctor said I had schizophrenia but on the second admission they said I had bipolar, so that's when it was explained to me but it wasn't explained that clearly.
- 118. Wasn't recognized at all until I went and seen a doctor myself when I was about 22 [referring to a diagnosis of OCD]
- 119. Well I'm not actually sure you know. They just chuck labels around. They don't really know what's wrong with you.
- 120. Well they said it was endogenous depression. But then other people say it is manic depression. Then somebody says it is, well, I don't know.
- 121. I don't know they've probably conjured up a few more names since 1983 about what you call it. I mean I just think it is people being depressed. God, I mean all these labels, Jesus Christ! I suppose they've got to have something to fit you into
- 122. Oh Bipolar. Umm dissociative disorder. Post traumatic stress disorder. Well that would be obvious that would. It comes around when you're in war zones every day ... and sometimes they try to put borderline personality ...
- 123. ... my doctor ... believes that there are these chemical imbalances and people who suffer from anxiety disorders can also have that sort of disturbance in the brain and clearly medication keeps it under control

EXPLANATORY MODEL OF ILLNESS

- 124. ... the pain was so deep that I started to go off to this other place where it wasn't so painful for me [referring to death of infant].
- 125. But it took me a while to be able to accept it even after I was told, I thought no, not really, I just got overstressed and it took a while learning and reading about it
- 126. So running away from reality a million miles an hour is what happens when you're hyper and you're running away from grief and loss so you go hyper to avoid it
- 127. At one time I was on the floor crawling on the floor up and down the passage way. Now for anyone seeing it was really bizarre for them but for me, I could, in my own mind, I felt I'm just going to get down here and be like a baby and trying, try to get close to my son and that was really weird for them.
- 128. ... when I look back at the experience, I had a big lot of marijuana and that's when I had my first, really severe attack when I was still experiencing a big surge of marijuana
- 129. That was the reason why I ended up on the rock because I had a disagreement with this man who I thought I could trust him but then seeing his behaviour towards his children, my trust was shattered, and so I've always loved nature, I found a great peace in nature but I've spent time in the desert and I've spent time in the forest and I've spent time on the ocean but I've never felt what happened to me out there.

Appendix G:10

MANAGEMENT OF ILLNESS

OVER-RELIANCE ON MEDICATION

Similarities

130. ... And I said oh look I'm really distressed ... it has triggered stuff with me and I just need someone to hold me. And she said that stuff shouldn't affect you. And I just could not believe me. They offered me medicine. But I didn't want the medicine. I just wanted to feel like I wasn't alone you know. I needed that touch you know.
131. ... there was a GP in Perth who is supposed to have a good knowledge on depression ...and I was there and like in five minutes he diagnosed me and gave me the pills.
132. No. Just pills. All different types of pills. And I didn't know what they were or what they were for and at first I refused to take them because I didn't know anything about them and they just got me to take them.
133. She said to me you're the most sane and stable person I have come across. I think this is peri menopausal ... she said to me how are you feeling and I said not bad and she said I want you to try anti-depressants Then I had to go for an ultrasound ... it turned out I had gallstones and anyway I was sort of alright ... but I still not great so my doctor said to me to increase the dose. I am still on medication. [Three years later].
134. ... the minimum I would be on it would be 18 months ... [referring to anti-depressants]
135. ... that first trip to the hospital ... they didn't put me on medication thank God that time. Like I regret it ever since that they did. The second time I went in they did and they decided to dump heavy doses of medication on me and of course my environment didn't change at home.
136. So yes they did, they drug you to the eyeballs but they need to get you functioning.

LACK OF APPROPRIATE THERAPEUTIC APPROACHES

Similarities

137. They didn't look. ...But nobody. Not once did ever anyone ever go into any past stuff. No. Never.
138. They said I could go and see my psychologist but he cost \$150 an hour. I don't think so!
139. ... for instance ... they want you to come into a room in a circle and I go, I don't want to come ... I'm too scared to tell them the reason why because ... when the ritual abuse happened of course they all form a circle so I don't want to go to that, "But it will be good for you", "Yes I know it will be good for me but I really don't" ... I'm really too scared to tell them why I don't want to go because I know they will start pillaging into me "Well it's not like that in here now. You know you're in here with safe people." But ... I feel this is not a safe place for me to be ... I'm trying to establish safety for myself and they are trying to drag me into something that for me doesn't feel safe

Appendix G:11

140. ... in group therapy, and I was with people who seemed to be a lot more depressed than I did that that they showed very little emotion in them and almost everything they said was negative and I was already starting to feel a little bit better and after a couple of sessions of that I almost felt like that was dragging me down because you don't really notice that when you are feeling really bad yourself but after you start to feel better and you are with people so are so negative yeah I felt that keeping me in a group environment with people who were still in such a negative frame of mind might have been unhelpful.
141. ... we had occupational therapy a lot and activities to do but they were all like kids, very childish level like we'd sit down and cut out things or colour things in and it wasn't adult occupation
142. Oh they tried to but you get patchy bits. [referring to individual counselling].
143. ... and then they've got groups. The dreaded groups! [Laughter] which you have to do to get out of there to pass the test. Yes, then, then you would have lunch and then on the weekend nothing happens ... Well, they like you to go and also there's nothing else to do. There's absolutely nothing else to do
144. ... they just leave you there actually.
145. Like they'd get you in a big room ... and men in there and its like you're sitting in there or lying in there trying to relax with a whole lot of people in a dark room after as a child I've had all that abuse, its like wakey, wakey, I don't like being in here but I'm going to be here because you say I have to be here.
146. ... one I saw decided to do hypnotherapy. She wanted to take me back to some situations in my life. Didn't find that helpful ... another one kept trying to convince me that I must have done all these things in my life that I've blocked out. ... So that was strange because I mean it was like she was pushing this stuff on me. ... This is exactly what happened to you, you just don't remember. [recalling incident with social worker].
147. I mean I was pretty big with my OCD then and anyway she lectured me about how you were to relax ... she made me go and have a bath in the hospital bath. And I was just sitting in there in this bloody bath I could not stand but she made me do it and said just relax, relax. And I can't relax and she just carried on like "You should relax what's your problem, you're your worse enemy." She couldn't understand I had a problem sitting in a bath that wasn't my bath that millions of other people had sat in it. ... But she made me sit in that stupid bath you know.
148. Woke up. Have breakfast. Have a shower. Go back to bed. Lay there. Watch your TV. Nurses would come in "You should get up and go and have a walk". I used to go for a walk. That was it. And just had my medication every day.
149. Typical day is like get up, have breakfast, go to the Day Hospital, go to groups, self-esteem.

Appendix G:12

150. ... they stick you in these assertive groups and the self-esteem groups, well, how the hell can you get self-esteem back when you've never even known what self-esteem is. And, how can you get it when you've still got all this underlying stuff there. You can never get it until you've dealt with it and explored it. But they say "Oh we don't want to explore that"
151. I mean God your self-esteem is rock bottom and I think they are a waste of time those self esteem groups because you need to do something to get self esteem its no use talking about it ... you've got to be able to practice it you know and then maybe go into the groups and practice it because sometimes you don't even know what it is. You know it can be there in black and white on the board but it doesn't relate to you. No, you don't relate to it. You've got to actually do something physically, practically to get that self esteem. It is no good talking about it. That's a load of words off paper.
152. Oh you get up or they make you get up usually. They try to get you up. Go and get breakfast. You don't want breakfast then you do without.
153. They used to do that but they don't do that. They don't encourage that now because they think it keeps people there ... [referring to eating breakfast in bed].
154. Oh no you have to get up and go into the dining room.
155. Oh you just don't get your meals No. No. You just don't get anything. [referring to missed order].
156. Well ... everything is very routine and like at 5.30 do this and 6.20 you do that and there's no sort of flexibility
157. It wasn't so much my diagnosis that got me into hospital [referring to OCD] but the depression which was so severe, ... I was just wasn't functioning. I was put in the normal [Rural] Hospital and the doctor [GP] would come in and visit me everyday. Make sure I was taking my medication. "Hi, how's it going. Are you alright. You're not going to kill yourself are you?" And that was it.
158. Formula! Like five o'clock give them their medication, meal times are this, meal times are that. Oh god when you are mentally ill, that's another thing that has to be revised is having these structured things in a person's life. You are probably in there because your bloody life has been so flaming structured and so ruled, you know and then you go into another rule that victimizes you again. You know they say you can go in for a rest, a break. A rest? Break?!
159. Oh well when I did try to talk to a doctor about getting some help he said they don't deal with issues of child sexual abuse in the mental health services.
160. We keep telling them we don't want to see a male doctor or a male nurse. But we keep having to see them. And they keep saying there's not enough to go around. That's fair enough, there's not enough to go around but we don't want to see them.

Disparities

161. Well we would wake up and have breakfast, very nice breakfast ... get dressed then at some stage a little later in the morning you had group sessions.

Appendix G:13

RESPONSE TO TREATMENTS/INTERVENTIONS

Similarities

162. I remember once when I had been pinned down by those four nurses and given the needle. I had been sure I had been raped ... they started giving me this medication and ..., one of the side effects was it would make my breasts bigger and I would leak. And so I was certain then that I was pregnant and that it was these four guys who had pinned me down who had done it ... I was really crying and upset about it and one of the doctors, ... she just held me and she said oh no X its just the side effect of this drug you know.
163. I said just hold my hand X. Just hold my hand. And I could feel, she's very calm, and I could feel her energy counteracting my energy and it automatically started to calm me down you know.
164. Well after I left the hospital I actually did a two week course in cognitive behaviour therapy [offered by the hospital] and then after that I got to speak to a psychologist individually because there were some things you know that were personal to me that weren't really probably discussed in enough depth in the group discussions anyway.
165. ... just before I went home I started on a full two week course on CBT. So ... I knew that for every day for two weeks ... I would be going back to the clinic for the whole day. So there was a very caring structure in place which was brilliant because if I just gone home with nothing it would have been very frightening. So that by the time I did go back into the world I had had three weeks of care and of very rigorous, appropriate attention.
166. ... I would be much more quick to discuss how I was feeling with other people more openly. [referring to CBT]
167. ... when you are in a crisis ... you need those skills and you need to be given those quickly, to give you the confidence to move forward. You need to have that quickly. If you go once a week, and think of what they do in two weeks full time, and it is not all CBT, in the afternoon it may be relaxation but if you have a program that's like that that runs from nine to five for ten days, you are packing in months instead of an hour with a psychologist.
168. You are living it [CBT] for two weeks and it doesn't mean that you are going to keep it forever ... I am often aware of my thought processes and then I think hey wait a minute, you've learnt ... not to think like that [referring to CBT], what's the matter with you, but you know one does revert
169. ... my occupational therapist wanted to touch my finger one day and I just flinched. ... she tried to do ... touch therapy or something, I couldn't touch her finger and in the end we worked through it and we can hug one another. ... she could always tell when I was like a block of wood. Eventually I used to come out of being a block of wood so I could feel her hug and she could feel mine. I'm much more able to do that now. I know when I am a block of wood. I can feel it now. Before I didn't know. Now that's what she was able to develop for me. So there are those sorts of things for people like us get not to experience.

Appendix G:14

Disparities

170. ... I remember this young girl whose boyfriend had just died and she had tried to kill herself ... because my boyfriend had died years ago and so her situation, one night triggered lots of stuff ... all this grief was coming out. And I was really distressed ... and I just wanted ... this woman to hold me who was a nurse ...? And I went up to her and she said what's the matter? She was very cold. She was ohh very cold ... I said "Oh look I'm really distressed about X and it has triggered stuff with me and I just need someone to hold me." And she said "That stuff shouldn't affect you. ..." I just could not believe ... they offered me medicine. But I didn't want the medicine. I just wanted to feel like I wasn't alone you know. I needed that touch you know.
171. ... I went to see a social worker I was getting this grief thing. And I was also feeling angry. I wanted to talk about the anger about the services and I felt angry about lots of things ... the social worker said to me "Well yes I felt angry when my mother lost the negatives to my wedding photos". Ahhhh well I sat there ... "I said you can fix that and go to the photographer and he'll take photographs and you get more negatives." I felt humiliated. I felt so bad that I had gone in there to try and get some expressions, thoughts or something that was really deep inside me and I walked out of there and thought I shouldn't have said that. I felt so bad. Oh my god I felt like a clot. I did. I felt really bad so I just went up to my room and felt so bad.
172. ... there was one morning and had what I thought afterwards must have been a panic attack and sort of not expecting that. So that was quite scary. That was scary. [Episode related to medication].
173. I first tried to get off Aropax about two years ago and ... and felt terrible ... I tried to get off because I was putting on weight. I had spoken to him about the putting on of weight before and interestingly he said they didn't know when they were doing all the trials that it did not emerge as a side effect and it was only when the drug was in use that they started to get reports around the world about weight gain and one of the things is that they don't know what it is. They don't know why. But they do know that it happens and it is significant and it is very difficult to lose it while you are on the drugs. I tried Zoloft briefly and didn't feel great and got a terrible skin rash so I went back to Aropax and every time I went back I put on weight and eventually ... I had been on Aropax for two and a quarter years, I tried Prozac and I tried it for about six months and I did lose a bit of weight but I just didn't think that it was the right thing so now I'm on Sepramin. ... I've discussed with them about coming off or not coming off but basically I do have underlying problems with my anxiety and I can feel that its there. And she said to me there's no way you are coming off.
174. Yes. Yes. About 15 kgs.[referring to weight gain after taking anti-depressants]
175. ... there is no doubt for me Aropax was the best drug but I am not prepared to go through life like a hippopotamus

Appendix G:15

176. ... medications disturb your dreams. When I have changed medications, which I have done a couple of times because of the weight, I said to her when I was on Prozac my dreams were absolutely all over the place, I was having the most bizarre dreams.
177. Mood swings. And the Pothedine is for the depression to send me up but you see because I've got rapid cycling mood swings, the Pothedine is a bit of a risky one to have because it can actually send you up too much.
178. Ohhh god no I wouldn't dream of saying that [referring to refusal to take medications]. Its like sometimes if you're not taking it because it really does interfere you know, like ... what they want to give me, is some stuff for the hypermania ... its horrible, it gives you really bad side effects and I wouldn't want that because I don't like the side effects
179. No Largactil or Merralol. Usually Largactil. And they have also given me that Alanzopine ... I found out from somebody else, way down the track after I had been taking it, that anyone who has breast cancer in the family shouldn't take it. Well my mother died of breast cancer. And they were giving me all this stuff. And I've gone in on the internet since and I must admit, pressing all the buttons and looking at all the drugs what they do and what they don't do, and I'm saying hang on they're not telling us this. The pothiadin that I take, I was having a nerve conduction test ... and the doctor ... in the medical ward said to me, have you had a blood test lately. I said no. Ahh he said maybe you should go and have a look because you are bleeding funny. ... I was covered in bruises ... I went off for a blood test and ... there was something wrong And then I went ... and said to the pharmacist ... what are the side effects. He said the worst side effects are bruising, low white blood platelets and all this other stuff. Blow me if I wasn't having all these side effects and they hadn't checked me.
180. No they don't tell you. All they tell you is dry mouth, blurred vision basically. Now I know the Epilim, my son used to take it for epilepsy and I'm supposed to have liver function tests done.
181. ... and often you're given the wrong medication and that can make you a lot worse. You know I'm allergic to a particular medication and often they give it to me
182. ... he did something, something incredibly stupid, he told me to stop taking Xanax immediately and I had been under it for some seven months and it is a highly addictive substance and he put me on this drug, Nortryptiline which I mean – just zonked. So I was suffering from withdrawal and being knocked out and ... it was a nightmare. That week was horrific.
183. I just stayed in bed ... I was completely dysfunctional ... but that was drug induced you know. It was really awful. I mean the drugs were knocking me out until four in the afternoon and then I had a little bit of time when I maybe felt a little bit better and then I would have to take more.
184. Well I increased the dose and of course in the morning I couldn't get up, you actually almost pass out ... you just keel over.

Appendix G:16

185. I'd like to see them all try a tiny amount of medication because you know one of the biggest problems is side effects ... so I would like them to have a little sample of it just to see what it does for them. ... they are very good at giving medication ... you go to hospital and they dose you right up and then you are expected to do all these chores and do groups and that to get better and yet the medication is not as refined as everyone thinks
186. So I started taking Aropax and I took it for five days and I went into the city again and I had a major, major panic attack and I thought it was the drugs and I said I'm not taking these which was a big mistake.
187. No. I was taking up to ten tablets a day and it wasn't helping. I still wanted to die so they didn't help really.
188. I was on Anafronil. They are specifically, supposedly designed for OCD. No. I was depressed. They didn't help.
189. Especially after having the ECT ... because I don't remember anything for the three months after that. ... I had short-term memory loss for about three months. Now looking back I cannot remember those three months. At all. Like it feels so strange to me that someone says you came to my birthday party then and you bought me this and they are showing me this thing and normally that would trigger something, you know ... oh yeah that's right No. It's gone. And the thing that scared me the most about that, ... the thing that bothers me about it is that ... what if I lost three months before instead of three months after. That three months before, that was my whole son's life that I would have lost and I wouldn't have been able to forgive anybody for that. [given ECT 18 months ago].

STAFF BEHAVIOURSLACK OF UNDERSTANDING*Similarities*

190. I had a patient ... masturbating in front of me in this television room ... I was scared to death because I was in there with all my flashbacks ... and I told the nurse ... it was around eleven o'clock at night ... and you know what she told me, I could not believe it, she just laughed and said oh its due to his medications. Never forgotten it.
191. The staff were very cold and non-understanding.
192. ... for instance when they want to do these sessions sometimes and they want you to come into a room in a circle and I go "I don't want to come". And I'm too scared to tell them the reason why because they start giving me a lecture. Because when the ritual abuse happened of course they all form a circle so I don't want to go ... "But it will be good for you", "yes I know it will be good for me but I really don't", but I'm really too scared to tell them why I don't want to go because I know they will start pillaging into me "Well it's not like that in here now."
193. They had no idea. No understanding whatsoever. They made me feel like a liar. They made me feel like. I was degraded. I was humiliated you know. I felt like a worthless piece of trash. And that's how they treated me.

Appendix G:17

Disparities

- 194. Look you do have a choice. There were people who slept through the whole day. But they encourage you to attend, to go and if you don't go you are just going to lie in bed and be miserable. So you may as well get up and go. They do really encourage you.
- 195. They will not, if they think you are lying around feeling sorry for yourself, they will try very hard ...
- 196. There were people occasionally who just couldn't cope. But they did encourage everybody to their best extent.

LACK OF EMPATHY/COMPASSION

Similarities

- 197. The main person I spoke to about my brother [infant died when participant was eight years old, participant now 27 years old] was a minister who was a social worker and that was like the biggest mistake I had ever made in my life. He just pushed his spiritual beliefs and made me feel like a moron by the time he left because I was letting this control my life and basically let's pray about it and it will go away. And if it doesn't go away through prayer then it must be because Satan is playing a major role in your life. So yeah I needed to think that I was evil like I had been treated all my life. And yeah, hello, full confirmation, you know what I mean.
- 198. ... well the medication did get me out of that deep depression but they were still treating me that same way, I thought my god, they treat you the same way ... whether you are sick or well, there's no degrees ... in other words they are not really looking at the person as such, they are going by some formula if you ask me.
- 199. But if I was having a bad dream, its like well that's life you know.
- 200. ... I kept telling them "Don't you know I've just lost my baby" and it just, just, I was really, really amazed that it just didn't seem to affect anybody. They just didn't seem to show any compassion or yeah, it still seems very strange to me.
- 201. ... they put me in the lock up and I've never forgotten then. That was really traumatizing and no one talked to me. That was dreadful. No one talked to me about anything. And when I tried to talk about the baby I had lost and everything it was like they don't want to know. Its like "Oh well that happened years ago ..."
- 202. Then like in [Hospital] after all those people who have killed themselves in there lately, I knew them. And I've been telling staff ... yeah they were in a room with me while I used to be a patient ... and you tell them all this and its like they just look at you ... you are holding all this trauma in ... and us consumers, we've been patients in there knowing all this but no body has talked to us about it. And we are telling them. These people were our friends. We knew these people. It's like "Oh yeah."
- 203. No. Never. And never talked about anything that was umm really important to me, like the death of my son. Or how was I feeling about that. It was always nothing complicated.

Appendix G:18

204. Because I wasn't physically sick, what was my problem? And there were nurses in there that even made comments like ... "You can't mope around". "You can't wallow in it." "You've got to get up and you've got to make the best of your life", and "You're your worst enemy". All that sort of crap. "We all have bad times. We all feel depressed. What's your problem?" So I basically felt as though they were looking at me as though I was making any excuse I could to go to hospital. For God sake I don't know why! So a couple of nurses were actually really bitchy about it and they made it very clear how they felt

Disparities

205. There was one night nurse from NZ and she was just fun, she would come and tuck us in and give us a hug. You know she was just amazing.
206. They would touch me. If they saw that I was distressed they would reach out and rub my back or give me a hug. [referring to psychiatrists].
207. There were very nice. Probably the most positive thing was at night like the nurses would come and go through with you what you were thinking about and that sort of thing. That was one thing I found very useful. Because it can be very distressing to be you know away from home. Especially when you are not in a good frame of mind anyways. So it was nice to have them there to sit and chat and they were very sympathetic. [referring to nurses].
208. They are kindly and understanding to an amazing extent. They are also gently, gently firm. They will not, if they think you are lying around feeling sorry for yourself, they will try very hard [referring to nurses].
209. ... the ... doctor who put this stupid label on me, borderline personality, another one on me. ... he said "Oh well that's because of your childhood." Anyway ... I went in and this doctor ... he was from India, just come to [Hospital], sat there, obviously gone through my notes, ... and I said to him, they keep putting labels on me, this borderline personality because I've got bipolar, all these other ones, why this one. "Don't worry about it" he said "I'm amazed you've survived. You're a very courageous person" he said. "Yes, you have had a traumatic experience in your childhood, yes anyone with that kind of experience would be feeling exactly like you are, it's only a label my dear. Forget it." Anyway he says, "It's nice in Perth, I've just come to Perth" [laughter] Hang on what's going on here I'm supposed to be seeing a doctor. You don't talk about, I mean we talked for an whole hour about ordinary things Fantastic [laughter]. Jesus! Forget about all this borderline stuff. He agreed with me yes you need to come in for a rest, ... but you know we talked ... I walked out of there feeling as sane as anything. I thought this is the first time a doctor, in my career, I call it a career in mental health, has talked to me like a person and I felt wonderful

LACK OF APPROPRIATE CONTACT WITH STAFF

Similarities

210. I never saw a doctor hardly. I never saw anyone

Appendix G:19

- 211. ... well I had a psychiatrist but I never saw him, I only saw him once when I went in there and then I had a social worker or psych, I'm not sure what his position was
- 212. ... one of the nurses, ... he actually put in a referral for me to have the psychologist come and visit me in hospital every day. ... and then he tried to come and visit me at home once a week but like it didn't happen like that. He would turn up once and then ... I would be ready for him to come the next week and he couldn't and then I would have to wait another three, four, five or six weeks before I could see him again.
- 213. I mean if you've been raped or something, they'd leave you alone ... or if you've had postnatal depression or something like that.
- 214. They don't come in and see, you don't see them all day. [referring to nurses].
- 215. You push the buzzer but to no real avail. I mean, I wasn't a priority you know what I mean?
- 216. They sort of, like when you are having a meal, they stand around the room, or when you are watching television, there's always someone around there. They don't always talk to you but they always stand there and they have a notepad and they're writing.
- 217. ... they put me in the lock up and I've never forgotten ... that was really traumatizing and no one talked to me. That was dreadful. No one talked to me about anything. And when I tried to talk about the baby I had lost and everything it was like they don't want to know. Its like "Oh well that happened years ago"
- 218. ... you have to sign this book everyday if you want to see the doctor and ... say we want to see the doctor and we go down the next day and say we want to see the doctor ... write it down and we haven't seen him that day. And they say "You've just seen him walking down the corridor" and you say "Oh okay". The only time we really get to see the doctor is when we go in because its protocol and because we have to and when we go out, because it is protocol and they let us out. But inbetween you just never get to see them.
- 219. ... sometimes you speak to the nurses
- 220. The nursing staff they would come out to the smoking area and just sort of talk to anybody who was there.

Disparities

- 221. There were very nice. Probably the most positive thing was at night like the nurses would come and go through with you what you were thinking about and that sort of thing. That was one thing I found very useful. Because it can be very distressing to be you know away from home. Especially when you are not in a good frame of mind anyways. So it was nice to have them there to sit and chat and they were very sympathetic. [referring to nurses].

Appendix G:20

THREATS/ABUSE/RIDICULE

Similarities

222. ... I saw these brochures and there was one about sexual abuse that I started ripping up ... and one of the nurses just stood there and said "You'll be going back to the lock up at thingy if you don't control yourself".
223. And I would be threatened "If you don't settle down, you'll be getting a needle."
224. They threatened me with a needle. If I didn't shut up.
225. There was one nurse who ... liked seeing me spinning out and he would wait. On my notes it had ... my medication from 8 o'clock to 9 o'clock. By half past seven at night my paranoia and fear that everyone was out to get me and I'd try desperately to handle that last half an hour and I did, but I'd want it by eight o'clock and I knew I was allowed to have it from eight o'clock and there was this one particular male nurse. I would go up to him and ask for my medication. "Its eight o'clock its time you gave that medicine". "You don't need that till nine o'clock". And I'd say "No but on my notes it says from eight o'clock." He says "From eight o'clock to nine o'clock." But whenever my family were there he would come and give me my medicine at eight o'clock but if I was on my own ... he would not come near me. And he would not let me get my medication at eight.
226. ... you got teased a bit ..., for being there. Because ... I've been in hospital lots of times you know, so "Oh you're back again. What did you do wrong this time"
227. When you're ill you don't do rational things, so they may say "Oh here comes that idiot that did this the last time" but you are not rational.

PERCEPTIONS

PSYCHOLOGICAL IMPACTLACK OF POWERLESSNESS*Similarities*

228. ... start forming groups so that I can help them from my own experience to have a voice through art too
229. ... I think we are getting a bit more of a voice
230. Well I think we are all consumers. Even the mental health workers are consumers because you never know when you might be there yourself.
231. I think the strength of it at the moment is the consumer representation
232. I'm just a consumer. I hope I won't be in the system when I'm 80 or else I'll be making sure there's another system. I'm working on that one [Laughter]. In my twilight years I'm going to make sure ... we get moving on that to get it changed.
233. I think it is part of the system, it is part of the structure, it is part of an organization. It has to be dealt with because it makes it better for the staff that are working there. The staff have to succeed. ... I have actually spoken to staff and they have said about their difficulties and they said they haven't got a voice themselves. They can't say anything but maybe we as consumers have more of a voice in the say because we don't have to rely on jobs.

Appendix G:21

234. ... it is all very well for me to say oh well I've coped but that was because I've had 18 years of experience of being like this... This is what I mean about having a voice. This is what I say about no language, it is not a language barrier. This is a voice from experience I am using. This is my voice from my experience I'm using after 18 years and how I negotiate this.
...
235. ... it's not the individual and I think we are all implicit in this. I think as an individual we need to speak up about these things and I realize it is very difficult for staff in these situations because they have to be employed. They rely on wages. But as a person that can stand on the outside looking in ... the staff themselves are overstressed and it comes from the top.
236. ... I just went along with the flow of it but now I've become more empowered

Disparities

237. Well this feeling of not being in control of yourself actually. This feeling of not having a voice. The feeling of, like going to this person, and I reflect back, oh god I was so capable, so coping, ... they didn't acknowledge that side of it.
238. Umm I've tried that sort of thing but umm its quite hard to access people like that. [referring to access to consumer representatives].
239. Well sometimes I've been in to talk to a psychiatrist in the hospital and I've said I'd like to see a GP and that's hard, I didn't get a GP in. You only see the Board of Visitors come around once a year so
240. Ego and power. Power. Power over a layer. Yes power is in layers. At the bottom. [mental health consumer's place in hierarchy]
241. Well you are certainly a patient you know.
242. Well its still a long way to go.

FEAR

243. Yes. ... you stand there ... this is so belittling you feel like a child, they are all there in their station and you are in distress of some sort or you are there to speak to somebody about something and I'm so timid to say anything. ... but right now ... I would be too scared, even if I walk in there as not a patient and I may walk into that ward to see somebody or whatever I get this feeling in myself.
244. ... [laughter] Well you feel like a child. Its like your going up asking for something you shouldn't have. You feel like a child. You're scared. You stand at the desk and you're so scared to ask that you're in distress of some sort in your head or whatever, where this distress is coming from, and you're just too scared to ask that you just don't ask in the end so you're actually, my whole experience in psychiatric hospitals is exactly the same mirroring experiences of what I experienced as a child. And it is still like that for me. That's why I wont even contact them now because I'm having some difficulties because I don't want to be re-abused ...

Appendix G:22

245. Why don't I ever get any when I'm very meekly and mildly trying to get some help. Maybe I should cause them some havoc. Maybe I should just let it out and cause havoc but I'm too scared to do that because they carted me off to the lock up at [psychiatric hospital] once when I did that ...
246. That's the thing. I mean the first time I got really distressed is what happened to me. I went and got needles and got put to sleep. After that I went to my bedroom and I used to cry in my bedroom by myself because they didn't come in there. [referring to nurses].
247. I know how they think. And I know from my past experiences that I'm getting less and less safe enough to go and do that [getting help from hospital]
248. I just behaved myself. Just watched everything I did. [referring to discharge]
249. Oh things that we've heard you know like from other people like if they retaliated or if they wanted something they're told off or made to feel horrible and all that and you just don't want to be made to feel like that you know. You just don't want to disrupt them. You don't want to cause a disruption. You just don't want to disrupt anything.
250. That they were on their own [referring to children]. Dreadful. But I had nowhere to, I was too scared to say anything to start with too much in case the welfare would have taken them saying I was mentally ill, that's it ...
251. And I would also say that tainted the rest of my life because in April I just had a miscarriage but ... I'm just going to be under eagle eyes again. I've just got to make sure nobody sees that and that I've got to act as normal as possible because I know where I'll go.

STIGMA

252. Well it does have an impact on your life ... because you get embarrassed about it.
253. It depends on what the world is like. If the world has stigma and it very unforgiving then I haven't got much chance but if you have a few things happening in your life that are positive, like if you find work and find a partner and you stay well for a while, then you've got a chance ... I'm not that suicidal but a lot of people, I've known a lot of people who have been and they are no longer here ... I'd say 30% of someone's illness, unhappiness about their illness is related to how they are perceived in the community.
254. ... my son constantly watching for me to make a wrong move, is he ashamed of having a mother with a mental illness, like he always say, don't say anything, oh yeah, he's really protective over it. Doesn't want anyone to know.
255. Well I have been ill enough ... felt so ashamed ... because of the stigma attached ... because knowing what labels I've got ...
256. ... they say we've got stigma and discrimination right on the outside but believe you me, the biggest stigma and discrimination actually comes from inside the system itself. They stigmatise us big time compared to the outside.

Appendix G:23

257. When you've got professionals turning around and writing things up ... like there's got to be a buffer between society and people with mental illness and it will be ill-tolerated by the community, then you've got to question yourself my gawd if they've got those perceptions inside the service and we are trying to educate the outside place to tolerate us, and they keeping this framework inside the service ... they might as well put us on Rottnest and then they can chuck everyone off Rottnest.
258. Oh good God no! The guy next door I think they'd run.
259. I suppose it would be depending on what kind of job I had. Where was I going to be employed. I suppose if I was in a kitchen as a chef they would be a little worried about the knives and things like that [laughter]. I suppose it would be depending on what environment. But then I thought maybe I may be putting this stigma on myself.
260. ... I feel people instinctively shut off in some way, they don't want to know.
261. I think yeah people feel they have to keep it to themselves so its not something that others might think less of them. And I think if people realized how common it was then they wouldn't feel that way and maybe be more inclined to seek help sooner.
262. ... he said What's your disability and I said mental illness and I'm not quite sure, I've got this deep depression and having treatment at the moment, I've had a few things go wrong. He said to me "Oh you better not tell your supervisor that" and I didn't because I'm aware of this and I thought my god, ... bloody counselors ... and yet I'm not to tell my supervisor.
263. ... you take a risk every time you divulge it you risk. There is a big risk and especially when you've got people in counselling positions that tell you not to tell your supervisor

Disparities

264. I mean its amazing how many people will say to you yeah I went through a period of depression when they hear about what has happened to you. ... I never realized until I was sick, how common it is. And I think that's one thing that probably needs to be brought out in the community generally.

BEING STEREOTYPED

265. ... I mean there were only two people who were friends who came to visit me in hospital but I'm sure they are scared because they don't know what could happen, what I might be like.
266. ... I would say after a few visits they have made up their mind about you. So yeah I'd say after a few visits, like you might go in three times and the fourth time they'll treat you like they did the other three times. [referring to nurses]
267. That they were on their own [referring to children]. Dreadful. But I had nowhere to, I was too scared to say anything to start with, too much, in case the welfare would have taken them saying I was mentally ill, that's it ...

Appendix G:24

268. Better than going there and thinking I'd better not say because they'll start writing their notes down and they are going to say you've got this personality or that personality, stuff that personality. I don't care what they think. I'm either mad, bad or sad. That's one of the things and that's a sign of distress basically.
269. Probably asking me about the medication, tell me I'm mentally unwell. "Oh you're having an episode". [laughter]. You've got to be joking. I'm not going to be told I'm having an episode.
270. Yeah. And they would look at me kind of strange.
271. Yeah. Totally. I was just sick. I was, I was mentally unwell [referring to not being believed by staff].
272. And I said to this nurse, my doctor told me I'm 99% fine and it's just the one percent and he said, yes but it's the one percent. Like he really focused on that one percent you know
273. ... you are able to see a much clearer picture about why you exhibit what they call mental illness. ... What they call mental illness. They have to have a label for it because nobody can understand it otherwise and we all have to have labels
274. We have to start becoming aware it is a social construct. It is not something that we are born with.
275. How can like a SIDS parent tell a non-SIDS parent, something like, "I can hear him crying at night still". They would be like, "Jesus you need to be at [Hospital]", you know. But to a SIDS parent to another SIDS parent, its like "Yeah, I'm having that too". So I think it really scares people. People who haven't been through a particular situation in relation to another person, it scares them, because they have absolutely no concept of what, where this person is coming from.

BEING DISCOUNTED

276. Proper help, respect and care. And being believed. Sometimes we are in great distress and that's all it is sometimes. And we are human beings.
277. I get fed up with doctors. These ones popping the pills telling me all sorts of crazy messages. Telling me my messages are crazy in my head and I'm going "Hang on a minute, I don't feel like they are crazy in my head. This really did happen to me and this is how I feel about it and they are telling me I shouldn't feel like this and I shouldn't feel like that and I'm going Cripes, there's really something madly wrong with me.
278. Probably asking me about the medication, tell me I'm mentally unwell. "Oh you're having an episode". [laughter]. You've got to be joking. I'm not going to be told I'm having an episode.

Appendix G:25

279. ... if they announced that somebody was going to knock Broome off the side of the earth with a war, how long do you think it would take them to take a whole pile of stuff up there, ten minutes? Exactly. And its going to take ten years for one little simple thing. Why? If they can get the forces in a matter of minutes to go and kill a load of people off instead of getting the resources to help somebody live then you really have to start questioning the system and values. You know what does all that come down to. Money. ... But I didn't tell them that because then they would really think I've gone mad.
280. ... I had asked these nurses if I could eat my dinner outside because I wanted to watch the sunset. They said yeah okay, just bring the fork and knife back in. That's all they were worried about, the frigging knife and fork.
281. This is why we have so much mental illness because we the people who develop a mental illness are the ones ... made to feel that it is our fault. That we are inferior. ... instead of addressing the issues that have brought us to this stage and validating our experience they don't.
282. ... I did have a physical ... tangible illness and they were ignoring that. It was like as if it's all in my mind it's got nothing to do with that. You know like there's not a real illness there. They were treating me as if it was all in my mind. So there was this complete mind body split. ... And I don't think either was being taken care of properly. Because they weren't acknowledging my physical pain and therefore they were saying to me I've got this mental stuff ... they weren't acknowledging either.
283. I do not want to be insulted and abused again by their theorizing and ... them not listening and thirdly, I just feel it is a waste of time. I'm fed up with repeatedly coming up with the same stuff.
284. I thought there would be more respect from the nurses. The younger nurses were more aware of that. You know they would just treat you as normal really. But it felt like the older, they were better than, they were okay and you weren't okay.
285. Do you know it took three days for the police to come and if I had been out on the street they would have been there oh within an hour one would think. But it took three days. So for three days I was a mess. [referring to violent incident with fellow patient].
286. The view I have is people should not be frightened of their positions and thinking that they should not allow somebody in there who is not as educated or they haven't got a degree or they haven't, they haven't got a value in the sense of what society values you know like this position ... that these people don't know anything and also people mustn't be frightened of their positions in other words they have to be open and listening to other people and that other people have very valuable stuff. They have to get out of this mindset of thinking "We're the experts. We've got the degree. We know all about this" because you never know everything and if you are open minded, you are far more literate in yourself and far more able to make sound policies and planning if you open your minds and listen and don't get entrenched in your own ego.

Appendix G:26

287. Now I've got a heart problem, and they still ... nothing. Now that's weird because if I was in an ordinary ward and they would have taken me off to get an ultrasound, and they would have come back, maybe even shown me the X-rays, I don't know they would have certainly given me some notes or something. ... No. No. I haven't seen anything [laughter] ... [referring to results of X-rays].
288. Like the usual piece of trash that I always thought I was. No one cares. Really no one does care. It was just confirmation I guess.
289. I think it is something I feel myself. And also from my experiences from some of the things that have been imposed on me too. And it is layered. ... they just create another layer of shame. ... Creating another layer of shame and guilt.
290. Nothing ever came of that. I never heard what happened. It was like I was the one, ... but there was no procedure in place that acknowledged that I wasn't in the wrong. That this person was totally out of context of what she had done ... [referring to incident with nurse]
291. There needs to be, they need to be accountable for these things [referring to incident with nurse] because it set me back because I do find that if I have to go for help now ... I find it very difficult to relate or even go into a hospital situation because of the experiences that I have had.
292. ... they are treating people as if they are robots, the language they are using nobody can understand. I doubt if they understand what they are saying themselves actually.
293. ... if they announced that somebody was going to knock Broome off the side of the earth with a war, how long do you think it would take them to take a whole pile of stuff up there, ten minutes? Exactly. And it's going to take ten years for one little simple thing. Why? If they can get the forces in a matter of minutes to go and kill a load of people off instead of getting the resources to help somebody live then you really have to start questioning the system and values. You know what does all that come down to. Money. Because they are making money out of war. But I didn't tell them that because then they would really think I've gone mad.
294. The environment inside the system, the people, the way they do things, the bandaids is great. ... they are talking about changing everything and all they have done is talking about the number of beds here, the number of beds here, now this is the reform ... and all it talk about is moving beds around. Musical beds I'm calling it. ... I know they've got to put beds down but let's start talking about real stuff.
295. This is why we have so much mental illness because we the people who develop a mental illness are the ones ... made to feel that it is our fault. That we are inferior. ... instead of addressing the issues that have brought us to this stage and validating our experience they don't.
296. ... they took me from [Hospital] and put me, dumped me in [Hospital] and I say dumped because that was the way I felt
297. I think they should never forget their position in life is like mine. They should never forget that they might need the system themselves.

Appendix G:27

298. I think they would have possibly thrown me in a locked ward. ... maybe they would have thought for my own benefit but I think it would have been more for their benefit in the sense had I done anything to myself there would have been an inquiry. I doubt now if there would have been an inquiry because it would have been pushed under the carpet you know.
299. Well they actually like you. [Laughter]. Everybody likes you when you are a patient, a physical patient. They can cope with it. Yes. [Laughter] I'm sorry but this is my perception.
300. I didn't realize that's what it felt like ... you know I was very tempted to ring them up yesterday and say "Look I'm having a bit of hypermania going on here, there's something happening" but then I thought because all they'll say is, I don't know what, they'll just say something stupid.
301. ... you know we often get told oh well forget about it, put it in the past, but its in the past, we know that, but there's something in the present that's happening from grief and the loss
302. Oh they wouldn't like you. [laughter] You would be told you were very naughty and they might not want to deal with you [refusal of medication]
303. Absolutely. Yeah. Once you are in crisis then they'll do something. And when the dam breaks then that's when I show up at the hospital because I know inbetween there's nothing else or I just feel ashamed because I feel ashamed. I feel shame.
304. No. No I'm not valued. Not valued in society because I've had a mental illness.
305. Well sometimes I've been in to talk to a psychiatrist in the hospital and I've said I'd like to see a GP and that's hard, I didn't get a GP in.
306. Yeah I know what it is. They just don't want to know. Because I reckon too many people will get well actually. Sorry. [Laughter]. So they don't want to know. Keeps them in jobs. Oh look I am making a generalization here. I have come across some good people but they are few and far between. Not many of them.
307. Yes. That's how I felt. ... they kept them as separate entities and how I came to realize this, I did have a physical illness there, a real, physical, tangible illness and they were ignoring that. It was like as if it's all in my mind it's got nothing to do with that. You know like there's not a real illness there. They were treating me as if it was all in my mind.
308. You know I think when you are dealing with people no matter what they've got whether they've got a physical illness or mental illness you've got to treat the whole person and, and they, they treat you like children. They are so patronizing, its unbelievable. They think that you are senseless.

Disparities

309. ... I just took a risk and it was a risk. I rang up my supervisor and when I spoke to my supervisor I said "... I'm sick of bloody hiding it, I've got depression at the moment and I'm not sure whether its manic depression or bipolar but I'm not feeling well and I said I can't do my thesis". And he said "Oh that's fine, I've got friends that have got bipolar".

Appendix G:28

310. I think yeah people feel they have to keep it to themselves so its not something that others might think less of them. And I think if people realized how common it was then they wouldn't feel that way and maybe be more inclined to seek help sooner.
311. I mean its amazing how many people will say to you yeah I went through a period of depression when they hear about what has happened to you. ... I never realized until I was sick, how common it is. And I think that's one thing that probably needs to be brought out in the community generally.

MANAGEMENT OF ILLNESS

LACK OF CONFIDENCE IN TRAINED STAFF

Similarities

312. Well the first one I saw decided to do hypnotherapy. She wanted to take me back to some situations in my life. Didn't find that helpful. ... I mean whether that was right or not I don't know.
313. Umm there was one woman who came but I didn't like her because she thought pot was alright and I don't know I just didn't connect very well with her [referring to case worker].
314. ... umm as I got a little bit better it came quite clear that there were some staff that shouldn't even be in there treating people with mental illness.
315. Well the social workers ... I've never had much luck with them.
316. My worst experience would be, my worst experience would be all that session with the kids and having to watch my abusive partner go off with the kids ... child abuse ... they [referring to the hospital staff] were the perpetrators.
317. I did have a couple of experiences with social workers and I found them to be of no use whatsoever.
318. People who were in the field of mental health. They know better but nurses ... are not really trained for mental problems.
319. Umm let me out. Just talk to me. But I don't even know if they had the skill or training to deal with that anyway. [referring to locked ward situation and nurses].
320. ... it was really the psychologist who was barking up the wrong tree ...
321. ... he did something, something incredibly stupid, he told me to stop taking Xanax immediately and I had been under it for some seven months and it is a highly addictive substance and he put me on this drug, nortryptline which I mean – just zonked.
322. Psychiatrists in [Hospital] turned out to be not psychiatrists but umm doctors studying to be psychiatrists so they weren't fully qualified psychiatrists. But so-called psychiatrists, I would see them about umm once every week and a half.
323. And I would really like my ideal ward to have doctors that weren't just training. I mean, doctors that were actually qualified because they get doctors from Russia and China you know but the doctors who qualify don't stay in the public system, they go into the private system, so qualified doctors would be good.

Appendix G:29

324. Somebody who is experienced and trained on knowing how to handle. Its hard for them you see because they are not trained to deal with these issues, not properly trained and I think, you don't need head doctors all the time, you definitely don't need head doctors all the time, I mean my mother was mentally ill before she had us, she had been in psychiatric wards ... she was even having shock treatment while she was pregnant with us ... anyway, I don't think people are trained enough. They are certainly not trained for things like this.
325. ... I thought I couldn't go and see this doctor and then he would sit with his pad like he did the other day and start drawing all these little boxes and put these thoughts in boxes in squares and things and I was getting so confused by these boxes and being asked all this stuff. ... I thought geez he got me so confused and I thought I can't go off for any more of that. So I went and did my cleaning job. ... and felt good. After that I expelled some energy ... it was excellent. I came back feeling wonderful and I thought if I had been up to that doctor, I would have come back feeling confused, irritated.
326. But you see some of the nurses don't read it, so, like when I take this medication that I'm allergic to, I get very ill, mentally, I go really high, it's like crack or something for me. And then my family would complain and it would happen next time and I've had a key worker from [Hospital] and when I've talked to them about it they've said "Oh, its just human error."
327. No they just talk about it. I don't think they are qualified to help [case managers]
328. That's what I found really strange and I thought about that a lot. I mean how can you help people if you don't find out what the cause of the problem is. Rather than just looking at the symptoms, I mean what's that. Yeah. They just try to fix the symptoms.
329. But it was all very business like, cut and dried and I thought for this hallowed woman, I thought it was appalling.
330. ... if you haven't got the staff which they are not available to deal with you being traumatized in there with you blocking stuff in, its dangerous. ...
331. ... they knew he was abusing them [referring to husband], the social workers had already taken that into account, from the [Agency], god knows why they didn't do anything either but anyway ... and then when my sixteen year old tried to commit suicide ... this is considered a genetic thing.
332. They have to get out of this mindset of thinking "We're the experts. We've got the degree. We know all about this" because you never know everything and if you are open minded, you are far more literate in yourself and far more able to make sound policies and planning if you open your minds and listen and don't get entrenched in your own ego.
333. They make these decisions that are not based on experience and ... on reality.
- Disparities*
334. They were very good. You must remember that when I went in I was in a bit of a state. So ... I do remember being there and being interviewed and ... I was very aware from the very beginning how nice they were. Everybody.
335. And the psychologists who worked there were very good.

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336. There was nothing that they did that I felt was inappropriate or unfair
[referring to nurses in private hospital].
337. ... they are faced with a dilemma as well because they don't know because ... practices they come along with are practices that are archaic you know and they need to chuck that away and start becoming more contemporary and start to rethink it ...

LACK OF CHOICES

338. Nobody in the mental health services. [referring to accessing people in times of crisis].
339. A consumer? Doesn't consumer imply choice?
340. I've asked to see a psychologist and I still haven't had anything back from them. ... then I rang up to speak to my case worker ..., and she's gone on holiday and I didn't even know that. So there's nobody there that you can actually talk to.
341. I'm seeing a psychologist at the moment and they've always been on the team, but it was only by accident ... found there was one on the team, but if I had known years ago well then I would have seen one ages ago.
342. Very limited and totally inappropriate.
343. Nobody talked to you about what was really going on
344. Absolutely. Yeah. Once you are in crisis then they'll do something. And when the dam breaks then that's when I show up at the hospital because I know in-between there's nothing else or I just feel ashamed because I feel ashamed. I feel shame.
345. Well I know they need more services in the country areas.
346. I mean if the psychologist went on holidays, no one saw a psychologist. That was basically it because he was the only one down there doing it
347. That's what I found really strange and I thought about that a lot. I mean how can you help people if you don't find out what the cause of the problem is. Rather than just looking at the symptoms, I mean what's that. Yeah. They just try to fix the symptoms.
348. ... because I knew I was like this and there was no denying I did have something wrong with me, physically and mentally, at that stage but had it been acknowledged that it came from outside and it was, and I was coping with it in this way, there was nothing wrong with coping with it, I mean I had the situation, I mean there was cause for it. Had they acknowledged that in the first place ... I know bloody well I wouldn't have been in the state that I was in for so long.
349. ... that first trip to the hospital and they didn't put me on medication thank God that time. Like I regret it ever since that they did. The second time I went in they did and they decided to dump heavy doses of medication on me and ... came out and then got dumped back into the same environment, I mean that hadn't changed. That was still there, my kids was still there, my abusive husband was still there, so that one thing didn't change. But in the meantime no body did anything

Appendix G:31

- 350. ... its quite interesting the way they treat your body as a separate entity to your mind. And I find that totally bizarre because I carry my mind with my body and in fact in my mind I can't split the two you know. This is this dualism stuff that they come cross with.
- 351. I should have been dealt with as a whole person and not this bit here and this bit here. And I found that even when they did treat me physically the people who were treating me physically weren't taking into account my state of mind.
- 352. Because it was always what I was going to do about the problem. Not about what the problem caused me to be like ... and acknowledging that outside my problem there were these other problems that really do need addressing in society. I was it. It was always this it was back on me. I acknowledge that I am the only person that can actually jump ahead. But I think my jumping ahead would have been a lot quicker if they acknowledged my pain and my feeling about that social stuff that that initiated all this.
- 353. I don't want drug companies involved in services and research. They are involved in too much of it. ... if you can get an organization that's not got the drug companies involved behind it then you've got a pretty secure bet, hopefully, that its going to be running on the lines of doing something as opposed to drugging something.
- 354. Yeah the biggest gaps I would say are they are too reliant on medication to fix everything when they could use psychology for psychological problems and I think they could be more inventive when it comes to activities to do with you in hospital.
- 355. ... looking at alternative medicine instead of being bombed out on psychiatric medication and
- 356. This is what we need to start doing. We need to start looking at things in a different framework because so long as they keep treating this with drugs
- 357. No. The only family therapy we got which I realized that's what I was told years down the track that's what it was with that abusive stuff and the mirror thing and I was drugged to the eye balls and they were asking all these stupid questions.
- 358. There could have been more alternatives. You know like psychology. Someone to talk to ... Herbal tea available. I mean that's a really basic. Yeah. I mean that's on a very, very minor scale. But it's still relevant. I mean normal tea is caffeine. It heightens.

LACK OF CONSISTENCY IN CARE

- 359. ... I rang up to speak to my case worker as they call them, and she's gone on holiday and I didn't even know that. So there's nobody there that you can actually talk to.

Appendix G:32

360. Oh! Totally! For me, for people like us where I've lived in 52 houses in ... 55 years, ... in my first year of life I had five houses. It is very disruptive. There is no consistency. And if you are coming from childhood where a child needs consistency and maybe if you've flipped back to being a child and there is no consistency there ... It's dreadful! I can't tolerate that anymore. I couldn't tolerate it. I just went along with the flow of it but now I've become more empowered I can't tolerate that inconsistency. ... it doesn't do anything to really help me. I actually feel worse.
361. I know my way around it now. But its always changing [referring to the mental health system].
362. ... after you get out of hospital you go to X Clinic which is a follow on and then I got another psychiatrist right who was great. She is no longer there ... which is another thing in the system that's really bad.
363. Then I had to see a new psychiatrist because there are changes in the system and I saw her for the first time last Thursday
364. ... you know they keep chopping and changing, you get somebody and then somebody goes and you just get this rapport and then piss off and then somebody else comes and you think "Oh God you've got to start this whole thing again" and it never really gets, its not that conducive to anybody finalizing some things, you know to actually talk about some things.
365. Well give me consistency. Instead of changing the doctors for me every three or six months, don't do that to me because that's disastrous sometimes and I can't tolerate that. I would not be able to count on my fingers, feet and toes how many doctors, because they change all the time.
366. Actually you don't get a relationship with the doctor because they come and go
367. It's hard to find. Umm there are some good nurses. There are some good doctors but few and far between and they seem to be moved around very quickly. Why? I did come across a good doctor and all of a sudden he disappeared.
368. But to get a bit of consistency and to be able to work through it is like you can't keep there in the sludge. Because in the end it becomes like when the dam breaks doesn't it. And when the dam breaks then you've got a lot more chaos to clean up around that dam when it is broken.
369. It's the same with the doctors. Well when I was in, before I saw a private psychiatrist, I used to see a new doctor every six months, so they have to reacquaint themselves too.
370. A case manager is a community nurse who comes out and sees you and gives you an injection if you need them or if you're like me, you just go out for a coffee and you talk about things and maybe structuring your life a bit more. ... I've got a case manager now, I've been seeing a hospital key worker for about two and a half years and I talk to them a lot about everything Oh I've had different people. ... Well they have this file which is about twenty foot thick ... and the new guy comes along and they say here read this

Appendix G:33

371. If you don't like them or if you don't get along with the person then its tough bikkies and you might have to wait for the shift that comes on that you like. And then they change them all over all the time anyway. Even if that next shift comes on that you're thinking that person that you've managed to engage and feel comfortable with might be on the other shift again. ... So it's not consistent.
372. He doesn't know anything about me. No look I tell you, I can walk into any GP ... I just go "I need some Prozac" and show them the packet and they give me it. ... I've done it. ... Nobody really knows. My notes are not with me. They don't know me from Adam. They just know me as X.
373. Oh yeah, just like going in for the Pill. It doesn't matter. I mean I haven't had my medication reviewed for about six years. Till I had a bit of a relapse. I just used to go into any old doctor ... but they are not up to date notes because I've been getting medication since in all those suburbs.

LACK OF APPROPRIATE TIME

Similarities

374. But he could only come in and spend two minutes with me. He had other things to do. [Referring to GP visit to the hospital].
375. But so-called psychiatrists, I would see them about ... once every week and a half.
376. Oh they just sit and chat with you a few minutes a day [nurses].
377. I mean with some people they need to talk to them more than once a week for an hour you know what I mean [referring to psychologist].
378. Well the nurses used to look at you and sometimes if you wanted to talk to them, like they either be too busy or they'd go outside and smoke with all the smoking patients outside
379. Well we haven't got time allocated ... like yesterday it was great I was just getting to the stage when its going to be really beneficial and then "Oh I really don't have any more time". It is difficult for them, That's the logistics of it.

Disparities

380. I guess the thing that impressed me the most was, apart from the psychologists who ran the programs were unbelievable, but the nursing staff that were in charge were out of this world. They were each assigned 4-5 per session and they would come and find you and say I'm your nurse for this morning or this afternoon and if you've got any problems please come and speak to me. And they would come and see you and check how you were and a couple of times when I was feeling really bad I would go and say, can you come and talk to me and they would come and sit, sit and talk, and discuss whatever was worrying me. They were unbelievable.

STAFF BEHAVIOURS

LACK OF UNDERSTANDING

Similarities

381. I expected them to be more compassionate. More understanding. More prepared to listen. But they weren't.

Appendix G:34

382. I guess not put limitations on how long you should grieve for ... that if I am still grieving about something that happened decades ago, don't worry about it, mind your own business ... Not have those limitations. Not have someone come up to you and say, "You're depressed but umm snap out of it".
383. They had no idea. No understanding whatsoever. [referring to nurses].
384. But it was down here on paper. [Referring to file accessed through Freedom of Information]. ... that people had written about me made me think You had no idea at all what I was going through. This is only one person's opinion on how I am and it was so totally different to what I was actually thinking and if you had asked me I would have told you and you would have found out why I was doing these things and it would have been more logical to you ... I mean there was this big thing on what's normal and what's not normal, what is appropriate behaviour and inappropriate behaviour. And I'm looking at this saying "X is showing inappropriate behaviour". How can that be inappropriate for my situation? That's their own opinion of what they would do in the same situation. [referring to bereavement and nurses' notations]
385. Just some acknowledgement actually that it wasn't my fault that I was like this. It was like as if I was being blamed for being like this. I wanted some acknowledgement. Acknowledgement for my pain, my pain, apart from the physical pain
386. This is why we have so much mental illness because we the people who develop a mental illness are the ones ... made to feel that it is our fault. That we are inferior. ... instead of addressing the issues that have brought us to this stage and validating our experience they don't.
387. Because it was always what I was going to do about the problem. Not about what the problem caused me to be like ... acknowledging that outside my problem there were these other problems that really do need addressing in society. I was it. It was always ... it was back on me. I acknowledge that I am the only person that can actually jump ahead. But I think my jumping ahead would have been a lot quicker if they acknowledged my pain and my feeling about that social stuff that that initiated all this.
388. I know how they think. And I know from my past experiences that I'm getting less and less safe enough to go [referring to accessing mental health services] ... you know we often get told "Oh well forget about it, put it in the past", but its in the past, we know that, but there's something in the present that's happening from grief and the loss
389. They don't understand and until you have actually been there maybe in that position, but then I think that comes down to attitude and training ... what they teach them. You know I think when you are dealing with people ... whether they've got a physical illness or mental illness you've got to treat the whole person and ... they treat you like children. They are so patronizing, its unbelievable. They think that you are senseless.
390. Oh not participating! And they put that in your notes you know. Whoa they wouldn't like that. Not participating in groups! Minus, yeah. Bonus if you do it.

Appendix G:35

Disparities

391. My doctor was okay. He was fairly sympathetic towards it because from what I heard his mother had severe depression and he grew up with it so he was really understanding about it.
392. ... he gave me real encouragement and he acknowledged he didn't have all the answers. And I think that was very important at that time. He would help me as much as he knew how to. He acknowledged he was a human being like me. [referring to social worker].
393. That was fantastic because he dealt with my condition in a really positive way, in the context of what it was but then he was also, well I thought my god you don't get too many of those ... [referring to psychiatrist].

LACK OF EMPATHY/COMPASSION

Similarities

394. I expected them to be more compassionate. More understanding. More prepared to listen. But they weren't.
395. Like some of the nurses are really terrible. No compassion. No nothing. Just like a robot and others mainly women, there was one nice Chinese man who was very gentle ... they didn't know what to do because I was just yelling.
396. ... to become a nurse one of the prerequisites ..., the first subject was science, when really it should be compassion you know.
397. ... the psychiatrist ... wasn't very good at putting me at ease. When I first got there he told me basically the effect my illness would have on my insurance policy and how I would have a loading for the rest of my life and even being in that slightly distressed state that I was, I thought that was a very strange thing to say to somebody who's obviously distressed, to talk to them about the long term insurance consequences.
398. Yeah like you're melodramatic. Like you're wanting to be in that space for sympathy You're wanting to stay in it for attention. So they get sick of you.
399. Yeah. Inappropriate. Inappropriate behaviour. And I found that really, really strange to look at that word and thought "How would you know what inappropriate behaviour is if you lost your son".
400. The doctors [laughter]? Interesting. My doctor, he, he didn't show his emotions very well and I thought gee I must be ill because I cannot see emotions in other people.
401. Ohhh [lengthy silence]. Well they weren't very good actually you know ... they were like robots actually. That's how I can explain it. They were a bit like robots and I'm not saying all of them but that was my immediate impression
402. This is why we have so much mental illness because we the people who develop a mental illness are the ones ... made to feel that it is our fault. That we are inferior. ... instead of addressing the issues that have brought us to this stage and validating our experience they don't.

Appendix G:36

403. You can have empathy. You have to as a service provider, this is it, you have to as a service provider trust the other person to be able to see it for themselves when they can reach that next step but give them support to do it. Not push them. Give them support to do it
404. Well they seem to work to a pattern. You know ... it's a pattern, it's not real, it's not genuine. They are not genuine. I mean I'm not saying they have to be genuine but I think if you are dealing with people who have emotional problems you have to be genuine. It can't be run by the book. Its like they picked up a book, oh we are going to do this first, oh yes we'll treat this first like this because it says so in the book. Oh god!
405. I know how they think. And I know from my past experiences that I'm getting less and less safe enough to go [referring to accessing mental health services] ... you know we often get told "Oh well forget about it, put it in the past", but its in the past, we know that, but there's something in the present that's happening from grief and the loss
406. All my life I feel that way and in those two weeks as well. Like I'm choosing to stay where I am because it provides me with attention and it provides me with sympathy.
407. Definitely. I would have been given pain relief you know. But if I was having a bad dream, its like well that's life you know. It would have been better for me to have gone into hospital and have something traumatic happen to me like having a couple of black eyes ... then I would have got sympathy ... like if I got in there and said my husband beat me up today, sure, but if I said my husband beat me up five years ago and I'm having problems with that, forget it, ... People have got to see that physical evidence straight away, that's the hard thing about mental stuff.
408. ... they haven't got the insight or ability maybe or they haven't got the empathy They don't understand and until you have actually been there maybe in that position, but then I think that comes down to attitude and training ... what they teach them. You know I think when you are dealing with people no matter what they've got whether they've got a physical illness or mental illness you've got to treat the whole person and, and they, they treat you like children. They are so patronizing, its unbelievable. They think that you are senseless.

Disparities

409. ... she came to see me three times in hospital with no charge just because she cared which meant a lot to me. And then when I got out she saw me three times without charging me either because she knew I needed to talk about stuff but I could not afford it [referring to private psychologist].
410. They are all very kind and gentle. [referring to nurses].
411. They are kindly and understanding to an amazing extent. They are also gently, gently firm. They will not, if they think you are lying around feeling sorry for yourself, they will try very hard [referring to nurses].

Appendix G:37

412. ... the occupational therapist was very good ... I'm not sure which country she came from, she wasn't Australian, she came from an Asian country. Its like all the Asian workers care. It's true though that is what we've noticed and we as consumers say that.
413. Yes. I could have got up in the morning and said I just can't go this morning and they would have probably said why do you feel like that and they would probably say look lie down for another 15 minutes and we'll see how you feel then. So they would have encouraged me to go but they would have respected it if I just couldn't do that.

REFLECTIVE COMMENTS

MANAGEMENT OF ILLNESSTALKING/EMPATHY/UNDERSTANDING

414. Even just sitting there. Just sitting there would do. Just sitting there.
415. I mean with some people they need to talk to them more than once a week for an hour you know what I mean. [referring to psychologist]
416. Counselling. That is the number one thing. If somebody had actually spoken to me it would have made a difference. I think that's the reason I wanted to get out so much because I was getting that at home. Everybody was talking to me and I had a lot of conversations with parents and friends and able to talk about him and with somebody else who also knew him and was also feeling really bad about the fact he died. But not in this situation. There was nobody there.
417. Counselling. Counselling. But then again you have to have the right counselor. I saw [private psychologist] more regularly and other people in the same situation. And support groups. That helped me a lot. Learning from them that other people whose babies had died years before and how they have gone through the processes and things like that was very helpful. But ... going into a psychiatric ward for grieving. It just doesn't seem normal.
418. I think in my case it was much more important to talk to somebody.
419. There's a mutual respect and mutual obligation. And that is when you can have a mutual obligation. When you have mutual respect then you have greater understanding [referring to therapeutic relationship with counselor].
420. Well it comes from the dialogue you have with the other person you know the counselor and you're coming up with stuff ... they acknowledge stuff ... if they are good listeners, and good thinkers ... and it might not be too clear to you but ... they can suddenly articulate that feeling that you've got inside you and ... You feel safe. You think oh god they do know what I'm thinking about because people can tell me "oh you should be so proud of that" but unless I'm actually feeling it then its bloody nothing to me. So ... by listening and having ... mostly feelings, having acknowledged that feeling and even acknowledge that feeling they don't understand by saying "I really don't know what you are on about, and I really don't understand. I wish I did. Maybe we could talk more about this and maybe I will gain an understanding". It has got to be a reciprocal thing. It can't be anything else.

Appendix G:38

- 421. [Value in seeing psychologist] Of course... support, understanding, listen, care, validate, normalize, lots of stuff.
- 422. Well have psychology. You know people available to talk.
- 423. A place to go that is not a psychiatric unit where people are suffering from a range of anxiety and depression rather than severe mental illness like schizophrenia or psychosis and so on and to let them be looked after and to stabilise in that situation. To remove them from the stresses of their lives and to just nurture them to the point where they can go back into their life and start functioning again. And certainly I think intensive therapy is extremely important.
- 424. I think heaven for me would be a hospital where people who really wanted to be there and are caring ... and its sort of a place where you can come together quite quickly instead of being jam packed in somewhere and ... everything is like it was in the seventies ...
- 425. Yeah. I do find that helpful. It's the first time I've seen one. [referring to psychologist]
- 426. And its not tracked back enough and there's no screening done and quite often a person may not come up with it straight away. I was lucky enough, fortunate enough, to be broken down enough to come out with it straight away
- 427. Yeah the biggest gaps I would say are they are too reliant on medication to fix everything when they could use psychology for psychological problems
....
- 428. I haven't had any help for about eight or nine years counselling. I have been my own counselor. I have gone outside the system because there's nothing in that system that really, really addressed what I was looking for inside myself. I had to search for that myself.

BIOPSYCHOSOCIAL APPROACHES TO CARE

- 429. My ideal ward would be somewhere where you could ... like you had your own nurse, because it is a very intensive experience, having an episode. ... maybe somewhere in the country, away from the city, umm and maybe looking at alternative medicine instead of being bombed out on psychiatric medication and ... the biggest thing I would really love is when you are there do some groups or activities that are really realistic instead of just cutting out squares and sticking them on paper
- 430. I think there needs to be a collaborative approach with consumers ... we have got to be doing with all issues of social things and this includes mental health because it is so disparate, they box everything. They've got mental health there, delinquency there, child welfare over here, this here, all these little boxes and nothing ever meets ... we are talking about somebody's physical and mental health they cannot be divided and mental health is part of everybody's lives

Appendix G:39

431. I think to address mental illness you have to address the emotional aspect, the intellectual aspect, the physical aspect and spiritual aspect. And the sexual. You cant, just, it cannot just be on the mental level because the human being is made up of different, its not one part you know. You have to address the whole person.
432. Because it is too enormous a problem and it scares people. Because when you start dealing with this ... you are not only going to be dealing with mental illness, you are dealing with drug abuse, alcohol abuse, people in prison, rapists and you've got to be dealing with people who are at war.
433. ... well there are all categories of trauma umm I think that we would need to be dealing with two issues here because the trauma obviously precipitated the person's having the emotional unwell being ... mental illness or whatever you want to call it, I think we cannot deal with just that mental illness ... you just can't deal with alcoholism you have got to deal with why they are drinking the alcohol. So why is a person keep getting mentally unwell. I mean nobody likes to be mentally unwell and if its stress that is bringing on the mental illness where is the stress coming from in the first place.
434. I think they could be more inventive when it comes to activities to do with you in hospital. I'd like to see the banishment of locked wards but I suppose that's a piped dream
435. ... this comes to do with structured systems and the way they are governed and the way they are. It is a philosophical thing. It is an organizational thing. It is a cultural thing.
436. The problem with things we are so entrenched with institutions and its like there's this little square box and ... if people within the institution would start thinking outside that square box and make it round and not this contained thing and make it a circular thing that allows you to slip in and out, oscillate, it is far beneficial ...
437. I think what they really need to do is action based research. You know proactive stuff. Not this inactive, sitting around with bureaucratic biscuits

ENVIRONMENT

Similarities

438. Yeah it was nice. It was nice, ... just sitting outside and there was a little garden out the back so that was fairly quiet and tranquil.
439. When you enter the [Hospital] you don't feel like you are entering a psychiatric unit.
440. It came through right from the beginning. When you walk in, there's nothing, when you walk into [hospital] there is nothing that indicates that you are entering any sort of medical facility. You could be in an office of any description.
441. Yes. That's right. First off the nursing staff are not in uniform. I think the reception staff do ..., but it is all very informal, all first names.
442. ... you walk into the room and you feel like you are in a hotel. The only thing that you would know that you are in any sort of hospital facility is the call button in various key spots.

Appendix G:40

- 443. That was an open ward. That was a lot better. They had activities that you could do.
- 444. The outside area was quite nice.
- 445. The only way I was recovering was that I was getting plenty of sleep and a rest and a break from the home and the kids you know.
- 446. Just the physical rest.
- 447. I just thought that it was the utmost wonderful place on the planet.
- 448. I think it is just a wonderful place
- 449. It is a good basic service but I would not say anything beyond that. It is a basic, good basic, solid basic service

Disparities

- 450. ... there was a lovely garden, had a gazebo in it but they had it locked.
- 451. Umm no. No I can't [unable to relate positive aspects].
- 452. Like all the hospitals I've been in its like living in the 70s.
- 453. Totally bloody worthless, well I felt like I was going mad. I felt as if I was actually going mad
- 454. They've got young people in there which I think is totally inappropriate having the young people with the oldies because they put this music on, you know this head banging stuff ...
- 455. ... oh its dreadful that place its like Nightmare on Elm Street.
- 456. ... there's too many but the main, some that stand out are, you often get into fights with people because you're both ill, physical fights, and often you're given the wrong medication and that can make you a lot worse. You know I'm allergic to a particular medication and often they give it to me. So that's a negative.
- 457. I was put in a four bed room with old ladies you know and like they were senile and you know all the stuff that goes with old people and I did ask to be moved because ... I ... thought one of them was going to die any minute

INTERACTION WITH STAFF

Similarities

- 458. But I can't say there was anything good about the system as such. I can only say there was something good about that particular individual at that time of my need.
- 459. The doctors were the most positive aspect of me being in hospital.
- 460. Probably the most positive thing was at night like the nurses would come and go through with you what you were thinking about and that sort of thing. That was one thing I found very useful.
- 461. In fact I actually phoned my friends from the [psychiatric hospital], close friends, and said to them you must book yourself in here for a week. This is the first time that I had time out in 22 years and I think we all deserve it. And somebody to care for you and look after you and, and nurture and be concerned only about you. Not too concerned about anybody else in the family ... they are just concerned about how you are.

Appendix G:41

462. ... I suppose the positive thing is they did get me to a stage where I could actually function and in the sense that I was able to go home and cook a meal and do those sorts of things. It got me to that stage where I wasn't dependent upon the hospital. That was one good thing.

463. They encouraged me and got me to the stage where I could take the next step

....

Disparities

464. I find that 'consumer' a strange word but I had no intention of being there and I don't know why I was in there anyway. And I wasn't treated very well while I was there and it was just a balls-up.

PARADOXICAL STAFF BEHAVIOURS

Similarities

465. I was in hospital when I had a miscarriage years ago. Its just amazing the difference. The compassion. It's just different.

466. Of course!

467. Oh like they can look busy when they are hovering around you, checking your stitches and doing this and doing that with the baby or you. But when you are in there because of a mental problem, there's nothing for them to do.

468. Definitely. I would have been given pain relief you know. But if I was having a bad dream, its like well that's life you know.

469. Oh god yes!

470. Well they actually like you. [Laughter]. Everybody likes you when you are a patient, a physical patient. They can cope with it. Yes. [Laughter] I'm sorry but this is my perception.

471. Well they don't patronize you. They ask you what you want. What you need. [referring to stay in general hospital]

472. Well not really. Well no. No they don't. They don't. They don't ask you what you want and what you need. [referring to stay in psychiatric hospital]

473. Bugged if I know. They just give you things. I wasn't asked whether I wanted medication when I first went into hospital. They just came along with this trolley you know and suddenly "Take this".

474. Two different experiences. Totally different.

475. Oh you mean like being in the hospital like a normal patient with physical things? Oh they treat you as a person. [laughter] You get towels every day, you get asked how you feel and you can actually say how you feel. "I'm in a bit of pain" and they'll believe you and they'll do something about it. It's different.

476. No. They just bring you what, if you didn't mark your lunch order, they'll just bring you anything because it's too late. Surprise! You get what you're given because you should have been up to do it you know, like, you know you have to do this.

Appendix G:42

477. Now I've got a heart problem, and they still didn't, nothing. Now that's weird because if I was in an ordinary ward and they would have taken me off to get an ultrasound, and they would have come back, maybe even shown me the X-rays, I don't know they would have certainly given me some notes or something. But I've gone back to thinking well, okay No. No. I haven't seen anything [laughter]. Probably I should, I should ... [referring to results of X-rays].

Disparities

478. They are very, very different. The nursing staff at the [general hospital] are also very nice but it's not the same. There is an element that applies at the [psychiatric hospital] of genuine, real concern about how you are. The [general hospital] is excellent and I'm not knocking it in any way and I'm simply saying ... that they check you and you might get a nurse who will have a little chat with you if you have established a rapport but basically they've got all these duties to do and they are going to come in and do all those duties.
479. Well I had my children in England under the National Health system. So you are just a number. My experiences having children under the NHS were, I mean it was just a baby producing system and it wasn't incredibly positive. And it was very sergeant-majorish. ... So that was very regimented.

INADEQUACY OF SERVICESMORE SERVICES

480. Respite centers. Respite services definitely. More qualified people down there [in the country].
481. There could be more services available on the weekend because mental illness is not confined from Monday to Friday, nine to five.
482. The only thing is that they are trying hard to deal with mental health in the community but I think sometimes they often get money, but they spend it, the nurses and doctors spend it on themselves rather than on the patients. ... for instance like I've got a case manager who comes out here, he's always getting a new car or new telephone, new mobile phone but I don't get any trips or anything out of it.
483. ... we need somewhere, when you have had forty odd years [participant distressed]. ... Yes very difficult. When you've had a lifetime basically things like this and yet you can still function but you can't form relationships not even with your own children and you go to mental health places and they say "See you in six weeks". Six weeks! Hang on, its taken forty odd years to get here
484. So four police people carried me downstairs into the back of a paddy wagon and I don't have any recollection of because my mum and my sister followed the police car to [Hospital] because they had called PET and they wouldn't come ... and I don't know why [participant was diagnosed with psychosis].

Appendix G:43

485. One of the things I would really like to change if I had any say in the matter is, is the PET team which is the Psychiatric Emergency Team, its only about four people, but you ring them up and say oh my friend's just had an overdose or you know I'm really going out of it, but they only come around these days when there's a police emergency
486. ... it seems like there's only four people [re PET team]
487. Well they only seem to come out when you are on the verge of committing a criminal act like you know I rang them before when I had a friend who had overdosed and they didn't do much and yet when I filled my flat up with water and I nearly assaulted someone then they came around, so I don't know how they make the distinction
488. ... spend time at community gatherings, trips somewhere with people who have an illness or improving the hospital

CONSUMER GROUPS/SELF HELP GROUPS

Similarities

489. No nothing. Once you leave the hospital, that's it boom. You know there's no other group that they suggest you go to.
490. No. I just go to my GP.
491. And I don't know. I don't know. I haven't been given any literature.
492. Not that I am aware of.
493. Oh yeah but I don't belong to those groups. [consumer groups]
494. Well, I'm in a support group at the moment but I wouldn't like to do it for that long but its just people have a lot of problems and you end up finding out too many problems
495. I eventually went into an OCD support group which was nothing much ... So that didn't help. So I come away from there feeling like shit.
496. You know there's no other group that they suggest you go to.
497. Yeah. But they are so negative. I don't want the negative stuff. I don't like, its so negative

Disparities

498. ... this came out in the individual therapy sessions, there were a lot of long term beliefs that I had about myself and things that had happened to me that that really needed that individual attention because they were so deep and in groups you can get to surface things but you cant really always get to the things that are the root of your self-perception.
499. I saw [private psychologist] more regularly and other people in the same situation. And support groups. That helped me a lot. Learning from them that other people whose babies had died years before and how they have gone through the processes and things like that was very helpful.
500. ... the upside of the group experience is being with people who have been through similar things and you realize how common your experience is whereas when I was feeling at my worst I felt really very alone and its good in a way to see that there are other people who have had similar experiences that can often relate to the things that you are going through.

Appendix H: Excerpts from National Standards for Mental Health Services
and
Recommendations from the National Inquiry into Human Rights and Mental Illness

National Standards for Mental Health Services

Standard 2 – Safety: The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

2.2 Treatment and support offered by the MHS ensure that the consumer is protected from abuse and exploitation.

Notes and Examples: Safety is considered in terms of physical, social, psychological and cultural dimensions. Consumers are protected from financial, sexual and physical abuse.

- The other people that I was with, it was very scary. Because I didn't know what they were capable of and if they are in there then I don't know why I am in here. So if they are in there, they are obviously suicidal or have ... really bad problems and some of the looks ... some of the statements were made to me were very scary. And threatening. ... Threatening, some of those patients. (Quote No. 88)
- Because they thought it was a drug induced psychosis ... one of the reasons why it kept happening was because just after I got admitted into hospital I got beaten up by another patient So that just worsened my psychosis of feeling that everyone was out to get me. (Quote No. 115)
- They threatened me with a needle. If I didn't shut up. Because I was yelling at security ... because in my mind ... I should feel safe in a hospital whether I'm in a psychiatric hospital or in a normal hospital ... I should feel safe and I'm not safe [referring to physical assault by another patient]. (Quote No. 90)
- ... there was a man ... who used to get very confused ... he used to walk around with an erection and he really scared me because he used to keep walking into people's rooms. (Quote No. 91)

2.6 A consumer has the opportunity to access a staff member of their own gender.

- We keep telling them we don't want to see a male doctor or a male nurse. But we keep having to see them. And they keep saying there's not enough to go around. That's fair enough, there's not enough to go around but we don't want to see them. (Quote No. 160)

Appendix H:2

Standard 5 – Privacy and Confidentiality: The MHS ensures the privacy and confidentiality of consumers and carers.**5.3 The MHS encourages, and provides opportunities for, the consumer to involve others in their care.**

Notes and Examples: Family, carer(s), friends, significant others, home visits are available, adequate private space for visitors is provided and visiting times are convenient, play space for children, involvement of General Practitioners, private psychiatrist and/or other person nominated by the consumer.

- Well sometimes I've been in to talk to a psychiatrist in the hospital and I've said I'd like to see a GP and that's hard, I didn't get a GP in. You only see the Board of Visitors come around once a year so(Quote No. 239)

Standard 10 – Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.**10.5 Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered.**

Notes and Examples: Files are audited regularly.

- They gave me the wrong medication. A man died in front of me, had a heart attack in front of me. And that just made me think oh shit they are just using this man as a guinea pig. ... they are just playing games ..., that was my fear.
- ... and often you're given the wrong medication and that can make you a lot worse. You know I'm allergic to a particular medication and often they give it to me(Quote No. 181)

**Standard 11.4C – Medication and Other Medical Technologies
Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.****11.4C4 The consumer and their carers are provided with understandable written and verbal information on the potential benefits, adverse effects, costs and choices with regard to the use of medication and other technologies.**

Appendix H:3

- No Largactil or Merralol. Usually Largactil. And they have also given me that Alanzopine ... I found out from somebody else, way down the track after I had been taking it, that anyone who has breast cancer in the family shouldn't take it. Well my mother died of breast cancer. And they were giving me all this stuff. And I've gone in on the internet since and I must admit, pressing all the buttons and looking at all the drugs what they do and what they don't do, and I'm saying hang on they're not telling us this. The pothiadin that I take, I was having a nerve conduction test ... and the doctor ... in the medical ward said to me, have you had a blood test lately. I said no. Ahh he said maybe you should go and have a look because you are bleeding funny. ... I was covered in bruises ... I went off for a blood test and ... there was something wrong And then I went ... and said to the pharmacist ... what are the side effects. He said the worst side effects are bruising, low white blood platelets and all this other stuff. Blow me if I wasn't having all these side effects and they hadn't checked me. (Quote No. 179)
- No they don't tell you. All they tell you is dry mouth, blurred vision basically. Now I know the Epilim, my son used to take it for epilepsy and I'm supposed to have liver function tests done. (Quote No. 180)

Recommendations from the National Inquiry into Human Rights and Mental Illness

- Medication should only be administered for the welfare of inpatients and to alleviate the symptoms of their illness. Staff in hospitals should never use medication as a 'management tool'. (p. 915)
- Alternatives to medication should be considered wherever appropriate. The views and preferences of the consumer should be considered at all stages of the treatment process. (p. 915)
- Attempts must be made to minimize the occurrence of assaults and abuse in hospitals by employing sufficient numbers of skilled psychiatric nurses and other mental health professionals committed to establishing therapeutic relationships with inpatients; by avoiding overcrowding or inappropriate patient mixes in wards and by working to defuse tension and create a positive living environment. (p. 915)
- A treatment plan should be drawn up for each inpatient as soon as practicable after admission. The plan should be regularly reviewed in consultation with the individual wherever this is possible. (p. 916)
- Greater emphasis should be placed on environmental and psychosocial factors in the diagnostic process. (p. 931)

Appendix H:4

- GPs and mental health professionals should provide patients with clear and comprehensive information about:
 - a) drugs which are being prescribed (including possible side effects and/or addictive potential);
 - b) alternative non-pharmaceutical treatments. (p. 931)