FACTORS LEADING TO FREQUENT READMISSION TO VALKENBERG HOSPITAL FOR PATIENTS SUFFERING FROM SEVERE MENTAL ILLNESSES

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master in Public Health in the School of Public Health, University of the Western Cape.

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care pathways



ABSTRACT

Factors Leading To Factors Leading To Frequent Readmission To Valkenberg Hospital For Patients Suffering From Severe Mental Illnesses H.M. Smith

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This descriptive and analytical mini-thesis aimed to explore systemic health service problems that are related to frequent readmission of persons suffering from severe mental illnesses to Valkenberg Hospital through a comparative study of perspectives of mental health service providers and consumers. Reduction of acute and chronic beds in the Associated Psychiatric Hospitals, Western Cape over the past decade has led to increasing pressure for beds and rapid inpatient turnover, many of these inpatients being 'revolving door' patients. Integration of mental health service into general health services, an intrinsic part of the comprehensive primary health care (PHC) approach in South Africa, is supposed to make mental health care more accessible to the public, therefore research into why patients are being frequently readmitted at secondary specialist level is indicated. Qualitative data was collected during September/ October 2004 from six in-depth interviews with service users and two focus groups with service providers. Emergent findings were that the health service platform provides insufficient protection to families against violence associated with mental illness, insufficient mental health promotion and psychosocial rehabilitation, insufficient community support systems with poor community tenure for mental health care users, care pathways need much improvement and staff resources across the mental health platform are inadequate to address the 'revolving door' problem. Resources have not been put in place at PHC level. As result of lack of comprehensive mental health care patients are rapidly revolving through Valkenberg Hospital. This indicates that deinstitutionalisation and devolvement of mental health care cannot work without provision of the necessary infrastructure at community level. It is hoped that this context specific, small-scale study will sensitise service providers, programme managers and inform policy makers to the root causes of frequent readmissions to Valkenberg Hospital with a view to informing further research and improving mental health service provision to the public.

DECLARATION

I declare that ... is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Helen Mary Smith	May 2005
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Signed:	

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CHAPTER ONE: INTRODUCTION

Incorporation of mental health services into the primary health care approach in South Africa is in a difficult stage of transition. Mental health, along with other health services in the Western Cape, was challenged with the necessity of rationalisation with the 1994 provincial health plan. A Provincial Cabinet Resolution in 1998, the result of public lobbying against Valkenberg Hospital closure, led to restructuring into the Associated Psychiatric Hospitals and reduction of psychiatric beds mostly through de-institutionalisation of long term patients but also closure of acute beds across the four psychiatric hospitals in the Western Cape.

Consequently the acute psychiatric units at the four psychiatric hospitals in the Western Cape are cur rently experiencing a crisis with the unremitting influx of psychotic patients from the Metropole and rural areas, and neither staff nor bed capacity to admit more patients. The Healthcare 2010 plan for the Western Cape specifies that human resources be de volved together with patients to primary health care (PHC) level, but staff patient ratios are such that the staff capacity to devolve to PHC level does not exist at Valkenberg or the other Associated Psychiatric Hospitals (APHs), all of which are classified as secondary regional hospitals with specialist functions of psychiatric treatment. Although hospital beds have decreased, the number of acute admissions per annum to the hospital has increased. This is accounted for by the increased flow of population into the Western Cape as well as higher patient turnover. The higher the turnover of patients, the higher is

the cost of human resources and therapeutic drugs in respect of diagnosis, treatment, rehabilitation and discharge with sufficient medication.

Mental health legislation makes provision for involuntary admission to designated health establishments of persons who are assessed as mentally ill and a danger to themselves or others. Therefore Valkenberg Hospital cannot refuse patients admission or put them on a waiting list in order to retain patients who are inadequately stabilised on treatment. Where further stabilisation of these patients who are discharged to PHC level then fails to take effect, rapid relapse and readmission within weeks of discharge is all too frequently the result. It could be that the 'revolving door' syndrome and high chronic morbidity is a cyclical effect of inadequate mental health services due to scarce resources at both hospital and PHC level. Whilst rectifying the problem of scarce resources may at this stage elude us, perhaps there is scope for improving referral pathways in the vulnerable transition period between Valkenberg Hospital and PHC level. It is important to establish how consumers can be treated effectively at community level and what impediments are experienced.

National health policy of treatment at PHC level, and our mental health legislation are not contradictory policies. The new Mental Health Care Act 2002 emphasises the least coercive form of psychiatric treatment and accessible primary health care. Both the Mental Health Care Act 2002 with its emphasis on human rights and Healthcare 2010 compel service providers to deliver better mental health care despite scarce resources and to integrate mental health care within generalist health services. The underlying principles of Healthcare 2010 in addition to the above

include deinstitutionalisation of chronic care, collaboration between all levels and cost effectivity. But it is not cost effective if a certain proportion of patients are frequently readmitted. Does this mean that these patients and their caregivers find PHC "inaccessible" in respect of treatment efficacy, and is there adequate intersectoral collaboration in respect of social needs like affordable housing for people who are disabled by chronic mental illness and on State disability grants?

The Healthcare 2010 configuration allows for 80 per cent of resources to be allocated to PHC level and that admissions will not be reduced instead patients will be devolved to other levels of care. Concerns are what share will be allocated to mental health care, and how 80 per cent of mental health contacts are going to occur at PHC level, given that so many patients are non-compliant on treatment and only come to Valkenberg Hospital as involuntary patients. Can frequent readmissions to Valkenberg hospital be reduced through provision of more resources at PHC and community level? Healthcare 2010 policy says that reduction of psychiatric beds will afford greater community based care for patients with mental illnesses with additional R50 million funding. Yet ironically at Valkenberg Hospital we may be 'putting the cart before the horse' if we are reaching our Healthcare 2010 targets ahead of resource allocation for increased community based care at PHC level.

Concern is mounting at service provider and consumer level regarding inadequate public health provision for the needs of the severely mentally ill and their carers. It is hoped that modest findings of the mini-thesis would contribute to current local research with positive implications for mental health service provision.

PROBLEM STATEMENT

Current public health services at secondary specialist hospital and PHC levels are inadequate to address needs of carers and clients suffering from severe chronic mental illnesses as indicated by frequent readmissions for acute inpatient treatment. We have insufficient knowledge regarding factors responsible for frequent readmissions or how best to solve the problem, given the scarcity of human and material resources.

AIM

To explore factors related to frequent readmission of patients suffering from severe mental illnesses to Valkenberg Hospital, Western Cape.



OBJECTIVES

- To explore perceptions of care giving relatives regarding factors leading to frequent inpatient readmission of persons suffering from severe mental illnesses to Valkenberg Hospital.
- To explore perceptions of mental health care users regarding factors leading to frequent inpatient readmission of persons suffering from chronic severe mental illnesses to Valkenberg Hospital.
- To explore perceptions of service providers regarding factors leading to frequent inpatient readmission of persons suffering from chronic severe mental illnesses to Valkenberg Hospital.

- To compare the perceptions of service providers to perceptions of consumers of services for patients suffering from chronic severe mental illnesses.
- To make recommendations to various stakeholders for further research and provision of better services to mental health care users and their carers.

The thesis will describe the international and local literature as regards the 'revolving door' trend that has followed in the wake of deinstitutionalisation. The topic is investigated from a qualitative perspective on what mental health consumers and service providers regard as factors pertinent to the 'revolving door' pattern of readmissions to Valkenberg Hospital through use of in-depth interviews and focus groups. Thematic presentation of salient findings from a wealth of data, will be followed by discussion of the implications, challenges and recommendations for delivery of more effective mental health care and rehabilitation, with due respect for the limitations of a mini-thesis.

CHAPTER TWO: LITERATURE REVIEW

TRENDS IN MENTAL HEALTH POLICY INTERNATIONALLY AND IN SOUTH AFRICA

Mental health is a neglected area of public health services in the United Kingdom and internationally, according to Thornicroft and Strathdee (1991), who discuss the Health of the Nation report based on a 1989 public health survey of English districts and how mental health issues have been historically sidelined. WHO Health for All by 2000 mentions one mental health goal of reducing suicides but sadly does not discuss other goals. They say "mental health targets should extend beyond mental illness services, and should include the domains of prevention, promotion and the psychosocial aspects of general health care." (1991: 410) They draw attention to the high mortality rate for schizophrenia, more than double that of the general population, and also cite surveys of 26% of the population who consult family doctors yearly for mental health problems. Further they note that social factors such as unemployment play a key role in psychiatric mor bidity and the need for more intersectoral collaboration is identified. They state clearly that mental health services need to be more central to primary health care for this large group of the population whose disability leads to marginalisation and poverty. (Thornicroft and Strathdee, 1991: 408-412)

As alluded to above, mental health services are relegated quite low down the list of public health priorities in all countries. Users of mental health services in the severe categories of illness constitute the poorest of the poor and are characterised

by downward social drift internationally. As such it is important to consider equity of health service distribution to the mentally disabled.

Thornicroft and Tansella (1999) have done extensive work in the field of public mental health and promote a matrix model regarding appropriate levels of interventions, in respect of mental health prevention, treatment, promotion and rehabilitation for individuals and populations (see appendix 2), but point out that their research has been done within the developed world paradigm (: 2). They discuss the need for mental health practitioners to incorporate a public health approach alongside the individual-health approach for provision of services irrespective of client ability to pay; and that responsibility for coordination must lie at region and country level. They discuss the public health impact of mental disorders according to criteria of frequency, severity, consequences, availability of interventions and public concern (ibid: 15-18). Severity of impact is expressed by the global burden of disease for neuropsychiatric conditions, which calculated in disability adjusted life years is 10.5 %, exceeding that of cardiovascular conditions at 9.7 % (Murray and Lopez, 1997a in Thornicroft and Tansella, 1999: 18). They argue further that mental health care should be an integral part of mainstream health care (ibid: 19).

There is a dearth of literature on 'revolving door' patients in South Africa as an emerging country, comparative to the developed world. Saxena et al in World Psychiatry (2004), a free electronic access journal that assists mental health research in developing countries, argue that most mental health research has been done in high income, developed countries and as such may be irrelevant to the

needs of developing countries in that the socio-economic and cultural contexts are extremely different.

Patients with severe mental illnesses are assessed and treated at specialist health care level but need ongoing long-term treatment follow up at community PHC level if frequent readmission to psychiatric institutions is to be prevented.

Baumann (1998), a senior specialist psychiatrist at Valkenberg Hospital discusses the harm that has resulted from the separation of psychiatry from general medicine in previous decades, leading to fragmentation of care and inaccessible health care services, "inappropriate to the needs of the majority of people in southern Africa." (: vii). He says the following of severe mental illness:

"Psychotic disorders represent the most severe forms of psychiatric illness, and can cause extreme distress and disability over long periods of time. These disorders are nevertheless treatable and relapses are preventable. Pharmacological treatment is necessary to control symptoms but psychological support and social interventions are also required to improve the quality of life and prevent deterioration in functioning. Fear and ignorance add to the burden of suffering. The primary health care worker has an important role to play in alleviating the burden, in educating and supporting families and communities, and through appropriate and rapid interventions, preventing further and unnecessary suffering." (: 340)

Chopra et al (1998) discuss all major health problems in South Africa as entrenched in "poverty, inequalities and disempowerment", for which reason the comprehensive PHC approach was adopted as most appropriate for the needs of South Africa's citizens. They warn that the proposed 'core package approach' to PHC service provision in South Africa is in response to external pressure from the World Bank towards selective PHC. This is driven by "economic policies of strict monetary controls, encouraging the privatisation of health care delivery and the

cutting back of State services". (: 1563). Extrapolated to mental health care selective PHC disguised as comprehensive PHC would provide for the bare bones of psychiatric treatment without broader fleshing out of social care to address the underlying causes of ill health. We can therefore expect the 'revolving door' to continue, and worse yet for some people to receive no treatment at all if such issues are ignored.

The Department of Health, Primary Health Care Package for South Africa – A Set of Norms and Standards (September 2002), is the central policy document that details what level of care consumers can expect to receive at PHC level. Norms given for mental health are (paraphrased):

- Regular visits to clinics from mental health or psychiatric nurses from health centres, hospitals or mobile teams.
- At least monthly access to specialist mental health expertise from district or regional level
- Each clinic has a member of staff who has received continuing education in mental health or psychiatry in the past year
- Each clinic has a minimum of one person trained in counselling and treatment of victims of rape and violence.

There are accompanying standards (paraphrased) in respect of:

- Availability of mental health policy documents, assessment guidelines, emergency protocols, essential drug list, and current mental health legislation admission procedures.
- Essential drug list medicine and supplies
- Competence of Health Staff
- Patient education, empowering and destigmatisation
- Requirements for record confidentiality and data availability of local mental health indicators
- Community and home based activity ensuring staff involvement in local community structures
- Collaboration with other services, like traditional healers, community organisations and the hospital.

Mitchell (2003) concluded a small scale situational analysis in December 2003 for Associated Psychiatric Hospitals (APH) of mental health services in place in the Western Cape at community clinics, the aims of which were to identify areas for improvement and to assist comparison with future models of service delivery.

The main themes identified in her conclusions are paraphrased as follows:

- Access to a multi-disciplinary team was inadequate with too high a discrepancy between required and actual staffing levels.
- Referral pathways were not moving towards the Health Care 2010 model
 that stipulates the use of district and regional hospitals where possible.
 Instead most clinics referred only to psychiatric hospitals, chiefly because
 the other hospitals are not equipped with the necessary secure rooms, or
 adequately trained personnel. 33% of clinics were unable to follow up
 noncompliant clinics.
- Many psychiatric nurses felt inadequately supported by the employer, and most felt that training was inadequate.
- More training in mental health for generalist nurses would support psychiatric nurses and also reduce stigmatisation at clinics.
- Most nurses felt unsafe in their consulting rooms due to absence of panic buttons, and often being situated at a remote part of the CHC away from security guards.

On the positive she reported integration of mental health into generalist community health care, and staff committed to improved client care. She also identified a good support network between psychiatric nurses, availability of essential drugs, commitment to avoid unnecessarily referrals to psychiatric hospitals, good relationships with clients, support from the CHC medical officer, in many clinics integrated folders and psychiatric patients waiting alongside general clients, availability of group therapy, many nurses do home visits, access to emergency medication protocols and treatment guidelines. Aspects not covered but recommended as meriting study were substance abuse, user perspectives, treatment compliance and readmission rates, and accessibility of care. (Mitchell, 2003: 1-62)

New legislation, the Mental Health Care Act 17 of 2002 came into effect 16

December 2004, and is of the most progressive anywhere in the world, with strong emphasis on human rights. The Act emphasises accessibility of mental health service delivery close to people's homes. Implementation of the Act is parallel to many Healthcare 2010 planning issues. This puts mental health care practitioners in the decision-making role of whether or not patients are admitted to a psychiatric hospital, first time or readmission as the case may be. The role of professional nurses at both community and hospital level has become far more prominent in this respect, also that of other multi-disciplinary staff. Committal for involuntary psychiatric treatment is no longer arbitrated through the Department of Justice.

Instead the Head of the relevant psychiatric establishment has subsumed the role that a magistrate previously played.

'Risk assessment' and managing the risk of violence with people suffering severe mental illnesses who live in the community is a problem that is receiving increasing focus. This is especially the case amongst a sub group of patients who have a 'revolving door' pattern of recidivism back into psychiatric hospitals, and who have poor treatment compliance. Thus a counter argument is that frequent readmission is not necessarily a bad thing in that the individual is treated, the public protected, respite provided for care giving relatives and cost effectivity is better than for long stay. A study in North Carolina on a sample of 331 involuntary outpatients with major mood disorders and psychotic disorders, looked at the specific circumstances and the surrounding characteristics of violent incidents. Violent behaviour was found to be present for half the sample in the 4-month period preceding a rehospitalisation and multivariable analysis found a significant

association between violent behaviour and co-occurring substance abuse, criminal victimisation and younger age of the respondents. Diagnosis and symptomatology were not found to be associated. This and other such studies raise questions of priorities for service delivery and need for further research. (Swanson et al. 1999: 185-204). It is of interest to consider a case review of New York State "Kendra's Law", August 1999. A patient with schizophrenia killed a young woman after having been repeatedly turned away when he sought psychiatric treatment in state health facilities, including the long-term psychiatric wards, despite a long history of violent episodes. "Kendra's Law" has enabled physicians, case workers, relatives or other interested parties to obtain a court order whereby a mentally ill person is obliged to comply with treatment and it is mandatorythat mental health institutions grant treatment. This was accompanied by legislation that ensured provision of funding for the financially depleted state mental health services. (Rottgers, H. & Nedjat S., 2001)

THE INTERNATIONAL TREND TOWARDS DEINSTITUTIONALISATION

Levine (1994) decries deinstitutionalisation as practised over the latter quarter of a century, argues against creation of resources at community level, and says that a considerable percentage of 'schizophrenics' need long-stay institutionalisation in 'asylums'. He rather disparagingly discusses poor compliance with rehabilitation programmes, substance abuse, and impulsive suicide, antisocial and criminal behaviour. Yet perhaps insufficient public funding is made available for the socioeconomic needs of the severe chronically mentally ill. The article makes clear that effective community care probably costs more than institutionalisation, but does

not say that greater long-term rehabilitation benefit to the client would be worth the added expense. (Levine, S., 1994: 39-42)

Global deinstitutionalisation of patients and reduction of bed numbers in psychiatric hospitals has not been an unmitigated success. Powell et al. (1995) conducted a four-year survey of Greater London's acute psychiatric units to measure bed occupancy. They found that whilst there was a steady reduction in bed numbers of 10.3%, occupancy rates had become unacceptably high, increasing by over 7% over the 4-year period. A significant finding using the Jarman UPA Underprivilege Score was the strong positive correlation between degree of social deprivation and level of bed occupancy, supporting previous similar findings of other authors. In many cases beds were 100% occupied. Literature supports occupancy rates of 70-85% as acceptable. Problems identified with high occupancy were hidden costs with contracting patients out to private hospitals, premature discharge of patients to unsupervised environments and 'new long stay' patients as many as 31% housed on acute wards. Careful pla nning and monitoring is required to ensure balance in the adequate provision of acute beds in relation to supportive community infrastructure. (Powell et al. 1995: 765-769)

Shepherd (1998) reviewed the literature on what effects reduction of long stay beds would have on mental health services in the UK and found that 'old' long stay patients were coping in the community, but 'new long stay' patients were accumulating in acute inpatient hospital units, revolving in and out of acute inpatient care and poorly cared for in the community. They say

"Although it is clear that there is a shortage of acute beds especially in inner city areas many of the these beds are currently occupied by patients who would be better (and less expensively) cared for in community alternatives if these were available. " (: 127)

They comment that there is evidence forthcoming that 'new' long stay patients can be reintegrated into the community if appropriate residential care, employment opportunities and assertive outreach teams are designated. A 'systems' approach that ensures cost effectiveness, efficiency, and good co-ordination could achieve positive outcomes. (Shepherd, 1998: 127-134).

There has been considerable debate regarding drastic reduction of length of hospital stay for people with serious mental illnesses, related to deinstitutionalisation over the past 30 years. A Cochrane review covering 1966 - 1998 concluded that a planned short stay policy did not appear to result in readmissions to any greater degree than discharge after long stay. Definitive criteria for what constitutes short and long stay are not given. Hence the time span could vary greatly across different studies reviewed. The authors suggest that further research in 'developing' countries that still have old 'long' stay patients would be valuable. (Johnstone & Zolese, Cochrane Database System Review, 2000)

Haver et al. (2003) pertaining to Israeli public health services discuss transfer of treatment for the mentally ill from psychiatric hospitals to the community over recent decades, and positive reforms whereby funding is allocated to develop community mental health services. They review various research studies from the USA and Canada in the 1980s, some of which found community settings models more effective than hospital settings models of treatment in reducing psychiatric

readmissions, shortening length of hospital stay and facilitating good community reintegration. However other research they reviewed found an increase in homelessness, in mortality rates, and in 'revolving door' patterns of readmission for the more severely mentally ill. They say that in order to avoid the latter scenario, enough planning and funding need to be given to the development of community support structures, attuned to the needs of the population at risk and also to the reduction of psychiatric hospital systems. This would need to include guidelines for evaluation of the functioning of such community services. (Haver et al, 2003: 235-237)

PREDICTORS OF PSYCHIATRIC READMISSION

Various factors contribute to difficulties with community level treatment and care:

Severity of illness

A cohort study conducted in Copenhagen 1968-1988, explored early predictors of later readmission and found severe early diagnosis, particularly that of schizophrenia and affective psychoses, to be significantly related to rapid relapse and the 'revolving door' syndrome (Pedersen & Aardkrog, 2001: 1-4). It should come as no surprise that severity of mental illness is of itself predictive of readmission. A verill et al. (2001) have motivated for the use of psychometric screening procedures to identify patients at high risk of readmission. They mention that factors associated with frequent readmission have been widely studied in the hope of reducing financial burden and improving treatment outcomes. They refer to the recent dramatic increase in psychiatric readmissions, involving a subset of

'revolving door' patients that has paralleled deinstitutionalisation. In their study psychometric data was taken on 131 patients over a 9-month period. Their conclusion was that the Brief Psychiatric Rating Scale -Anchored and the Beck Depression Inventory could be useful in proactive prediction of patients at increased risk of readmission. Early identification of the 'revolving door' population at risk would be useful. Mental health service providers could then plan proactive case management outreach for a select group of patients discharged from the psychiatric hospital to community primary health care level. (: 215-235).

Non-compliance

Causes and patterns of relapse amongst 63 'revolving door' inpatients with schizophrenia at an acute admissions psychiatric unit in New York were studied, with a view to best treatment options and sustainability on discharge. Most common reasons for rehospitalisation were found to be firstly, non-compliance with medication (n = 25; 50%) and secondly, non-response to treatment (n = 13; 26%). Treatment available for the study was oral conventional antipsychotic, depot conventional antipsychotic (either haloperidol or fluphenazine decanoate), or atypical antipsychotic (either risperidone or clozapine). Selection of either depot or atypical treatment occurred, dependent on whether assessed cause of relapse was non-compliance or non-response. The recommendation was that medication for 'revolving door' patients can be specifically targeted during the time period of an acute admission (Weiden & Glazer, 1997: 377-392). An earlier study using a pharmaco-economic decision analysis model assessed the effects of switching treatment from either traditional oral neuroleptics or newer, more expensive 'atypical' oral treatments, to depot neuroleptics for non-compliant 'revolving door'

schizophrenic patients on outpatient maintenance treatment. It was found that this could prove more cost effective in respect of lowering total direct treatment costs, including costs of rehospitalisation. (Glazer & Ereshefsky, 1996: 337-345)

Substance Abuse

Haywood et al (1995) found that substance abuse and treatment non-compliance were significantly related to higher frequencies of hospitalisation, concluding that prevention of such behaviours through patient education could assist in reduced. "revolving door" patients. Leon et al. (1998) conducted a comparative study of psychiatric inpatients with and without co morbid substance-related disorders, and found that revolving-door readmissions were significantly higher for those with co morbid substance-related disorders, but for shorter duration. A 4-year prospective study follow ing relapse of schizophrenia in 99 patients found that non-compliant patients with a dual diagnosis of substance abuse (n=28) comprised 57% of all hospital readmissions for the cohort. Duration before readmission was shorter for noncompliant patients with dual diagnosis (median survival 5 months) than for non-compliant patients without dual diagnosis of substance abuse (10 months). For medication-compliant patients duration before readmission was likewise shorter for those with dual substance abuse diagnosis (10 months), than for those without the dual diagnosis (37 months). They conclude that treatment programs to address substance abuse and non-compliance could reduce hospital readmissions. (Hunt et al, 2002: 253-264).

Social deprivation

Boardman et al. (1997) conducted research in North Staffordshire U.K. and confirm previous studies that social indicators of deprivation are predictive of psychiatric admission rates for all diagnostic groups. They cite composite measures of social deprivation such as Jarman Underprivilege Area Score UPA (Hirsch 1988), unemployment rates, and other complex statistical models have been used to accurately predict admission rates. Most importantly, their study confirms previous studies that show social indicators can indeed be used to predict admission rates (: 457-462). Koppel & McGuffin (1999) likewise found socioeconomic factors to be predictive of psychiatric admissions. Certain individual measures of deprivation, namely unemployment and lack of car ownership, were in themselves strongly predictive. This was strongest for psychotic, substance misuse related and personality disorders. They emphasise that while factors of social deprivation are predictors of admission rates, we cannot infer causation. Economic deprivation results in susceptibility to mental illness, but mental illness also results in susceptibility to economic destitution. They cite references to the wellestablished phenomenon of 'downward social drift' amongst people with schizophrenia. A limitation of the study was non- differentiation between first and re-admissions (: 1235-1241). Thornicroft and Tansella (1999) cite Tansella and Ruggeri (1996) finding that patients at high risk of readmission to hospital or rapid relapse can be identified from a combination of variables, using existing clinical information systems to access data such as their diagnosis, number of previous readmissions, previous contacts, previous episodes, occupational status, and multiple agency use. They can then be prioritised for regular assessment, continuity of care and clinical input. (: 89).

CHALLENGES OF COMMUNITY MENTAL HEALTH CARE

Flisher et al (2003) indicate an urgent need for community mental health services to be expanded, particularly with the ongoing reduction of psychiatric hospital services and discharge of long stay patients to the community in recent years. Their document, 'Norms for Community Mental Health Services in South Africa' recommends what staffing and service needs are likely to be at community level, and underlines international findings that deinstitutionalisation is not a cost saving device, instead resources must be transferred to the community services. (Knapp et al 1994: 195-203; WHO 2001 in Flisher, 2003). Steps identified to improve community services were: training of general health staff in detection of mental illness, training of general health managers in use of the norms and of mental health service planning in relation to local service needs, information systems development, and the supply of adequate resources for mental health care in PHC clinics, day services and community residential facilities. (Flisher et al, 2003:3-37).

Human resources

Lund and Flisher (South African Medical Journal, 2002: 157-161) conducted a cross-sectional survey on staff/population ratios. They found that relative to international levels mental health service provision was very low in South Africa and there was high variability between provinces. This takes cognisance that all health services in South Africa have comparatively low staff/patient ratios. They also did a cross-sectional survey on staff/bed and staff/patient ratios in the South African public mental health sector. Again this was low in all nine provinces relative to developed countries.)

A paper entitled "Training For Transformation: Reorientating Primary Health Care Nurses For The Provision Of Mental Health Care In South Africa" (Petersen, 1999) advocates that the traditional biomedical care approach that has dominated nursing training should be replaced by a broader, more holistic approach in training programmes that encompasses psychosocial health of not just the mentally ill, but the population as a whole, especially given that mental health care needs are mostly rooted in the grave effects of poverty and violence in developing countries. (Desjarlais et al. 1995, in Petersen, 1999: 907-915).

"Mental health care in South Africa has existed historically as a vertical service within the health care system and has comprised, in the main, institutional curative care (Freeman 1992). With the new political dispensation, comprehensive, community-based mental health care, which is integrated into the primary health care system, has been adopted as the basis for the restructuring of mental health care by the National Health Bill (White Paper on the *Transformation* of Health Systems in South Africa, Government Gazette 1997). Accordingly, the *training* of primary health care personnel to provide a comprehensive, integrated mental health care service based on the principles of primary health care is a central feature of the restructuring process." (Petersen, 1999: 907)

Baumann (1998), whose views are sympathetic to the above, however cautions against a simplistic ideological notion that PHC makes specialist psychiatry and community mental health care redundant; the danger being that it could lead to resources being channelled away from the severely mentally ill (: vii).

"...health care workers will need to develop the confidence and skills to identify and manage both psyc hiatric disorders in primary care and psychological aspects of general medical disorders, and also to promote well being." (: viii)

Earlier work by Petersen and Pillay (1997: 1621) in a semi-rural area of Natal, researched the efficacy of the referral and information management system in

respect of the utilisation of community health workers (CHWs) in mental health services. Results were negative in that CHW roles in mental health were inadequately defined, they were poorly paid, unmotivated, had not been trained, they received little supervision and support, and referral channels were poor, with a lack of co-operation from health professionals at other points in the system. They motivate that increased access to and better co-ordination of a community base d mental health care system would reduce high relapse rates and the specialist hospital level 'revolving door' syndrome (ibid: 1621).

Scheduled readmissions

A clinical randomised control trial explored whether scheduled intermittent hospitalisation for persons with severe chronic mental illnesses would have a positive effect on their hospital utilisation, community adjustment and self-esteem. Patients in the experimental group had 4 scheduled readmissions per year each lasting 9 11 days, for two years. Control group patients had conventional access to rehospitalisation. Study conclusions were that scheduled intermittent rehospitalisation could be an effective treatment alternative for 'revolving door' patients as a means to avert crises and precipitous readmissions, giving the patient more sense of control over his health and hopefully enabling a higher degree of wellness. (Dilonardo et al., 1998: 504-509)

Assertive Outreach

This is a treatment model that has been much researched, and is widely used by countries notably U.K., USA and Australia as a key aspect of mental health service delivery to enforce psychiatric treatment compliance at community level amongst

people suffering from severe mental illnesses. Multidisciplinary teams conduct assertive community treatment with clients who have been discharged from inpatient psychiatric treatment and who are not under any legal requirements to continue treatment, but who have a history of poor treatment compliance and frequent relapse. Various studies have shownthe efficacy of this model for those patients who stabilise in hospital, but decompensate quickly in the community, resulting in 'revolving door' admissions. (Disability Management Advisor, 2000). Such a model is of interest to the South African context in that it could assist with reducing psychiatric readmissions. However it poses an ethical debate as reviewed by Williamson (2002: 543-547), namely a conflict between autonomy and beneficence. Denial of client choice is paternalistic, yet enforced treatment protects individual and public safety. He cites Burns & Fim (2002) 'Patients may not share our positive associations with phrases such as "preventing people falling though the net" where the service provider sees "net" as safety feature, the client reads "net" as something that fish are caught in, a social control. Williamson concludes that assertiveness outreach that focuses on clients' values and needs, such as housing and social benefits, is far more likely to provide a meeting ground between client and practitioner around decisions of type and dose of pharmacological treatment required. Positive aspects of the model that he cites are the emphasis on multidisciplinary teamwork, proactive engagement with clients, a comprehensive health approach and low practitioner client ratio, thus enabling intensive therapeutic input.

Involuntary Outpatient Treatment

Many states in the USA now have statutory legislation in effect whereby people with severe mental illnesses can be committed for involuntary outpatient treatment, instead of inpatient treatment. A Resource Document under direction of The American Psychiatric Association's Council on Psychiatry and Law has recently been compiled to inform the process of drawing up legislation for mandatory outpatient treatment. It supports mandatory outpatient intervention for that relatively small population of non-compliant, severely and chronically mentally ill patients who are continually going through the 'revolving door' of psychiatric hospitals (Gerbasi et al., 2000: 127-144). The new Mental Health Care Act of 2002 will make it possible for people to be certified as involuntary outpatients, thus averting the need for certain people to be involuntarily admitted to psychiatric institutions. The value is that there is less stigma and less disruption to the person's private life in respect of domestic and economic responsibilities, whilst affording safety for the person who is a danger to self or others in the community. How this will work is yet to be seen as there are bound to be logistical problems, but an assertive outreach model would fit very well within this paradigm. It could potentially be very helpful in preventing frequent inpatient readmissions. High-risk clients could be identified for intensive case management in the community.

Socio-Cultural Determinants

Rogler & Cortes (1993) discuss the need for culturally sensitive mental health care that is accessible and effective for socio-economically disadvantaged populations and explore by way of example the Hispanic population in the United States. They discuss not only the route that clients take in respect of the formal referral

pathways for mental health care, but also the socially and culturally sanctioned informal pathways. (Rogler & Cortes, 1993: 554-561). Parallels can be drawn to socio-economically marginalized communities in South Africa in respect of the role of language and cultural beliefs in accessing mental health services. Joyi et al (1998) (cited in Tshaka, 2003) conducted a study that explored reasons for non-compliance with psychiatric treatment amongst Xhosa speaking patients. Findings suggested that cultural belief systems were strongly implicated.

Burden Of Mental Illness On The Family

Shibre et al (2003) studied impact of schizophrenia on family life and the burden that relatives carry in rural Ethiopia. The romantic notion that traditional extended family structures cope better because they are more tolerant of severe mental illness was not borne out by this study. Instead they found that women and parents in particular were often emotionally, socially and economically crippled as result of caring for a schizophrenic relative. The authors' recommendations are that services in developing countries needed to include psycho-education, assistance in ways of coping with stigma and family burden, as well as intervention and support. Their findings have been confirmed by several previous studies (: 27-34). Research was done at Valkenberg Hospital during 1994 in respect of family satisfaction with service provision. Findings indicated insufficient professional involvement with families in respect of the treatment programme. Care giving relatives felt that they had received insufficient education around the implications and management of mental illness in the home environment. They experienced difficulty with arranging rehospitalisation, and a lack of supportive community resources such as supported housing, day care centres, rehabilitation, sheltered employment and financial

assistance. A need for psycho-educational family groups was expressed by 75% of the respondents as well as need for more professional counselling with care giving relatives. (van Staden, 1995)

MODELS OF COMMUNITY BASED MENTAL HEALTH CARE

There is evidence from studies since the mid 1960s for the efficacy of home-based and day hospital treatment as community integration modalities, in reducing frequent readmissions to psychiatric hospitals and in provision of cost effective, comprehensive mental health care outcomes, with a strong focus on rehabilitation. This is in the context of the reduction of psychiatric hospital beds, shorter duration of hospital stay, and accompanying increase in readmissions that has occurred internationally. (Brenner et al., 2000: 691-699)

A study by Dean and Ga dd (1990) in Birmingham, U.K. of a deprived inner city area found home treatment possible for about two thirds of patients with acute psychiatric illness. Factors that could have facilitated reduction in admissions were: existence of a community based mental health resource centre, a policy of rapid response to outside agency referrals as well as proactive follow up of missed appointments and maintenance injections and that "these factors may result in patients receiving treatment earlier in their illness than in a traditional hospital based service." (: 1023)

Successful transformation of mental health services in Jamaica in the past 30 years is an example of how deinstitutionalisation can work well if there are culturally

sensitive, comprehensive community psychiatric services in place that meet the needs of the service population as described in a study by Hicking (1994). There was a big investment in community psychiatric facilities, using trained mental health officers to provide treatment, care and supervision of chronic mentally ill people living in the community, with minimal supervision from community psychiatrists. Positive media coverage and public education helped to destignatise mental illness, as in this quote:

"In Jamaica the community has, with political maturity and greater awareness of mental health issues, put pressure on the government to provide acceptable care for mentally ill persons capable of harming themselves and others. The public's tolerance for non-dangerous patients in the community has been balanced by its insistence that dangerous patients be treated in hospitals and not released to the community until it is safe to do so." (ibid: 1126)

Chatterjee et al. (2003) did a longitudinal prospective study of outcome in clients newly diagnosed with schizophrenia, comparing community-based rehabilitation with outpatient care outcomes in a poorly resourced area in India. Findings indicated more positive outcomes for people in the community-based rehabilitation group. This model involves active community participation and relatively little professional expertise notwithstanding it is resource intensive. The study adds to the sparse evidence base on effective interventions for care and rehabilitation of clients with chronic schizophrenia in poverty-stricken areas of developing countries, where outpatient treatment is usually only care available. (: 57-62)

Shatkin et al (1995) urge mental health professionals to reach fuller understanding of the philosophy and principles of psychiatric rehabilitation, and suggest similarities in physical and psychiatric disability may assist in this quest. They say that although it was hoped that deinstitutionalisation would liberate people locked

away in mental hospitals, and allow them better quality of life, media coverage and scholarly research suggest that people with severe mental disabilities have not been successfully rehabilitated in the community, and now we have a 'spinning door' syndrome of psychiatric readmissions. (: 143-146)

Locally, Provincial Government Western Cape, Directorate: Public Health Programmes, Subdirectorate: Mental health and Substance Abuse have formulated draft policy and implementation guidelines (2004) in respect of psychosocial rehabilitation, the purpose of which being to provide a philosophical foundation from which to build mental health services towards attainment of Health care 2010. This process is informed by and feeds into policy formation at national level where PSR has been declared a priority. The guidelines discuss integration of PSR into PHC, saying that although PSR is regarded as integral to PHC at national level, implementation at service delivery level is not going to be an easy process.

"Historically, mental health has been the stepchild of health care, making the sufferers vulnerable and disempowered. It is thus essential that powerful structures and role-players, to avoid the possibility of continued low status and exclusion, acknowledge the role of PSR. There is acknowledgement for PSR within the PHC approach and the District health System (DHS), and this will pave the way to its integration into these health systems." (: 32)

Psychosocial rehabilitation can be seen as a means towards prevention of the 'revolving door' syndrome of frequent readmission that has paralleled deinstitutionalisation in developed countries (Behr et al, 2002: 369), if one considers carefully the following:

"The mission of PSR is to improve access to services, in line with Healthcare 2010, which will assist the functioning of mental health care users so that they can be successful and satisfied in their environments of choice with the least amount of

professional intervention. Environments refer to the areas of living, learning, socialising and working."

(Western Cape Province Policy and Implementation Guidelines- 2004: 16)

A study in Rome (1998) reported very positive results using a group cognitive behaviour therapy approach in a 'typically overburdened inner-city psychiatric general hospital unit' such as one might describe Valkenberg Hospital. A pre-post test design was used with 385 inpatients, 59% with schizophrenia or paranoid disorder. The total compulsory admissions declined by one third, violent episodes by almost half. The "revolving door" patients declined by 1/3 (p < 0.05). Patients' viewed participation enthusiastically with some requests for more of this treatment after discharge. (Bazzoni et al., 2001: 27-36)

Melchinger (2001) evaluated a program to prevent rehospitalisation of chronically mental ill and socially compromised patients. Clients are assigned case managers immediately following a communication from the hospital-based psychiatrist that the patient is discharged, primary goal being psychosocial rehabilitation. Results found that hospital readmissions were reduced through effective outpatient interventions that enabled clients to enjoy improved quality of life and were cost saving in respect of hospital bed expenditure. There was strong motivation for continuance of outpatient care programs of this nature. It is unfortunate that developing countries such as South Africa do not have the resources to render this level of community mental health care.

Non-compliance has been reported as a major cause of recidivism back into psychiatric hospitals. Findings of one study were that psychosocial rehabilitation

clubhouses offered support, vocational and educational options that resulted in improved level of functioning and quality of life. This in turn encouraged decreased inpatient readmissions to psychiatric hospitals. It was also found that compliance was higher for those on oral psychotropic medication if they participated in the clubhouse program, where the atmosphere fostered peer support and "normalisation" of psychopharmacological treatment. (Delaney, 1998: 28-34)

THE 'REVOLVING DOOR'

Alarming rise in readmission rates at Valkenberg Hospital which then amounted to 42% of all admissions particularly among short stay patients was reported by Gillis et al. as early as 1985. (SAMJ, Sept. 1985) Behr et al (2002) conducted a study from the premise that despite extensive international research, very little research has been done in South Africa on the effects of deinstitutionalisation, scarcity of psychiatric beds in respect of risk factors for acute hospital readmissions, and interventions needed to reduce risk of relapse. Study objectives were to assess what effect length of stay and administration of depot antipsychotics during inpatient stay would have on the time period before inpatient readmission. The setting was Baragwanath Hospital, Gauteng. A retrospective study followed up a random sample of 180 patients who were admitted over a 6 month period during 1996, for twelve months after their index discharge dates, by means of multiple hospital and community based record review. One interesting outcome was the duration before these patients were readmitted. Risk of readmission was greatest in the first 90 days post discharge. Only 21% of patients attended community clinics at all after

discharge (: 369-374). A local unpublished study at Valkenberg Hospital by Milligan & Flisher (2002) reported very similar results. (See appendix 3).

Anan Shah (Dec 2002) conducted a study on acute psychiatric admissions within the APH of the Western Cape, with the aim of analysing factors that are influential in admission rates. In the study he refers to admission rates of other developing countries, as well as literature around factors that influence readmission to acute psychiatric units. His conclusions indicated that the catchment areas for the three Western Cape APHs in the study were unequal in size and demographics. He identified pressure points where the demographics of the local population were conducive to the development of severe mental illness. He cites a substantial body of evidence indicative of a strong correlation between socio-economic status and rate of referral and admission to acute psychiatric units. This is identified as a pivotal explanatory factor for variations in readmission rates across the three hospitals of Stikland, Lentegeur and Valkenberg, ranging from 44% to 58%. It is further noted that there is a strong influx into the more socio-economically deprived areas from poorer neighbouring provinces in an attempt to access health services. (See appendix 2: Shah (2002). Tables 1.6, 1.7, 1.8 Total populations of the three catchment areas, with rural and metro breakdowns.)

Standardised rates of admissions between Lentegeur and Valkenberg Hospitals were similar, however for Stikland Hospital this was less than two thirds as much, as can be seen from Appendix 3 (Shah, 2002:15 Extract from Table 1.5.).

Whereas at Lentegeur the percentage of new admissions was greater than the percentage of readmissions, at Valkenberg Hospital the inverse applied. Stikland

Hospital, like Valkenberg Hospital, has a higher ratio of readmissions to new admissions. Standardised rates of admissions included new and re-admissions. Shah argues that the higher admission rates at Valkenberg Hospital and Lentegeur Hospital as compared to Stikland Hospital may well have related to differential socio-economic factors, indicated by significantly higher levels of unemployment that this study found in the Valkenberg and Lentegeur catchment areas. The readmissions are expressed as a percentage of total admissions, and therefore more complex to interpret.

There is value in looking at local comparisons. If there is a discrepancy explained by contextual differences within the Western Cape, it indicates how difficult it is to compare the phenomenon of readmissions across differing developing and developed countries.

Shah's analysis of community services found that deinstitutionalisation has placed additional pressure on clinics, without additional resources that should have followed. He says:

"The periods just before and just after an inpatient episode are deemed as the most critical for clients and the time when they require the greatest support, if they are to avoid an inpatient stay or relapse. From the review of the community services it seems evident that it is these exact time when the service renderers are struggling most." (: 43)

He concludes that this would be a key factor inducing increased readmission rates, which are critical to the overall admissions problem. He describes how the revolving door phenomenon continues as community teams cope with patients who have been discharged before adequately stabilised back into the desperate social conditions that triggered their illnesses. Admission rates are indicative of the

current service delivery position and pressure on the system. Hospitals cannot undertake significant rehabilitation as patients stay too briefly, and at community level, where it should happen, resources are hopelessly inadequate.

Notwithstanding these constraints, improved communication channels across the service sector could be key to stemming the flow of relapsed patients, if the services for Health care 2010 agenda are to be delivered.

In summary the major issues for the 2010 mental health care challenge identified by Shah (: 44-45) are paraphrased as:

- Inappropriate admissions to acute services by community mental health teams due to inadequate resources and support,
- Inability of acute psychiatric services to provide optimal care in suitable settings,
- Ineffective, unsupported discharge of clients back into under resourced environments

Changes in the health services with transition to an integrated, comprehensive PHC approach in South Africa dovetail a process of deinstitutionalisation of psychiatric hospitals in South Africa in line with international trends. The international experience of deinstitutionalisation has generally been that there is a parallel 'revolving door' process and the concomitant realisation of the need for adequate support services at community level. Although there has been considerable international research and models of community care have subsequently emerged in developed countries, there is perhaps not unduly cynical concern that this matter is going to slide off the political health agenda and be left unattended in South Africa. It is out of this concern that the research study that follows was begotten.

CHAPTER THREE: METHODOLOGY

RATIONALE FOR USE OF A QUALITATIVE APPROACH

Qualitative research recognises a complex and dynamic social world. It involves the researcher's active engagement with participants and acknowledges that understanding is constructed and that multiple realities exist. It is theory generating, inductive, aiming to gain valid knowledge and understanding by illuminating the nature and quality of people's experiences. Participants' accounts are valued, emergent issues within accounts are attended to. The developing theory is thus firmly and richly grounded in personal experiences rather than a reflection of the researcher's a priori frameworks. In this way insight is gained as to the meanings people attach to their experiencing. (Banister et al, 1994: 142)

The researcher wanted to reflect the multiple realities as experienced by the different role-players in the process of frequent readmission of mental health care users to Valkenberg Hospital. These role players are care giving relatives, mental health care users, staff within the Valkenberg Hospital context and also at primary health care level, but there are also other role players who for the purpose of this study were not consulted, such as senior management, both within the hospital and PAWC Department of Health who would have their own perspectives and accompanying agendas.

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The caregivers' reality may be that life is at risk, as result of a relative's mental illness; so urgent re-admission is frequently required. The Valkenberg Hospital nurses reality may be that there are no beds into which to readmit mental health clients with the result that clients have to be prematurely discharged.

What this study tries to do is to reflect on some of these processes in the discharge to readmission route, by visiting different stations along the way.

STUDY DESIGN

Interpretive qualitative research methods were employed in a descriptive and interpretive study to evaluate policy implementation in respect of frequent readmission of mental health care users to Valkenberg Hospital. The design needed to be critically sensitive to relatives and service providers who feel marginalized and disempowered politically, socially, and economically in caring for the mentally ill. A positive spin off hoped for is that such methodology would encourage participants to engage in social action in respect of improved mental health services (Quantz, 1992). The research process was inductive and flexible in allowing the design to emerge out of the investigation.

Findings will be discussed with various stakeholders, namely consumers, caregivers, and service providers at PHC, District, Regional and Associated Psychiatric Hospitals Head Office level. Hopefully the results can supplement further research aimed at convincing senior management in the health services to make more mental health care available as part of comprehensive primary health

care. It is further hoped that improvement in referral pathways may lead to more effective community treatment. Findings will be shared with NPOs and consumer advocacy groups rendering mental health services in the Western Cape.

DATA COLLECTION

1. Individual in-de pth open-ended interviews with care giving relatives

In depth interviews, some conjoint, were conducted with five sets of care giving relatives of clients frequently readmitted to Valkenberg Hospital with severe mental illnesses. They were from Langa, Gugulethu, Bridgetown, Athlone, and Zeekoeivlei, in order of social deprivation, the former being poor and the latter middle-income bracket. The researcher allowed a naturalist setting as far as possible. Relatives often prefer to have each other for company as support in coping with the stress of a mentally ill relative, when coming for interviews at Valkenberg Hospital. Two of the sessions were conducted in the caregivers' homes, because this was their stated preference. The researcher arranged two separate co-facilitation interviews involving two Xhosa colleagues with the two Xhosa care giving relatives. This had benefit in setting the participants more at ease, by allowing them to speak in their first language. However the cost of additional interviewing time and translation probably did not justify the benefits in that the participants were sufficiently fluent in English, and it meant that the researcher had less control in coverage of all aspects in the interviews.

The interviewees were all keen to engage with the research question, with the exception of one who was indifferent. They seemed to derive therapeutic benefit from "being heard" and taken seriously. Four of the five hoped there would be a secondary gain, namely that the researcher as social worker might be able to put them in touch with resources, or raise awareness with influential people of the plight of relatives unable to cope with the demands of caring for the chronically mentally ill. The researcher took care not to raise false expectations, nor to promise the undeliverable.

Information gleaned was rich, varied and imbued with passion revealing the daily hardships with which caregivers and clients contend. The researcher guarded against reinforcing the interviewees response, instead tried to listen with empathy and not ask too many questions. The researcher commenced with the central question regarding what the caregiver felt was the reason for frequent readmission of their relative.

In all but the one case the interview flowed very freely, with the researcher steering back to the subject when the respondent became too tangential in account. In each case towards the end of the interview the researcher prompted around those areas of the interview guideline not covered by the respondent. In one interview the sister in law had little to say and the interview was shallow. What was revelatory was that she did not regard the research question as having much relevance. To her it was clear that her brother in law required frequent readmission, which Valkenberg Hospital always provided. She provided the basics of board and lodging in compliance with her husband's wishes.

The researcher encouraged respondents to phone her if they had more to tell. One respondent phoned a week later to advise that her son had been discharged, to her great disappointment as he was not yet well, then some weeks later readmitted, then he absconded, then he smashed up her house and killed her puppies, was found by the police and readmitted again to Valkenberg Hospital. So even as the research was being written some months later this was a readmission story in constant process. She phoned on several subsequent occasions. This all helped to clarify further layers of data around the emergent themes of dangerous behaviour linked to mental illness and lack of support systems to cope with the care of the mentally ill in the community.

Interview preparation was done with care as per interview guideline (see appendix 1), consent to participate was obtained from the respondents; times arranged and rescheduled as necessary and permission requested to use an audio - tape recorder. Data collection took place not more than two weeks after discharge from hospital, as interviewees often modify their interpretation of events with passage of time (Sandelowski 1993: 4). Two of the mentally ill relatives were still in hospital at the time of the interview. However in the one case the hospital records were temporarily mislaid and as result it was not possible to contact the relatives until four weeks after discharge. The researcher went ahead with the interview, as it was an interesting and information rich case of dual diagnosis mental illness and HIV+ diagnosis.

2. Focus Groups with Service Providers

Kritzinger (1995: 299-302) suggests that focus groups have great value as "a method that facilitates the expression of criticism and the exploration of different types of solutions is invaluable if the aim of the research is to improve services" (Ibid: 301) The researcher hoped that this would emerge out of the focus groups.

Two focus groups were conducted with professional nurses. The one group consisted of eighteen professional nurses rendering psychiatric care based at primary health care level at community health centres in the Valkenberg drainage area. The other group consisted of six nursing managers and professional nurses from the acute admissions units at Valkenberg Hospital. A second session was held with the former group as it was large and there were a few issues that needed further exploration and clarification.

The researcher used a nondirective approach, starting with the first question of what the group thought were factors related to frequent readmissions. Towards the last twenty minutes of the session the researcher picked up on aspects not covered during the session by using prompts from the focus group guideline [see appendix 2]. The first session evoked ardent participation amongst the community nurses.

The session with the Valkenberg nurses seemed less spontaneous, possibly because the researcher was more self-conscious as she has had close collegial contact with some of them.

This method was chosen over that of individual interviews with service providers, as it was cost effective and stimulating. With both Valkenberg Hospital and community nurses it provided rich insights and focused engagement with the research topic. The researcher had hoped that it would prove to be a morale building and supportive experience, which it may have been but it may also have left members wondering as to whether anything positive was likely to come out of what is effectively a very small research project. As such it will be important that the researcher provide feedback to them regarding what positive steps could be taken as result of the key findings at the end of the research process.

SAMPLING

Purposive sampling methods were used to search out cases that could shed some light on the phenomenon of frequent acute psychiatric readmissions. The sampling frame was care giving relatives and service providers of frequent mental health care users in the acute male and female admission units of the hospital. Cases were selected by going to the folder records of those users who had been recently discharged following a readmission, and who had more than three admissions during the 2004 study period. The sample size was small in keeping with qualitative sampling norms. Where the researcher had planned to interview approximately 8 relatives, in the end five in-depth interviews, (some conjoint interviews) were conducted with seven relatives. For the purposes of a mini thesis "saturation point" of interest was reached at that point (Rice and Essy, 1999: 45).

The purposive sampling approach was as follows:

The researcher enlisted support from psychiatrist consultants and registrars to search for cases that were unusually interesting for information rich in-depth study. Their verbal consent was also obtained to interview the relatives of the mental health care users in question. Extreme case sampling illustrated the interplay of severity of illness and underlying social pathology as in the case of the woman with a diagnosis of Mood Disorder secondary to HIV+ and substance abuse. It was hard to select out a few cases because the case histories of all the frequently readmitted patients were so rich and varied.

The researcher tried to include widely differing socio- economic and cultural backgrounds serviced by Valkenberg Hospital to ensure maximum variation sampling. However the extremely poor were sadly excluded as either caregivers were in informal settlements and not contactable, or there were no caregivers, and clients were homeless, of no fixed abode. A number of cases where substance abuse was heavily implicated in frequent readmissions were unfortunately excluded for similar reasons. On account of having to exclude the poorest of the poor, the researcher decided also to exclude the minority of relatives from affluent socioeconomic background. A larger qualitative study would need to cover the extremes of wealth and poverty. Both genders and varying ages were included. Diagnoses varied from schizophrenia, schizoaffective disorder, and major depressive disorder secondary to HIV, with dual diagnosis of substance abuse present in three of the cases. In order to achieve further variation an in depth interview with one mental health care user was also conducted. This was also done to improve triangulation by seeing the problem of frequent readmission from a client's perspective. This particular client came from an educated and more affluent home background and

yet was not more immune to the ravages of mental illness than any one else.

However his well being was dependent on staying in a group home for people with mental illnesses, which provided a strong support system for him.

The researcher took case histories from the medical records of the mental health care users who were selected for the sample as triangulation to substantiate the indepth interviews with the caregivers.

Triangulated sampling was further achieved by offsetting the in depth interviews with the caregivers and the client against the focus groups with service providers. Even across the two focus groups there was triangulation in that the one group was seeing from their perspective of being service providers inside Valkenberg Hospital; the other group from their perspective as community service providers who provide follow up treatment for mental illnesses when users are discharged from the hospital. (Rice and Essy 1999: 43)

ORGANISING AND CODING OF THE DATA

Data transcribed from the audiotape recorder to the word processor was coded straight after transcription, not from predetermined themes but from themes that emerged from the data as being directly relating to frequent readmission. Coloured highlighting and the copy and paste function on the PC Word Processor allowed data to be moved around easily, and was further categorised according to emerging sub themes. A one third page margin was used on transcriptions for questions, interpretations and insights.

ANALYSIS METHODS

The methodological approach was that of grounded theory in that data was systematically collected and analysed, and theory was gradually developed through comparing across the data sets, to find explanations for how mental health care users came to be frequently readmitted for inpatient psychiatric treatment. (Strauss, A. and Corbin, J. 1994: 273) In respect of what theory consists of and its relation to reality they say: "Discursive presentation captures the conceptual density and conveys descriptively also the substantive context of a study far better than does the natural science form of prepositional presentation [typically couched as "ifthen]". (Strauss, A. and Corbin, J. 1994: 278) This approach is thus very different to that of positivist methodologies that would start with a theoretical hypothesis, and where data analysis would either reject or fail to reject the null hypothesis.

Through looking at the patterns of interaction between various actors, the researcher was able to develop a conceptual framework and to organise the data according to consequential, interlinking and cyclical themes. [Ibid: 278]. Data yielded 'thick' detailed descriptions about the context of events and actions, the deeper lying intentions and meanings, and the evolution of consequences from those events and acts. The researcher then classified this into meaningful categories leading to a conceptual framework and searched for patterns in relationships and interconnectedness, ending when no further insights were gained from new data. (Gifford, 1996: .544).

The researcher looked at factors of culture, socio-economic status, gender, accessibility, availability and effectivity of services, social support systems and social problems such as substance abuse and homelessness. Much use was made of vignettes and direct quotes to emphasise veracity of results. Comparisons were made between responses of research participants for similarities and differences. In grounded theory this is called 'constant comparative analysis' (Glaser and Strauss, 1967: vii).

Most common approaches of qualitative analysis in public health as described by Gifford {1996) that were used were:

Thematic analysis. Exploration of stories told by relatives and focus group participants.

Contextual analysis. Exploration of how extracted themes interacted with each other. [By way of example, the theme of high risk of serious harm had to be analysed contextually against the theme of inadequate community support systems].

Event structure analysis. Exploration of the chronological order, logical sequences, conditions and contexts of events that led to frequent inpatient readmission, was done under the theme of inadequate care pathways.

(: 546-548)

RIGOUR

Methods for ensuring rigour as described by Morse (1994, pp 230-231) are "intricately linked with reliability and validity checks" with main methods described:

"Criteria of adequacy and appropriateness of data" which is met "when sufficient data has been collected that saturation occurs and variation is both accounted for and understood". Sampling continuing until there is repetition from multiple sources with results that are rich. The researcher did not look for generalisability to a greater population, but at what composed 'truth' for people within the sample, as specific cases of frequent readmission. Search for new data ceased when no new insights emerged, and where new data confirmed data already analysed.

"The audit trail" whereby interested parties can reconstruct the process, through data documentation in various stages from raw, reduction, analysis, reconstruction and synthesis products. The researcher complied with this and also kept a hand notated self-critique journal whilst processing the transcriptions from the tape recordings, to be available for auditing afterwards. Comments in the right-hand column alongside the transcription were also used, when appropriate, to reflect on the researcher's role.

"Verification of the study with secondary informants" whereby the researcher checks out the conceptual model of results with the research participants, was done

near the end of the research process with the Valkenberg Hospital and community mental health nurses.

(Morse 1994: 230-231).

Triangulation is emphasised as crucial to ensure rigour by various authors including Gifford who describes at least four types, namely data source, researcher, methods and theory triangulation. (1996: 60)

Data source triangulation in line with the study objectives compared perspectives of care giving relatives and a mental health consumer, with that of mental health care providers. One group of service providers were from within the hospital setting, the other from community primary health care level. As additional triangulation the researcher also compiled case histories from the medical records of mental health care users whose relatives were selected for the in-depth interview sample. Caregivers were representative of culturally diverse and relatively socioeconomically deprived backgrounds from Crossroads, Gugulethu, Zeekoeivlei, Athlone and Bishop Lavis.

Where the carers laid more emphasis on dangerousness and vulnerability of their mentally ill relatives, community nurses emphasised inadequate referral pathways from Valkenberg Hospital to the community, Valkenberg nurses placed emphasis on premature discharge, and the mental health care user emphasised lack of knowledge and insight as well as lack of opportunity to build a trust relationship with the therapist. They all strongly emphasised stigmatisation of mental illness

and the lack of community support systems to care for mental health care users in the community.

Methods triangulation was achieved through examining perspectives of caregiver relatives and service providers from different vantage points, through use of in depth interviews and focus groups. Findings were not contradictory but rather revealed different facets around the problem of frequent readmission, such as the positive value that relatives attach to frequent readmission. Stories of carers complemented that of service providers, which lent richness to the study and sensitivity to the pain, contradictions and immense complexities surrounding mental illness.

Researcher triangulation was attempted with the two caregivers whose first language was Xhosa, by involving a co-interviewer in the in depth interview, as cultural nuances or interpretations might otherwise have been missed by the interviewer.

Reflexivity is integral to the process of rigorous study as discussed by numerous authors. Brewer critiques ethnographers in qualitative research as being generally too unreflexive. He describes crucial aspects of reflexity, namely the context of the research, the theoretical framework and values of the researcher, integrity of the researcher, the authority and the complexity of the data. (Brewer, J. 1994: 235-236) The researcher is therefore reflexively aware of her own professional bias (Banister P.et al, 1994.) as a social worker employed for the past 14 years at Valkenberg Hospital, and believes that there are inadequate support systems in the hospital and

community for mental health care users and their carers, and that leads to frequent readmissions. The researcher's socio-political values are that more social service funding needs to be directed at all vulnerable groups, including the mentally ill and disabled. By liberal use of quotation the researcher tried to ensure that people's stories could be heard as they were told, portraying the lived experiences of those whose voices are seldom heard. (Brewer, 1994: 234)

For the purpose of the mini thesis, after 5 caregivers had been interviewed, and two focus groups held with service providers, the researcher was starting to identify similar themes and patterns across all the data, despite it being very rich and varied. At this stage new data was starting to confirm what had already been analysed, and was enough for the nature of the project. The researcher in the course of the reflexive data gathering, increasingly wondered what ones perspective on frequent readmission as a mental health care user would be. Thus as inherent to the purposive sampling, as a new facet to theory induction and as enhanced triangulation, an in depth interview with a mental health care user was incorporated into the study.

ETHICAL CONSIDERATIONS

The researcher was aware of the need for the clients' rights to confidentiality to be protected and that consumers receiving psychiatric treatment should not be interviewed. Clients recovering from severe psychiatric illness are in a vulnerable position, and as such not usually able to give informed consent to participating in research. However during the course of the data collection and analysis process the

researcher became aware of another ethical dilemma, namely that it would be disrespectful and against the principle of autonomy not to consult with mental health care users themselves, in the spirit of the slogan 'Nothing about us, without us' [Disabled People of South Africa].

Accordingly the researcher looked for a respondent who was very well in between serious relapses of mental illness that resulted in his frequent readmission. The researcher was careful to verify with his psychiatrist who is a senior specialist consultant that this client was mentally competent to give consent to participation in the research project. The client was eager to participate and his written consent was obtained.

Interviews with care giving relatives were anonymous. Written consent as well as written assurance that carers felt under no obligation to participate was obtained from those carers approached to participate in the research. Individual interviews were protective of the carers' privacy. Similarly, confidentiality was protected in the focus groups with service providers in that no information from the individual interviews with the caregivers was discussed. All names used in the findings that follow are purely fictitious.

CHAPTER FOUR: RESULTS

The results of the research project that was conducted during October 2004 are presented as a composite derived from the three respondent sources of mental health service consumers, community mental health nurses and Valkenberg Hospital nurses. Themes that emerged related to what precipitates and maintains frequent inpatient readmission were violent and high-risk behaviour as result of mental illness, lack of knowledge and insight of mental illness, lack of support systems, inadequate care pathways, and lack of state funded resources.

A brief description of comprehens ive client case histories derived from medical records for purposes of triangulation, which forms the base of one data source, is given before the thematic presentation. Pseudonyms are applied.

<u>Client 1: John</u> 37 year old male, unemployed, on disability grant, matric education, unmarried, no children, stays in Athlone in a back yard room on the property of his mother, sister, brother-in-law and two school going nieces. He is diagnosed with schizoaffective disorder and substance abuse, has no insight into his illness, poor treatment compliance, has had 9 admissions in 4 years, each of duration less than 14 days, is psychotic on every admission, but stabilises quickly in the ward.

<u>Client 2: Thabu</u> 37 year old male, unemployed, on disability grant, Std 8 education, unmarried, no children, stays in Gugulethu with his mother, who works long shifts away from home. He has schizophrenia, previous history of cannabis abuse, no insight into his illness, poor treatment compliance, and has had 11 admissions in 3

years, lasting from 2 weeks to 2 months. He is psychotic on admission and takes relatively long to stabilise.

<u>Client 3: Thandi</u>, 46 year old female, unemployed, on disability grant, Std 6 education, divorced, three daughters, stays in Langa with her sister. Her diagnosis is HIV seropositive, with mood disorder and organic brain damage, her insight into her illness is poor, she abuses alcohol, has had 4 admissions in the past year, varying in duration from 2 weeks to 2 months, and on readmission she is thought disordered with strange behaviour. Treatment compliance has improved.

<u>Client 4: Kallie</u> 48 year old male, unemployed, on disability grant, Matric education, unmarried, no children, most recently staying in Athlone in a back yard room on the property of his brother and sister-in-law, but used to stay with his elderly mother. He has no insight into his illness and is noncompliant on treatment. His diagnosis is schizoaffective disorder, he abuses substances, and has a psychiatric history going back at least 24 years, 3 readmissions in the past year and numerous previous readmissions, duration usually a few to several weeks, is psychotic on admission and has a history of absconding from the hospital.

Client 5: Shahieda 31 year old woman, unemployed, on disability grant, Std 8 education, stays in Grassy Park, with her widowed mother and two unmarried brothers, one of whom is quadriplegic. She is separated from a husband and has two children aged 11 and 4 years old, who are being reared by the paternal grandparents who stay close by. She is diagnosed with schizoaffective disorder, has poor insight into her illness and poor treatment compliance, is known to

Valkenberg Hospital since about 12 years ago, subsequently readmitted approximately 3 times a year, duration 2-8 weeks, currently still in hospital since last admission 17-09-2004. She was referred from Grassy Park CHC.

Client 6: Paul 52 year old male, unemployed on disability grant supplemented by a small amount that he earns from selling his art, tertiary education, divorced, has children, and stays in Observatory in a NPO-run group home for people with chronic mental illnesses. He has ageing parents and a sister in Cape Town with whom he retains contact. He has bipolar affective disorder, good insight into his illness and is treatment compliant. He is a known Valkenberg Hospital patient since onset of his illness 30 years ago, and has had 34 readmissions, 13 of which have been in the previous 4 years, each time in a psychotic state.

THEMES

THEME 1: VIOLENT AND HIGH RISK BEHAVIOUR

Care giving relatives gave violent and high risk behaviour as the most direct reason for frequent readmission, describing how the course, severity and momentum of mental illness impacted on the person's actions, putting the person's own life, property and that of others at serious risk. This was a theme that emerged from care giving relatives. Service providers alluded to this only briefly as in a comment from a community mental health nurses:

Families so traumatised by the first breakdown, so petrified for a relapse the minute they see something go wrong they are there and immediately want a readmission because they are scared of what may go wrong.

1.1. Danger to others

Care giving relatives described severe, even life-threatening consequences as in the following accounts:

Client 1: John

Interviewer: So you can almost tell when he's going off ...

John's mother: Yes

<u>John's sister:</u> Yes, he speaks to himself and he's constantly scratching his hair or washing his hair, you know, to get the se voices out of his hair... He's forever telling us the voice is telling him to, you know, to hurt us, you know, or to do something...

Sister: ... When he wanted to rape my mother, I think that was in July ...

<u>Mother</u>: Hooh, you know social worker, I thought I was dead and I thought he was going to kill me and when he is finished he is going to kill me. The most terrible part of all the years.

Sister: Yes, he's like an animal, he's so aggressive, he's like an animal....

<u>Mother</u>: We can't handle it. We <mark>are only</mark> women there; B's the only husband, he work on sea. He attack her husband also he threw her with a brick! with a brick, shame.

They also said that John bothers children at his nieces' school and although it is unlikely they cannot discard the possibility that he might sexually molest them.

Clients 2 and 4: Thabu and Kallie

According to both of their mothers they had to be hospitalised after incidents of violent aggressive behaviour when Thabu and Kallie, their mentally ill sons had hit them. One received stitches to her eye. Thabu's mother said that on two separate occasions he had killed her puppies, which he loved, on prompting of psychotic delusions and auditory command hallucinations. Damage to property and possessions during psychotic illness also related to readmission. Examples were smashing of windows, doors, and furniture that extended from property of the care

giving family, to neighbours' property. Neighbours would insist that the person either be readmitted to Valkenberg Hospital or criminally charged. Usually caregivers are too poor to make financial reparation. This is Thabu's mother's account.

<u>Mother:</u> ... he broke windows of my neighbour, one outside globe (lamp) fighting with my neighbour, push him and he was being beaten by my neighbour. At night I lock my doors, but sometimes he try to open the door, find him naked outside in front of children, but when I tried to confront him he start to fight with my neighbours, but my neighbours did not lay charges upon him.

Care giving relatives of the men all cited incidents of instigation of fires, usually on command hallucinations as necessitating readmission.

Client 5: Shahieda

Her mother related how Shahieda in her psychosis would sit holding her baby with a knife beside her to kill the devil behind her. She related another occasion when Shahieda was psychotic, tried to stab her, and in self-defence the mother had poured boiling water over Shahieda. In both crises the mother's recourse was to arrange readmission for Shahieda to Valkenberg Hospital as soon as possible.

Client 6: Paul

He related how lack of supportive community resources and mental illness can conspire with violence ending in tragedy, as in this tale of an acquaintance of his, who subsequent to criminal investigation was probably readmitted via the forensic route:

Paul: I would never have thought that could be capable to kill a six year old the way he did.... This was one of the main focuses of Carte Blanche... and I think, I don't think he is a killer by nature, I think he is a nice guy whose brain has gone haywire, off medication,

staying in a communal home in the Maitland boarding houses where conditions are horrific....

1.2. Danger to Self

Thabu's mother described him as not only aggressive but also vulnerable as he tried to commit suicide once. After admission to intensive care at a tertiary hospital, he was readmitted to Valkenberg. Recently, Thabu was recently again readmitted with third degree burns that had gone untreated for a few days after he accidentally caused a fire whilst smoking a cigarette in his sleep, and then ran away in fear.

1.3. Genderspecific vulnerability

'Wandering' in unsafe areas was described by four of the five caregiver relatives as jeopardising the mentally ill person's safety and resulting in frequent readmission but may have been more pertinent for women, who are more vulnerable than men.

Client 3: Thandi

Daughter: I took her straight here. [Valkenberg Hospital] I go to the police station and ask for a van because I didn't have a transport and my father was far in Khayelitsha, ... then we bring her with the policeman, and it was late at night. They took her even that day. It was raining and I was looking for her, she was walking around. When I found her she ... was wet and shaking and frozen, ... then I ask her where is she coming from? Then she told me that she was walking around...

Not only is Thandi's life seriously in danger as result of her inappropriate sexuality, but also she has HIV infection, which she could transmit to others. The

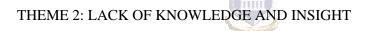
daughter described her mother's sexual disinhibition and promiscuity as being the result of her mental illness

Mentally ill women can also be particularly at risk in situations of domestic violence necessitating frequent readmissions to protect them.

Client 5: Shahieda

Mother: Now her husband used to fight a lot with her. You know what he do once with her? He took a spade on her head. He hit her so hard that the spade broke....

Yes, so after that we put our foot down and said it is enough, it's enough. We said, "You know [Shahieda] is sick, why do you lift your hands?" He run with her head, dooom, into the wall. That is why she is so sick! There is sometimes when [Shahieda]'s head is all right, and sometimes her head, this, is like this. You must just feel it. The other doctor can feel it. ... Sometimes that whole dinges here, come open, like this, here, like they hit X.



Public ignorance, stigma, fear, non-compliance and denial of mental illness, often associated with substance abuse were perceived as strongly linked to frequent readmissions.

2.1. Client's Non Acceptance of Illness, Lack of Insight And Non Compliance

Community mental health nurses discussed the lack of consumer confidence in psychiatric treatment and difficulty client have in accepting the diagnosis of a mental illness, and how this leads to frequent readmission:

The other reason (for patients being frequently readmitted) is that they lack insight. With the result patients try this and that, they take (the medication) for a while and then stop...Once they are stabilised they think they are cured. They feel well and stop taking the meds....

I don't know what happens in the ward pre discharge, whether the family gets educated. Often patients get to you, they don't know their diagnosis, they don't know why they were admitted, they were given these medications that make them feel better but have these horrible side effects, and all the rest that goes with it. Psycho-education needs to be started almost the minute the patient can comprehend or is out of psychosis, you see. Along with each and every visit of the family. We are all aware that resources are few, they are scarce, no manpower. This that and the other. But unless that is done you will have this 'revolving door'.

Valkenberg nurses concurred as in this observation:

We also have the younger client, who does not have the insight into the illness, so they tend to default because they have the notion, "I have been to hospital, I received treatment, I am better now, that is it, so it comes back to education, and the rehabilitation period while they are in hospital that is now non existent, you know, to a large extent

They felt that education about the illness and need for treatment compliance happens less so than a few years ago when Valkenberg Hospital had more staff. Furthermore they said that the hospital does not employ an interpreter for Xhosa speaking patients.

Care giving relatives all linked non-compliance on treatment very strongly to readmission of their mentally ill relatives.

Client 2: Thabu

Thabu 's mother said he reneges on fetching his medication from the day hospital, because he feels he has been on the treatment a long time but it does not help. Part of his lack of insight is that the medication cannot cure him completely instead only alleviates symptoms. It cannot fix his broken dreams. So he gets frustrated. He is one of the unfortunate few who break down within days of non-compliance. His

mother describes that when he is ill he believes that she has bewitched him, but that when he is well he cannot understand why he thought that. She accompanies him to the CHC (community health centre) to get his medication, but he often disappears. He is disinterested in psychosocial rehabilitation groups.

Client 5: Shahieda

One elderly mother finds it difficult to supervise medication compliance of her daughter Shahieda. Ironically due to poor treatment compliance Shahieda is not well enough to do things that would restore self-esteem, like walking her children to school. In all in-depth interviews care giving relatives referred to how non-compliance rapidly leads to relapse and readmission, with comments like "...he don't take his medication, that is the whole thing...". They described how clients feel frustrated that despite taking medication they will likely never again be employable, because treatment controls but does not cure severe mental illness. Relatives indicated that although clients may have coarse insight into the illness when well, this wanes when mentally ill. Interestingly they all said that clients cooperate with readmission to Valkenberg Hospital, even if treatment noncompliant in the community.

Client 3: Thandi

An interesting permutation of denial of mental illness was in the case of the Thandi who had HIV+ diagnosis. Her daughter's words were "So her problem is that she did not want to accept that she is HIV positive, then it end up affected her in the brain..." She hides behind the secondary diagnosis of mental illness, somehow more socially acceptable. They dealt with the emotional trauma through frequent readmissions.

Client 6: Paul

Paul the mental health care user explained how he loses insight into his illness when he is psychotic. He is then potentially a risk to himself and others, which results in frequent re-hospitalisation. Below describes how hard it is for him to manage his illness when it inevitably recurs, despite treatment compliance.

I am one of the unfortunate where medication does not really contain well, I actually get sick while I am on medication, I get high while I am taking the medication, I usually stop my medication once I have side effects, I think I am a fantastic person there is nothing wrong with me, there has been a misunderstanding the whole time, and then of course it gets worse and worse. What I am trying to say is that, um, I have had 34 admissions; I think it is 34 or 35, I have lost count...

Paul describes one of the problems connected with frequent readmission, as difficulty in confiding about his de lusions to family or professionals, as his first breakdown and admission to Valkenberg Hospital was so traumatic and mismanaged. Recently he has built up a trust relationship with his psychiatrist and two social workers, and he thinks may prevent readmissions in future, and certainly assist toward rehabilitation.

<u>Paul:</u> But what I had to learn is that I have had to get insightful. I am waiting for that first delusional thought. I will stop it in its tracks, so important. It happened, it was quite scary. I know it is going to come back.

Paul stressed his need for the health professional to explain symptoms when he becomes mentally ill, even if his insight is poor as psycho education does help.

<u>Paul:</u> You know what Dr L said to me about the random impulses and the cortex, I remember 30 years later, and I am still thinking about it, you know...so it might not happen immediately, [my] response, but... I sure wish I got more of that stuff...

2.2. Role of substance abuse

Community mental health nurses said they frequently arranged readmissions of clients where psychosis was co morbid with or induced by substance abuse. Tic tic, a popular drug, has become cheap and freely available over the past year, and is impacting heavily on mental health. One said that clients with drug-induced psychoses never attend clinic, and mostly all stay in the informal settlement, where they are untraceable. Valkenberg Hospital nurses said from their observation there is a high prevalence of substance abuse amongst psychiatric patients and that encourages non-compliance

The Substance of choice in the Western cape, in the Peninsula is dagga; it is cheap, freely available. Even those patients on disability grant can easily purchase dagga. It is cheap. And Dagga does have a sedative effect. So here I am with my high levels of anxiety and voices that are chronic, dis-ease in general and not coping well, and suddenly I can medicate myself with a substance. But there is a huge percentage of patients who are not taking their medication, so a small amount of people will take [their medication] despite their dagga use but the problem is that once they go too long they forget about their medication, and then they get a relapse.

Care giving relatives confirmed the above, the worst being that clients using drugs and alcohol are more likely to be treatment noncompliant.

Client 1: John

John's mother said that she noticed cannabis had a calming effect on him.

<u>Sister</u>: He doesn't actually smoke it on a regular basisNow and then when he may go to the corner....

<u>Mother</u>: And then the friends will give it to him and if they smoke, they will give him a puff, but he will never go to go buy it for himself.

<u>Sister</u>: Yes. But when he has the puff, then he's so quiet [R1: laughing] Yes, very quiet. You know there was a time when I just thought I wish I could buy him a world of these things just to get him quiet, that he can just sit there and smoke and smoke and smoke!

<u>Interviewer</u>. And he doesn't perhaps um I don't want to suggest that, like if he has had a few puffs at the corner, is that the day he forgets to take his medication, or not necessarily?

<u>Sister</u>: Not necessary, no not necessary. Just when he takes a walk down and whether he's had his medication ...we don't know, we can't really tell you. As I said, he's not like an addict.

Client 2: Thabu

Thabu's mother said that cannabis makes him more aggressive and his mental illness worse. He has no insight in this regard. When he uses cannabis he forgets to take his medication. Although she discusses this with him in the few periods when he is well, he ignores her advice.

Client 3: Thandi

One caregiver related that her mother, Thandi uses alcohol as self-medication, perhaps to emotionally cope with having HIV. She drinks alcohol with youngsters, is sexually disinhibited and behaves in an age inappropriate way. If she could stop alcohol use, possibly she would not need readmission to Valkenberg Hospital for risky behaviour that jeopardises her own safety as well as that of others.

<u>Daughter</u>: It is recently at this present, I think she doesn't want to accept that she is in this condition. Now she decide to commit suicide the way she is doing. I told her that she couldn't use treatment at the same time alcohol. She uses to yell at me and told me to look at myself because she is the one who is sick and she is going to die not me. She always is yelling at me with that.... I go in the evening and give her late tablets, she uses her medication but she doesn't want to accept her condition, because she can't mix alcohol plus medication.

2.3. Caregiver Fears And Lack of Knowledge And Insight

Care giving relatives expressed uncertainty as to what illnesses like schizophrenia were, either that doctors had not informed them, or they had not understood.

Client 3: Thandi

Her relatives had been unaware that the mood disorder and irreversible organic brain damage were due to the HIV+ virus. They had not been informed, as Thandi did not want her HIV+ diagnosis disclosed. Furthermore they did not understand why she could not stay in Valkenberg Hospital permanently, and kept having her readmitted.

Client 4: Kallie

Patients as well as relatives often continue in their lack of insight, despite psycho education. Kallie's sister-in-law did not think that psycho education could help Kallie to understand his illness and co-operate with treatment. She thought he would always need frequent readmission for his illness, and that no amount of professional health input would change that fact. Caregivers blamed the illness rather than the person, even as in the comment below from Kallie's sister-in-law:

It is only he himself that is to be blamed for this. [small pause] But shame ... I cant make that statement. He is not right; so I cant even say he is to blame. That would be very wrong. It is his sickness.

Caregivers interviewed all believed that Valkenberg Hospital was the appropriate place for their sick relative to spend a greater part of the year, in keeping with the custodial role that mental institutions have historically served in society.

Ignorance of the process of mental illness links to frequent readmission. One of the community mental health nurses described a scenario where a client was discharged from Valkenberg Hospital on Clozapine, but attempts to persuade the relatives that the medication was necessary to prevent a relapse were unsuccessful.

Comments from the community mental health nurses were that frequently relatives are insight-less and rejecting, as comment below:

The reason why they do that kind of things, they just want to get rid of the patient. They are having a conflict with the patient, are accusing the patient, not getting along with the patient, or they don't understand the patient, or they don't want to understand the patient, even if you can point out to them, as far as you have gathered, that the patient does not need any readmission. But they will keep on saying, but he needs to go to Valkenberg Hospital, you can see that they are angry.

2.4. Community Stigmatisation

Community mental health nurses reflected on the need for public awareness and mental health promotion to address the problem of frequent readmissions, and how society out of ignorance stigmatises and rejects mentally ill people. Their comment below relates how the media fuels public fear and stereotype around mental illness.

But I bet you if you asked anyone (from the public) about that poor psychotic woman who killed the eighty year old women by slitting her throat with a knife in the shopping mall in Gauteng last week, they would tell you it was someone with a split personality. Now anyone with a diagnosis from Valkenberg will be looked at with suspicion... The media give the gory details but do not make use of the opportunity to educate the community. That is why mental ill health will continue to be stigmatised and why ignorance will continue.

Valkenberg nurses said that often patients prefer the anonymity of inpatient readmission. Their mental illness would become public knowledge at their local CHC. Care giving relatives spoke of pressure from the neighbourhood that mentally ill do not belong in society and should be readmitted to psychiatric institutions.

Client 1: John

<u>Sister</u>: He's been shunned by the community. Our community don't accept people like that.

{They think}As a family we are abnormal and they think we treat him (John) like a dog.... There is some people that understand, but some people is very illiterate, you understand, so unless they stay with a person like that, they don't know what we have actually going to go through... Oh my children! I feel sorry for them. They are embarrassed... 'You got a mad uncle!' The one child said at school, 'Is that your uncle, you got a mad uncle!' ...Society presses him (John) down too. The children teases him, they aggravate him sometimes, throw him with stones because they know he becomes aggressive, you understand. They call him names, name-calling, you are mad

Case 3: Thandi

Thandi's daughter's described the shame and double stigma of the HIV+ diagnosis and mental illness as such that Thandi cannot admit to or talk about it to anyone. As an outcast from society, she is seen as a mentally ill waif needing psychiatric asylum.



Client 5: Shahieda

Shahieda's mother said of her ten year old grandson:

When [Shahieda] is walking in the street and the people said to her "You are mental" he just say "Mommy don't take notice, just ignore the people..."

THEME 3: LACK OF SOCIAL SUPPORT SYSTEMS

From what respondents reported disruption to family functioning and breakdown of support systems as result of the mental illness, is indirectly predictive of frequent readmission. Mental illness erodes the individual and wider family's support base, and a self-perpetuating cycle ensues whereby their mental health is further damaged.

3.1. Social Stigma and Alienation That The Mentally III Person Experiences

Society stigmatises mental illness and rejects people who have mental illness, the result being that they have to stay in terrible social circumstances because they are outcasts of society. Their inability to take independent control of their lives makes them vulnerable to being easily exploited and abused by an unsympathetic society. Their social support system implodes, and their very selves become gradually diminished, until they cannot cope in society, decompensate and have to be readmitted.

Community nurses discussed the alienation the client feels living within the home context because of the label of mental illness. The feeling of not belonging in society, indirectly contributes to frequent readmission. These are some of their comments:

The reason why they do that kind of things, they just want to get rid of the patient. They are having a conflict with the patient, not getting along with the patient, or they don't understand the patient, or they don't want to understand the patient, even if you can point out to them, as far as you have gathered, that the patient does not need an readmission. But they will keep on saying, but he needs to go to Valkenberg Hospital, you can see they are angry.

... All about accommodation. ... But above that, once you have a psychiatric diagnosis your autonomy gets taken away from you. You are no longer an adult allowed to make decisions for yourself. You cannot have a normal emotional response., without (Imitating the relative): "jy raak weer hand uit, jy word weer siek, jy moet na die suster toe gaan en die extra inspuiting vir die maand kry, because this behaviour is unacceptable. Often what you have to explain to people, besides the diagnosis this person ha a personality and they have a brain. They can think for themselves. And its like all that gets taken. They want to take over everything for the patient. (Imitating the relative): "Gaan nie soontoe, trek daai aan, jy moet so maak, doen dit, doen dat, moenie so maak". And they are very restless, these patients, and they walk up and down, and they smoke a lot. Yes it is taxing on the grant, but it also minimises the side effects of medication. (Imitating the relative): "Suster, sy bors! Hy weet hy kannie soveel rook nie (giggling), en hy loop heel dag op en af". You know, small things irk them. But it is part of living with a psychiatric patient.

...Because sometimes the devolved patients come to us and say... maybe an argument with a sibling, who is maybe a drug addict, stole his tablets, and smoked it, became drunk, arguments whatever. The first person that always gets blamed for any altercation in the home is always the psychiatric patient.

Community mental health nurses observed as below that patients find the psychosocial rehabilitation groups in the community supportive, some of which take place at the CHCs.:

...Yes because they share their problems, they share their feelings they visit each other they even make friends ...so and so is at Valkenberg, going through a tough time they really care for each other, they check on someone not coming to group...The other thing quite a few clients mentioned, that people are functioning at different levels in the same group. The higher functioning they go once or twice stay away because or they say no these patients too sick, so to get the balance can be difficult.

The Valkenberg nurses commented that patients generally stay with relatives, who are unable to provide them with adequate care, as in the comments below:

...the lack of support once the patient is discharged. My experience now is that those people who came back... either does not have accommodation or there is no caring family member, and the circumstances that prevail in the community where the patient is staying, of course stigma and substance availability and so forth...

... the new thing is the HIV patients they tend to come back all the time, They are at home for one day, two days, then they are back in the hospital because people cant handle the side effects. We had one patient she was quite stable in the hospital. And the day her children came to fetch her, she became so unmanageable; she was running up and down. They took her but she was back in 4 days.

S: They just feel safer, more care, out of the stigma of their diagnosis

So people haven't learned really, or the families haven't learned to look after the people. If
there is one problem at home they bring them back.

Care giving relatives also shared rich and valuable insights regarding the link between social alienation and frequent readmission.

Client 1: John

John's mother and sister described how he could not perceive them as his support system; instead in the agony of his paranoia, he believes that they are trying to poison him. They said that he screams out in terror at night deluded that monstrous spiders are in his room. He refuses help from his family in respect of personal hygiene. The only ones with whom he has social exchange outside his home are the few who trade dagga with him. John cannot trust or relate to the staff at the clinic. He was evicted from Fountain House, a social club for people living with chronic mental illness, on account of his aggression.

John's mother: I think why he's frequently admitted to Valkenberg. In society, you know, it's difficult for them also. I see it from him, he's bored, he gets lonely. ... There's no activities for them, it's basically the same, there's nothing to look forward when the sun rise in the mornings for them to look forward to. There's basically nothing, nothing for them. So sometimes I think that makes him [awful] and because of his behaviour, society presses him down too. .. somebody just triggers him off along the road and he comes home and takes it out on us... No, no dreams, nothing, that's it Yes, he's got no purpose. John's sister: He's not like wasting his life, like How can I say? It 's like he's not worthwhile because he's nothing worth now because he's just roaming around........

Mother: Yes, he's just roaming around

Sister: He's lonely.

<u>Mother</u>: Yes, he's just for lonely

Sister: Where can he go to where he walks out of our gate?

Mother: Nowhere.

Sister: Who can he speak

Mother: Nobody to? Nobody

<u>Sister</u>: You understand? I think that's where the voices come backI think he's got too much things on his mind. People shunned him

:that he pays too much attention to the voices...?

Sister: Yes. There is nothing that occupies him, you understand, to take away these voices.

Client 2: Kallie

Similarly, Kallie's sister-in-law also described his frequent readmissions to Valkenberg Hospital as related to having friends and a second home there, comforting as his life aspirations have been frustrated. As a young man he had a prestigious occupation, before mental illness affected his cognitive abilities.

Client 3: Thandi

Thandi has both HIV+ and mental illness. Her daughter described this as precipitated by a husband who divorced her, then a younger lover who discarded

her, shame and feeling she could not confide in family. It seems neither she nor her daughter can come to terms with the role reversal of care. Thandi appears to have no close female friends or relatives in her peer group, although she has the sister with whom she is now staying. She did not confide and find comfort there, as should have happened. Instead frequent readmission to Valkenberg Hospital offered Thandi strange salvation.

Client 5: Shahieda

Shahieda's mother and brother feel that her role in society as a wife and mother has been snatched from her, as result of her mental illness and her unresolved marriage break up triggers further psychotic relapses. Shahieda's husband denied paternity of her second child, who died by cot death. Childbirth also seems to trigger mental illness for Shahieda. Her children were taken from her and are being reared by the paternal grandmother. They stay down the road so Shahieda visits them frequently but nevertheless mother and brother think the loss preys on her mind and results in frequent readmissions. They describe how Shahieda sees Valkenberg Hospital as her support system, and has made friends there, whom she meets up with during mutual frequent readmissions. It is a haven for when home pressures get too much to handle. Shahieda's family report that she likes the quality of care at Valkenberg Hospital, the food is good, the environment attractive, company interesting and staff compassionate.

3.2. Strain on family relationships

Client 1: John

John's immediate family tolerate his condition, but related that lack of supportive relatives or friends and ostracisation by the neighbours added to the heavy burden of care and contribute to his frequent readmission. Church friends and extended family do not assist them, and as such they feel very isolated and vulnerable.

<u>John's sister</u>: Our neighbours are also fearful of him. They step back.

<u>Johns' mother</u>:. No one help us, no one help us [<u>sister</u>: They are scared, they are scared]. Everyone stand back.

<u>Sister</u>: Yes, they see him smashing things up; sometimes I am not at home, smashing my mothers' windows and everything ...

Mother: Yes, he smash and he hit me. He chased me with a broom, then I can't come out, I must first see where's he, I must first see where's John.. If I don't see him, then I have to lock the door and go out quick on my business.

Family gatherings are disastrous, as on the last occasion where John overturned the dining room table where the guests were seated for dinner. He wears down the family self-esteem by his constant delusions that they stink and depletes their energies, as they must be constantly vigilant for his aggression. They further described how his nieces are growing up under fearful circumstances of not knowing what next to expect, such as the time he unexpectedly chased and tried to physically assault the 9-year-old niece. This also causes tension in his sister's marriage relationship, even though her husband is understanding and compassionate. Her husband suffers estrangement from his own parents, siblings and their families on this account. They say how when he is readmitted to Valkenberg Hospital, it is a respite from constant strain that John's illness imposes on them as a family.

Mother: Yes, it's a holiday, a vacation

<u>Sister</u>: Outside, we can sit a little bit in the sun, enjoy some company, just in and out... you must see, my whole house is full of friends [laughter]...

<u>Sister</u>: The minute he's in for a few days, we say, "Oh, look how nice and quiet is it. When are they phoning us now to say we must come fetch him."

Client 5: Shahieda

According to Shahieda's mother who is frail, arthritic, and widowed the family take strain in that they all have health problems. Shahieda has a brother who suffers from severe mental illnesses, another brother who is quadriplegic, and one working unmarried diabetic brother who on a teacher's salary is the financial provider. They seem overwhelmed by each other's neediness. A few years ago as a larger family they were all crowded into a tiny council house in a lower socio economic area. When they were younger the two mentally ill siblings would be pacing around the tiny house in their psychosis, performing and shouting, playing music loudly all hours of the night. This distracted the younger sibling from his Matric studies.

Client 6: Paul

Where people stay together in a supervised group home for those with mental illnesses, the strain also takes its toll, leading to readmission as described during the in- depth interview with Paul, a frequently readmitted mental health care user.

<u>Paul</u>: You cant have a ... floridly psychotic patient staying in the house with other mental patients...'A' It does get infectious, and 'B' it is hugely destabilising for everybody. We have had a case with ... who was really went off her rocker a few months ago, and you know it really was difficult to cope with, I mean she trashed our joint...(laughing very nervously)...I see Comcare as my sanctuary and now my sanctuary has been defiled! How can this happen in this sacred place, you know? It was difficult to cope with...

Valkenberg nurses confirmed caregivers' accounts that sometimes patients are frequently readmitted because they are so chronically and severely mentally ill they cannot be cared for in the community, especially where there are other family members with needs such as children, the sick and elderly.

3.3. Burden On Primary Caregiver

Client 2: Thabu

This is well described in the case of Thabu whose mother works as a nurse aid to provide a living, so is away from home for a few days every week, and has no way of supervising Thabu's care. She must cope with the impact of his chronic psychotic illness herself, having no family to assist her. Thabu was brought up by his grandmother in the Transkei, and after her death came to stay with his mother, a situation that she feels he could never accept. He has not married, due to his illness, and is likely to remain dependent on his mother indefinitely, a situation which likely they both resent. Her husband died and she lost her other two sons tragically, in incidents of violence. There are no other surviving children.

Mother: he doesn't stay in the house. I am working night duty. If I have gone to work... when I come in the morning he is not there to have his medication and breakfast...

I am responsible for him, and um, he is my son, I never knew, I don't know how can I put it, it seems as if it was not enough to be his mother... I don't know. The way he said there at the grave, "I wonder who is going to look after me now when you are dead, granny..."Sometimes it affects my work, because like now I was supposed to work that weekend, I couldn't, I had to tell my boss, I wont be able to be on duty, my son has done that... Because he is not stable at home, he is in and off, wandering around at night, and I am working night shift, he is uncontrollable, there is no supervision while I am at work.... The social worker tried to find accommodation at Maitland...he told the sister that he was ill treated and starving so he did not want to go back there...

Client 1: John

John's mother described the impact on her physical health as follows:

<u>Mother</u>: He upsets me, yah. Lady, I had an open-heart operation. When T... start getting sothen my heart beat fast.

Interviewer: When did you have the operation?....

Mother: In 1986. And since that time that T... was fighting and going on with me so my heart become weaker, weaker and weaker...

Client 4: Kallie

In another case mother used to be primary caregiver but as she became increasingly frail so her mentally ill son, Kallie became increasingly demanding and physically aggressive towards her. When this collapsing support system imploded his brother and sister-in-law reluctantly took him to stay with them. Kallie just boards in a back room as his brother would not want him to live on the street. However Kallie wanders away from the home early in the morning so his sister-in-law has no control over whether he takes his medication.

Client 3: Thandi

The daughter described tearfully how emotionally hard it is to care for her mother, Thandi, who is HIV+, with a secondary mood disorder. She expressed relief now that her mother has gone to stay with her aunt. This works better, but she must supply meals for her mother every evening and pay financial costs. So the support system of extended family does not happen smoothly. She is young and recently married with new responsibilities to her in-laws, as is Xhosa traditional custom.

3.4. Poverty And Social Problems

Both Valkenberg Hospital nurses and community mental health nurses emphasised the link between social problems and readmissions. A patient may get a disability grant, but still have nowhere to stay, may roam the streets, and eventually be re-hospitalised. Community mental health nurses in the conversation below, related conditions for those living in substandard boarding houses:

JeanMaitland boarding houses... we are always talking about (the terrible state). Patients are just left in the home... the TV out there (in front yard?) ... the world so help me... two months ago a patient stabbed a five-year-old child to death in Maitland. This is what is happening there. Things that go on at the boarding houses. But nobody is <u>interested</u> in helping the patients.....

<u>Katie</u>: Smoking up. When you walk in, the rats!! They run around. I have been

<u>Katie</u>: Smoking up. When you walk in, the rats!! They run around. I have been working there for ten years. People stab one another, stealing each others medication, smoking it up, they knife one another, they bite one another!

<u>Lettie</u>: They still discharge these patients to those boarding houses. Especially patients who have been in Valkenberg a very long time. They are very institutionalised. They see the other patients as their family, they are placed out... from that day on they have no contact with their "family". I think it is cruel! So cruel! And the stress I have seen them go through, looking for that they left behind. They mourn! ... Where the boarding house owner abuses them, he plays DSTV throughout the night, he wakes them up in the middle of the night to fetch a bottle of Coke a Cola [brandy mixer] from the garage for him, the patients can't sleep because of that racket, get agitated, easily provoked into a fight

Katie: Substances.... The community is sick already and the patients are coming out. They discharge these people when substances are flooding the streets. Amazes me that the Government can spend a large amount of money treating and deinstitutionalising but no money on rehabilitation afterwards, no providing of group homes. Instead they go to unsuitable boarding houses. It undoes all the work into getting these patients well and healthy. The emotional trauma that the poor person has to go through.... Why are they not being put into suitable places, it is wasting of money, never mind the emotional trauma...? Lettie: I have been in psychiatric nursing for 14 years. This is my 15th year in community psychiatric nursing. I have had connections with night shelters. Many years ago they were for the homeless. They were mentally well but homeless. Now the night shelters are like an extension of Valkenberg Hospital. The Ark is an extension of Valkenberg Hospital. All the discharged Valkenberg patients go to the night shelters, the street, the Ark All these nongovernment places.

The comments about night shelters being "extensions of Valkenberg Hospital" were vociferously repeated in the second focus group session with community

nurses. They spoke of how degrading social conditions put disabled people at heightened risk for mortality and morbidity, including readmission to Valkenberg Hospital. With proliferation of night shelters and mushrooming informal settlements to accommodate homeless people, large pockets of impoverishment and deprivation are growing in areas previously advantaged. Valkenberg drainage area's client base has become demographically poorer over the past two decades. There was comment that downward social drift, alienation from family and marginalisation from society is known to be associated with psychiatric disability.

Community mental health nurses further discussed clients who are poor and suffer hunger. There is a public perception that pills should not be taken on an empty stomach, which adds to the likelihood of treatment non-compliance. High dosages of psychotropic medication need to be metabolised, increased metabolism often requires greater food intake, comment being "There is nothing like psych meds to make you hungry!". One group member said how travelling distance discourages clients from community follow up treatment:

There are two informal settlements at Hout Bay and another at Noordhoek. Patients sometimes come all the way via Kommetjie..... They mainly rely on public transport or walking. From Masiphumlele settlement they usually walk half the way, or maybe get picked up by a car. Patients come all the way But to walk that whole distance ...as some do.... Is far.

In short, the link between social conditions and frequent readmission is that patients decompensate, experiencing increased symptoms of mental illness that eventually lead to a readmission. One person said that her clients from Crossroads also seek readmission for respite, because they get access to food, a bed, general

health care, and 'Boxer' tobacco. They experience Valkenberg Hospital as a refuge. Another said,

"Their quality of life is so pathetic and horrible that they prefer to be in Valkenberg Hospital. They have an attitude 'well, I might as well not take my treatment, if I am in Valkenberg Hospital I will be better off', so there is no incentive for them to be mentally well".

Others find escape from desperate conditions of abuse and domestic violence. One community nurse said how for females with major depressive disorders from the Heideveld and Manenberg area, she frequently increased the medication dosage from what had been sufficient at inpatient level, because these women were discharged to such appalling home circumstances, that they became depressed and decompensated again. Many living in areas torn by crime, violence, drugs, gangsterism and killings suffer from chronic post-traumatic stress disorder. It would be abnormal not to be depressed, living in such circumstances. Husbands and children are often the sources of stress and violence. For them, a readmission to Valkenberg Hospital enables them to regain a little strength to somehow continue coping in the community.

THEME 4: LACK OF ADEQUATE CARE PATHWAYS

The correct care pathway is that initial screening and assessment for mental illness occurs at the local PHC level. Clients are referred from there to Valkenberg Hospital for inpatient treatment if more specialist psychiatric input is required. Inpatients assessed for severe mental illnesses in Valkenberg Hospital are discharged and usually referred back to the local CHC, for long-term

psychopharmacological treatment and rehabilitation. If a client requires readmission, referral in terms of the new Mental Health Care Act 2002 should preferably be made via PHC level, alternatively via any mental health practitioner or as an urgent admission directly to Valkenberg Hospital.

4.1. Readmission from the Community back in to Valkenberg Hospital

Community nurses said that typically Valkenberg Hospital does not phone to advise when a patient is readmitted, and they are left to wonder why the person did not arrive at the CHC for medication. Another common scenario is that patients revolve in and out of Valkenberg but never report for prescribed follow up treatment at the CHC. They reported that frequently they arrange readmissions of patients to Valkenberg Hospital, for some as regularly as 3-4 times per year. Often such readmissions can prevent severe relapse, costly both to the client's health and quality of life, as well as financially for the health services. From their perspective no inappropriate referrals for readmission go through PHC level to Valkenberg Hospital. The point at which a community mental health nurse arranges a readmission to Valkenberg Hospital is when the patient becomes violent, a danger to self or others, uncontrollably aggressive and disruptive, and is too psychotic to co-operate with treatment at the CHC. Suicidality and substance dependence are often part of this. They said relatives quickly request certification on social grounds of wanting to "get rid of" the mentally ill person. As frontline service providers they often avert unnecessary certifications, by other options like increased medication. This is not without its own stressors, such as relatives who desert the mentally ill person at the clinic, on a Friday afternoon. The group perceived that

'walk ins" to Valkenberg Hospital were rare. Mostly Valkenberg Hospital refuses to accept readmissions where referral protocol was not followed.

Valkenberg nurses described how most patients referred genuinely do need readmission, because they are so psychotic and have been off treatment for a while. Usually they were readmitted through the public health sector and magistrates' courts. They said that sometimes community nurses are so desperate that when Valkenberg Hospital is full they will force a readmission though involuntary committal, which is a contradiction of patients' rights for those who would come voluntarily.

Valkenberg Hospital and community nurses said that psychiatric beds are non-existent at secondary hospital level, due to lack of staff capacity, although according to the Healthcare 2010 plan they are supposed to have 6-bedded psychiatric units. One of the group related how she arranged admission to Jooste (secondary hospital) for a patient, while awaiting a bed at C23 Grootte Schuur (tertiary hospital), however it transpired that Jooste Hospital was less medically equipped than the CHC, and the patient receive d no psychiatric treatment while there. Valkenberg nurses said that tertiary and secondary hospitals send through patients for assessment even when told that Valkenberg Hospital is full, the ambulance not even waiting to hear whether the patient meets the criteria for admission. This impacts on the Valkenberg service, as other sick patients must then be prematurely discharged.

Care giving relatives described the different routes they would follow to get a mentally ill relative readmitted to Valkenberg Hospital.

Client 2: Thabu

Thabu's mother who lives in Gugulethu, a poorly resourced area described the hard, circuitous route to get her son, Thabu readmitted when he is severely mentally ill. She phones the police to take Thabu to the district surgeon and then goes to the magistrate's court for involuntary certification to Valkenberg Hospital. However the police can never help her at the critical moment. Meanwhile she gets the CHC mental health nurse to keep phoning Valkenberg Hospital until there is a bed available for him, and to arrange ambulance transportation. She has tried to lay criminal charges with the police after repeated violence of her mentally ill son towards her and the neighbours, but they refused to accept her charges because they think he should go straight to Valkenberg Hospital rather than through the Department of Justice. The experience of this relative was that there was no recourse to safety through appealing to the justice system.

Client 1: John

John's mother said how helpful the police were, accompanying them to the district surgeon, then the magistrate for an involuntary certification for John to Valkenberg Hospital. Like Thabu's mother, she said she had been advised by the psychiatrist to press criminal charges for assault, but did not want John mixed up with criminals in Pollsmoor prison. Her understanding was that he would be kept in Pollsmoor awaiting trial for an unspecified time period, then sent for a 30 day psychiatric assessment at Valkenberg Hospital, probably be found mentally unfit to stand trial,

and kept indefinitely as a State patient in a medium security ward at Valkenberg Hospital.

Clients 4 and 5: Kallie and Shahieda

Relatives of Shahieda and Kallie described how they put them in the car and drive straight to Valkenberg Hospital. The clerking doctor just admits them as they are well known patients and usually very psychotic. They have not been referred via the primary health care nurse. Shahieda's mother gave the following account:

The other time (her brother) take her to Valkenberg they say, "No, you can't bring (her) here. You must first have a letter form the court." He came home and said to me "Mommy, what are we going to do with this woman? They don't want to admit her!" ... so (he) put her in the car again, and he went again. He knock on the door and say "Hello, this woman are going to walk! And if she is going to walk and anything happen to her, I am not responsible!"

...As sy handuit te raak sal ons haar net in die kar sit en haar Valkenberg toe neem. We don't go to the clinic because the clinic can't help you. If [Shahieda] get aggressive I wont go anywhere, I will just tell her look Mr Mandela put the hospital there, and go put her there. Because I can't cope with her. That is why I say they can keep her a week or so and if she is al right she can come back again. Only to stabilise her, you understand? Client 6: Paul

He explained that he has poor recall after a psychotic episode, but thinks caregivers at his group home arrange readmission when symptoms of his illness recur, before his illness becomes unmanageable, to avert major distress for other vulnerable residents with chronic recurrent mental illnesses.

4.2. Period from Date of Admission to Discharge from Valkenberg Hospital

Valkenberg Hospital nurses said that patients are discharged prematurely from Valkenberg Hospital due to pressure for beds, as result receive only crisis intervention, and are then discharged back into communities where there are no

support structures to receive them. Psycho education and psychosocial rehabilitation in the hospital happens less than it did a few years back, because patients are discharged too soon. They felt it could thus be expected that patients will relapse quickly necessitating readmission because patients never have the chance to develop the insight and judgement that would enable them to co-operate with treatment.

<u>Valkenberg Hospital nurse</u>: They start a group, which maybe needs 3 sessions to prepare the patient, you know to deal with whatever outside. Patient comes to the first group she is gone. Next week they have to repeat the same story because they have new patients in the group again. You can't plan a proper programme

These nurses felt further that new legislation namely the South African

Constitution, and Mental Health Care Act 2002 emphasise human rights,

psychiatrists are far more cautious about high treatment doses than they used to be
and veer towards under medication.

<u>Valkenberg Hospital nurse</u>: So we go in there tip toeing over the psychosis, which means in any case it is going to lengthen the patients stay because of patient taking so much longer to actually settle. I don't say you must hit them cold. but I just mean we don't treat psychosis as aggressively as we did before

The community mental health nurses shared the above perception of a cyclical problem at Valkenberg Hospital whereby patients are discharged too soon thus setting in motion an inadequate care pathway in respect of follow up treatment in the community, and 'revolving door' re-admissions. They suggested that the following from Valkenberg Hospital side would improve communication:

<u>Community mental health nurses</u>: And then from there <u>before</u> the patient is discharged you make contact with the sister at the clinic, to arrange to get the clinical summary out, to

educate patient and family, 'Where to from now?' They came to the big hospital. They are going home into the real world with all the social problems that came before the diagnosis.

Care giving relatives reported no communication problems of note with Valkenberg Hospital staff, except that frequent changeover of doctors impacted on relationship building and continuity of care, and they were frustrated that Valkenberg Hospital no longer offered long term residential care, as below:

<u>Interviewe</u>r: Tell me, Mama, are the Valkenberg staff like doctors, nurses and social workers helpful to you when for instance, you ask about your son's progress at the hospital?

<u>Respondent</u>: No, sometimes I get help but most of the time I do not get any help, for instance I asked the doctor and the superintendent that I experienced some problems to stay with my son, then I thought it will be much better if the doctor or superintendent can keep him for long term in the hospital but the only answer I got was that it is not the hospital rules to keep the patient in the hospital, when she or he is well we discharge them.

Care giving relatives and the frequently readmitted client all said that the admission period, usually two to three weeks, was too short, and did not allow time for rehabilitation, as frequently the client is ill again in less than a week. Some described Valkenberg Hospital as a second home as in this comment:

"Mommy I don't want to be in that home, man [Fisherhaven Group Home], you can rather put me for <u>life</u> time in Valkenberg Hospital, I like that place."

4.3. Referral Process from Valkenberg Hospital multidisciplinary team to Mental Health Nurse at Community Health Centre, PHC level

When discharged from Valkenberg Hospital, a patient is issued with a registrar psychiatrist's referral memo that must give diagnosis, follow up treatment, dosage, routine investigations required, name of local CHC and date of CHC appointment. Continuity of treatment is further ensured in that a copy of the clinical discharge

summary is forwarded to the CHC and the original remains on Valkenberg Hospital medical records. Valkenberg Hospital nurses reported no significant communication problems with the community mental health nurses, except for tracking down when they were at which CHCs. They felt that Valkenberg staff made a concerted effort to communicate regarding treatment management with community mental health staff.

The community mental health nurses however, did not share this view. They felt the communication channels between Valkenberg and community mental health services were poor, doctors did not take them seriously and patients were discharged too soon. They expressed sentiments of wanting Valkenberg Hospital staff to include them more in the treatment planning process of clients due for discharge. They concluded that as community mental health nurses they knew their patients well, which needed to be respected and appreciated. They motivated this by saying that typically they attend their patients for twelve months, whereas Valkenberg Hospital staff perhaps attend those same patients for three months in any year. "Scanty" clinical discharge summaries were identified as another source of communication breakdown, inevitably fostering readmissions and keeping treatment control locus at Valkenberg Hospital, instead of shifting it to PHC level. They recounted their frustration when the registrar's discharge memo gave sparse information, and Valkenberg Hospital's clinical discharge summary had not yet arrived. Their ensuing struggle to contact the correct person at Valkenberg Hospital to establish what medication the client required was a waste of valuable professional time.

They reflected on the poor referral pathway when clinical discharge summaries arrive up to a month late, and longer. They also said that almost 50% of patients referred via these summaries from Valkenberg Hospital to primary health care level for follow up treatment do not arrive. Instead these patients just continue to revolve in and out of hospital as the treatment wears off and they start to relapse. From how the group responded it seemed that across all areas these patients form the bulk of Valkenberg Hospital's frequent readmissions. One nurse mentioned that clients with drug-induced psychoses seldom come to her clinic, and mostly all stay in the informal settlement, where it is impossible to trace them. They also thought non-availability of medication was linked to readmission, in that clients relapse very quickly without it. If communication between Valkenberg Hospital and CHC staff is inadequate that can result in the CHC not ordering the required medication. The client may then think that medication compliance is not critical. The following comment describes some of the frustration experienced:

Discharged too soon...Sometimes the medication gets changed on the day of discharge so they start getting side effects. The patient may become severely dystonic. Families do not know what is going on get this person. The family get really worried about what is going on....Sometimes registrars don't want to take our advice, when we ask for depot medication....This patient...He should be on depot. He is a regular defaulter on oral medication, two weeks later back in Valkenberg Hospital. Since March to August four times back already. I phoned and asked him, please put him on a depot. Upsetting...

They felt that, if readmissions are to be avoided, patients known to be noncompliant should rather be discharged on injectable than oral medication. They related one non-compliant client discharged after only two weeks stay in Valkenberg Hospital, on a non-therapeutic dose of Clozapine, an oral medication that is increased gradually over several weeks to a therapeutic dose. They discussed how Clozapine is very effective for treatment resistant psychosis, and how doctors

under pressure to stabilise and discharge patients, devote insufficient care and planning to continuity of treatment with noncompliant patients in the community when they prescribe oral medication. Many clients cannot afford public transport to come to clinic for weekly monitoring of Clozapine. Interestingly the group reported better compliance on injectable medication, despite more unpleasant side effects. However comment from care giving relatives was that side effects for depot are much worse than for oral medication.

Community nurses said that the referral memo that the patient and family receive on discharge is often shoddily completed, sometimes by junior staff, the consequences of which can be life threatening. Certain psychotropic medication requires a careful referral and monitoring for safe treatment at community level. They reported no referrals from Valkenberg Hospital for patients to be linked to the PSR groups at the CHCs where they would receive support and psycho education. Care giving relatives interviewed were mostly unaware of PSR groups attached to CHCs.

Community nurses discussed anecdotally how communication channels seemed better in Stikland Hospital drainage area, with it's lower readmission rate. They pondered whether size, population and socio-economic disparities across the three drainage areas related to effectivity of care pathways.

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4.4. Treatment follow up at the Community Health Centre

The referral process for inpatients discharged from Valkenberg Hospital has undergone great change since 2003 with the devolution of follow up treatment for patients from the hospital Outpatient Department to PHC level, in keeping with implementation of Healthcare 2010 goals. Simultaneously mental health care is being integrated into general health care at PHC level.

Valkenberg nurses felt that devolvement from Valkenberg Hospital OPD to PHC level impacts on frequent readmissions because structures and staffing resources are not yet in place at community PHC level to receive these patients. Some clients resist being devolved to the CHC because they have built up relationships and confidence in clinical and nursing staff at Valkenberg Hospital OPD over many years, and have regular access to a psychiatrist. Community mental health nurses discussed this devolution as difficult for clients, because they are monitored less frequently, queues are longer, the routine unfamiliar. Psychiatric clients often have poor communication skills, and may react with aggression, paranoia, avoidance or unassertiveness.

However community and Valkenberg nurses groups were particularly anxious about integration of mental health care into general health care at PHC level. The mental health nurse tries to assist with the transition, but this places extra workload on her: up until a few months ago mental health clients attended a separate clinic at the CHC. Now psychiatric patients have to wait a long time in the mainstream treatment then medication queues at CHCs. They are unmotivated, lack insight, become bored, agitated and leave without treatment. Once off medication they relapse, and then require readmission. Comments from respondents were:

Community mental health nurses focus group: I think that one of the other reasons (for frequent readmission) is that we are devolving patients into a community that is not ready, there is no training taking place for these communities. They are being devolved from you to us [community mental health nurses] to mainstream. Once a month they come to us. Any problems they would discuss with us. Then we need to devolve. Then they see a medical officer once every six months. The rest of the time they still need to fetch their injections or medication. There is no place for them to go to say "I am tired. I have had an argument with my mother..... when we get them back they are sick.

<u>Valkenberg nurses focus group:</u> ...people tend to come back all the time because it is more comfortable. it comes back to that that you have to wait so long at the clinic. So it is better to come here because the doctors they are here....They will ask you "How do I get to Ward 14 [acute admissions]...so you can send me jump or fly..."

Community mental health nurses said there is currently little in place at CHCs to address impact of substance dependence on mental health. SANCA were involved in a joint substance detoxification program at PHC level with Department of Health, but this was aborted as being too costly to finance.

Care giving relatives in the in-depth interviews confirmed the difficult transition to mainstream health care, particularly the long wait in queues. They found the community mental health nurses helpful and friendly, but not so generalist nurses who were often rude. They said security staff were afraid when their mentally ill relatives became aggressive. Community mental health nurses reported that generalist nurses were resistant to psychiatric nursing and had not had adequate psychiatric training; drug regimes can be complicated for generalist-trained nurses to understand; and they frequently give wrong doses with bad side effects and other disastrous consequences. If not brought to the attention of the mental health nurse, shortage of pharmacy stocks results in clients being sent back home from the CHC without medication. They said how psychiatric clients need empathy, reassurance and encouragement to be treatment compliant, which as mental health nurses they have been trained to provide. When workload allows, the mental health nurse

accompanies the client to the pharmacy injection room, because if left to the primary health nurse, the client will likely leave without the injection.

General problems described by care giving relatives, as relating to readmission were as follows:

Client 1: John

John's sister: He goes to the day hospital but they complain there also

John's mother: Yes, they complain. He hit her, the one sister....

Sister: The one social worker there, or the sister that's in charge. He took his folder from

her and he destroyed in the

Mother: He destroyed everything in it

Sister: He said, "This is a lot of shit you wrote about me...." And he destroyed it.

Mother: Yes, he destroyed it. Sister: She's scared of him! Interviewer: After this ...

Sister: After this, Dr Ferguson, that's the nurse in charge.

Interviewer: Dr Ferguson's the psychiatrist?

Sister: Yes, he attacked her also.

Interviewer: At the clinic?

Sister: Yes, at the day hospital. He told security..... He chased my mommy once down the aisles.[laughter]

Mother: People asked, "Is that your husband?" "No, it's my son."

Interviewer: He was chasing you in the day hospital?

Sister: In the day hospital! The security couldn't even help my mother.

Mother: The security was scared of him

Interviewer: And then, is it the mental health nurse that he?

Sister: Yes, the mental health nurse.

Interviewer: And what do the other nurses think of his behaviour?

Mother: They just said, "We're going to phone the police." ...he is performing here. Sister: They just see, the minute he comes in, they give his tablets quick and then that he can go. They know ...then it's hard to get him out of there, because he swears at

everybody and ...

Client 2: Thabu

His mother described how she works night shift so only gets to the clinic with him at 8.00 a.m. by which time there is a long queue because others have been there since 4 a.m. She waits until mid afternoon in the queue. and has accompanied him in vain, if he disappears when he becomes tired and bored. The doctor or nurse is

not allowed to assess, adjust or issue treatment to the caregiver in the patient's absence. She related how a doctor at the CHC "stresses" her. He tells her not to press criminal charges against her son because he is mentally ill, whereas Valkenberg Hospital psychiatrists advise her to the contrary.

Client 4: Kallie

Kallie's sister-in-law said he simply refused to go to the CHC for his treatment, whether or not she accompanied him, resulting in frequent readmissions to Valkenberg. (According to his case history he was also treatment noncompliant when he attended Valkenberg OPD.)

Client 3: Thandi

A daughter described immense frustrations in trying to access comprehensive treatment for her mother for HIV+ and secondary mental illness. Her home language is Xhosa, and communicating in English added to the confusion. She was shunted back and forth from Grootte Schuur Hospital, Valkenberg Hospital, Washington HIV+ and TB clinic and Heideveld CHC. The frequent crisis readmissions to Valkenberg Hospital were a part of the help-seeking process.

THEME 5: LACK OF RESOURCES

All research participants related how due to lack of resources the nature of health care is crisis intervention orientated, underlying social and health causes are not addressed, community support structures for the mentally ill are inadequate, as result they revert back into Valkenberg Hospital as readmissions.

5.1. Insufficient bed capacity at Valkenberg Hospital

Valkenberg Hospital and community nurses groups perceived frequent readmission as being related to patients being discharged too early before adequately stabilised. This was due to pressure for beds and number of beds too few for the number of patients genuinely requiring admission. Valkenberg nurses said that higher patient turnover at Valkenberg Hospital than at the other two psychiatric hospitals related to the service of a larger, more heavily populated catchment area. Similar comments were made by consumers:

<u>Paul, the mental health care user:</u> I am just thinking of what can be done to change the situation. You know I really thing that it is a question of more beds in the hospital, so that people don't get shunted out before they are well, um, just having to move on because a bed has to become available on the ward for a sicker patient...

<u>John's mother</u>:...no place for him because they need to make a bed available for the next patient, so I think sometimes they're just forced to send him home.'

5.2. Insufficient Resources at Primary Health Care Level

Valkenberg nurses said implementation of Healthcare 2010 at APH level has happened faster than what the community health services could keep pace with. Both Valkenberg and community nurses said that unfortunately infrastructure and resources have not followed patients to community level and that secondary hospitals have not stepped into the breach:

Valkenberg focus group member: I think I suppose another contributing factor, <u>major</u> ... 2010 plan for Health, it was decided that hospitals would be made smaller, community based care would be more but unfortunately the one happened and the other is <u>still</u> not in place now that we are in 2004 Hospital trying to devolve a lot of patients into the

community. I think because those structures are not really in place, it also assist in a way in a lot of patients landing up back into hospital, on a very frequent basis

<u>Valkenberg focus group member:</u> The way how the 2010 plan that local hospitals should have in place a 6 bedded ward where they are able to hold psychiatric patients. Up to now they would say that they don't have the staff, the trained experienced psychiatric staff to man the wards, they don't have dedicated areas in the hospital to keep those patients, so there is a patient that has to be nursed amongst the other physically ill patients with the result the patients are just being transferred to Valkenberg Hospital.

The Valkenberg Hospital nurses discussed dwindled staff resources as below:

<u>S:</u> Previously patients were not that reluctant to go to their community clinic to get their medication. Because also they were able to see a doctor I think more frequently than when they come here. They would at least see a doctor every 3 months or when they have a problem. Now the community sister has to deal with all those things.

<u>T:</u> But also the fact that the 2010 plan not completely in place yet. If we could have the community clinics jacked up in the way they have on paper, it should be able to work but at the moment the infrastructure is not in place, they don't have staff, there is one community sister per something The other day Sister 'F' quoted almost two and a half thousand patients, so how can you [as a community mental health service provider] spread yourself out?

Community mental health nurses expressed considerable anger at resource wastage, saying that spending at secondary specialist mental health care level has been cut but savings have not been transferred to PHC level. Furthermore ineffective referral of patients discharged from Valkenberg to CHC level resulted in poor utilisation of the few remaining resources. Excessive time to contact Valkenberg Hospital, lack of technical resources such as open telephone lines, computer networks and vehicles made communication difficult. Lack of staff resources and medication shortages also impacted on readmissions. Some of their comments were:

At times we do go and do home visits to our patients. But it is a waste of time, we left so many patients in the clinic, looking for one patient, spending one hour looking for the

address, then the patient is not there. It is worse when the patient is living in a squatter camp, or else the patient after discharge left for Transkei and you were not notified.

I thought I would bring up the shortage of medication. What happens they go to the pharmacy and get told there is no stock. Some of the patients go home without, a month later you notice strange behaviour, look at the card, see that he never got his meds.

The community nurses said generalist nurses at PHC level are disinterested in mental health care, partly because of ignorance and stigma attached to mental illness, partly because it is an additional workload. Resources have not been deployed to train them. Need for a caring ethic was expressed:

<u>Community focus group member:</u> Another thing you don't need nurses and doctors, you need an empathetic human being. You don't even need to be trained. You don't need a doctor to see a devolved patient. At day hospitals staff don't have the time.

Discussion followed that home-based carers are increasingly used at PHC level although not yet in mental health, and that their involvement, especially in support of treatment compliance could be very helpful. One nurse mentioned that use of community health workers as lay coursellors is already happening in Ocean View:

As jy siek word, dan maak die lay counsellor 'n afspraak vir jou by die kliniek......

...They go to the homes, see to their supper, give transport, help provide care. I think they only work in the South Peninsula...they are actually looking at training for these workers.

PSR groups are not fully functioning at all the CHCs due to lack of staff resources.

Many are run by NGOs who in turn have their own staff shortages.

5.3. Need for more Government funding for group homes in the community

Community nurses expressed strong views against the deinstitutionalisation of

patients to the community that has occurred without accompanying devolvement of

funding to ambulatory care and group home development. The inherent

contradiction is that money invested in specialist care at Valkenberg Hospital, is

wasted by premature discharge of patients to inadequate facilities in the community

where treatment and care cannot be sustained. Implicit was that health spending

needs to be backed by social development spending to prevent downward social

drift of the mentally ill and disabled. They felt that funding of affordable care for

the disabled in the community is less costly and needs to replace cutbacks on

tertiary and secondary level spending.

Caregivers also expressed strong views on the need for more group homes in the

community, geared towards those with intractable mental illnesses, alternatively

long-term stay at Valkenberg Hospital. John's mother expressed the need for more

residential and occupational resources for mentally ill people, particularly in

poverty-stricken areas. She felt the Government were doing nothing about the

problem, and that to criminalise the mentally ill was morally wrong.

John's mother: No, there's' no resources for us. Our hands is actually tied because you understand where do we go from here. The minute he's discharged here, he comes back to

haunt us. And where do we go from there again?...

John's sister: And Valkenberg already said we can't, you know, just bring him in and out ... We must make a case against him, so that he can land up in Pollsmoor. Now the big question there is, do he belong behind bars, with all these other animals, or have he got a

mental illness? Is he a criminal or does he suffer from some illness?

Comments from Shahieda's relatives were:

Shahieda's brother: ... The Government is not actually funding these homes.

Shahieda's Mother: Ja, that is why the places are closing down!

Brother: And there is lack of doctors also...

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<u>Mother</u>: If they can only had a place there in Valkenberg, say they got a section there, now the people, the parents happily say this look child don't want to get right, if they can keep them there for one full year, for a year, then they can give them that treatment for a year. The children they can give their grant, say for instance it is R700, they make it R1000, well the brothers and the other children they can come and put the other R300 in, keep this one there for one year, then that one will get well...

<u>Brother</u>: But there is too little doctors, and it puts a lot of strain on the doctors, the doctors can't cope.

5.4. Lack of Staffing Resources at Valkenberg Hospital

Community nurses said that inadequate staffing resources at Valkenberg Hospital no longer allowed the same degree of counselling, psycho-education, support and supervision to families of clients with mental illnesses, as in the past when there were more staff, particularly in nursing.

Paul, the mental health care user, in discussing his frequent readmissions as an inpatient, said it would help if ward staff and therapists took more time to engage with patients and to explain the course of illness. His comments were:

You know I kind of just went through the system, no interaction, there just weren't enough people with enough time, and its nobody's fault, it is the economy's fault, the governments fault, I don't know....I know, I trust S... (psychiatrist) very much and I know that what he does is for my best interests, but there is limits to what he can do, I mean he has got hundreds of patients, and he has got huge demands on his time...

...mmm, I mean, the staff in this hospital, I have seen some nursing staff, they really are going past their limits of their own health for the sake of their jobs and you know there just isn't manpower, what would cure that situation, more money, more staff, better facilities

...I am just thinking of what can be done to change the situation. You know I really thing that it is a question of more beds in the hospital, so that people don't get shunted out before they are well, um, just having to move on because a bed has to become available on the ward for a sicker patient. More staff, it is my impression that what is being done is being done right but there are just not enough people to do it, ...

CHAPTER FIVE: DISCUSSION

There was a high degree of consensus in the data, when comparing the findings that emerged across the in depth interviews with the mental health service consumers, the community mental health nurses focus group and the Valkenberg Hospital nurses focus group. This was particularly significant as a typical 'revolving door' patient profile was not expected to emerge from such a small sample of in-depth interviews, and triangulation with data from the focus groups give wider contextual support to the findings. Results are not intended to be generalisable yet it is interesting that literature triangulation supports the findings, which suggests that similar trends occur globally. The findings are also supported by studies of a quantitative nature, including an unpublished study at Valkenberg Hospital quite recently (Milligan & Flisher, 2002:Appendix 3). There were some surprise findings and some sensitive findings where participants found courage to express negatively laden material, in respect of how mental health services could be improved.

Results concurred strongly with the literature, as will be discussed. For the purposes of this study it would be good to identify what can be done to prevent readmissions whilst improving mental health services. There is a considerable amount of literature on predictors of readmission and the 'revolving door' syndrome from developed countries (inter alia: Tansella & Ruggeri,1996; Boardman et al, 1997; Koppel & McGuffin, 1999; Thornic roft & Tansella 1999; Pedersen & Aardkrog, 2001; and Averill et al ,2001), but little from developing countries, South Africa included (Behr et al, 2002: 369). Various models of

community based care and rehabilitation have been researched, many of which would be of interest in the South African context, but could be costly to implement in respect of available resources (Saxena et al, 2004).

Search for literature on improved care pathways found that Thornicroft and others are doing interesting and extensive work at international level, some of which could possibly be adapted to a South African context. Apart from very limited research such as Petersen and Pillay (1997) there appears to be a gap in the South African qualitative literature concerning 'revolving door' patients, and nothing specific that compares perspectives of mental health consumers with that of service providers was found. It can be seen as being of critical importance that the perspectives of the various role players, be they service providers or consumers, should be heard, so that they can work together as partners in achieving fewer readmissions and better mental health care for all.

What is apparent from the results is that problems with mental health service provision go back a very long way. This has probably always been pushed to the sidelines of general health care. Integration with general health care should ideally resolve some of these historical problems, but instead the problems that always existed are being aggravated by the new policy of integration of services. It does not have to be this way. Instead engagement with the process in the search for viable alternatives needs to occur so that people with mental illnesses and their families can be effectively treated and rehabilitated at PHC level. The current intentions of integrated mental health care are not happening. We need to know

what we can learn from the international experience as well as our mistakes, as well as successes to date.

Here follows a thematic discussion and comparison of participants' perspectives.

1. Violence and high-risk behaviour

Violent behaviour was the main reason given by care giving relatives for frequent readmission. What the results of the study portray are that immediate family of clients with severe relapse of mental illness can find themselves in a situation where their possessions are destroyed, their physical safety is jeopardised, even where there lives may be in danger and where there is little recourse to safety. Their experience is large ly that the police are unresponsive. Valkenberg Hospital is then justifiably the appropriate place, even if as is a typical case scenario, this is the fourth of fifth readmission in a year and in total the individual has spent four months of that year in Valkenberg Hospital.

Violence and high-risk behaviour did not emerge strongly as a theme for the service providers' focus groups. There were different nuances between the interview guidelines for the focus group and the in-depth interviews that could have contributed to this (see appendix). Nurses possibly engaged more around systemic processes and deficiencies in health and social services that lead to frequent hospital readmissions, and did not see the need to state the obvious regarding the association between mental illness and violent, high-risk behaviour.

It must therefore be emphasised that violent and dangerous behaviour is not a characteristic of every patient who is readmitted to Valkenberg Hospital. But for that subgroup of 'revolving door' patients who do fall into this category, the immediate household are fearful to wait in case of an episode of violence when they see symptoms of relapse, when they know how violent the patient has been on occasions in the past, and they will take the easiest route they can find to get a patient back into Valkenberg Hospital. They act immediately to arrange a readmission and even then sometimes it is too late to avert the violent episode.

Participants explained that such violence was caused by mental illness, for which their relatives could not be held criminally accountable. This is interesting in the light of the study by Swanson (1999) described under the literature review that found a strong association between violence, criminal victimisation, substance abuse, young age and readmission. Care giving relatives feel reluctant to take the forensic route of criminal proceedings, firstly in that they are realistically fearful that their mentally ill relative will languish in prison whilst awaiting trial, secondly in that they experience police as resistant to accepting criminal charges. If a person is found unfit to stand trial by virtue of mental illness, that person is made a state forensic psychiatric patient and will receive long term in-patient hospitalisation. Recidivism, namely frequent readmissions can be argued to be the most effective route for the protection of public safety.

Mentally ill persons who are regarded as high-risk can be admitted for involuntary treatment under the new Mental Health Care Act 17 of 2002. Where previously they could be certified through the magistrates' civil courts, now mental health

review boards of psychiatric hospitals replace this function. Hopefully that will not have unexpected repercussions of violent patients being refused readmission when psychiatric hospital beds are full, as happened before instatement of "Kendra's Law" in New York State (cf. Rottgers and Nejat, 2001). South African regional hospitals are in terms of the new 2002 mental health legislation supposed to institute 72-hour seclusion facilities for high risk mentally ill patients, but at present only George Hospital has a pilot study underway. The Healthcare 2010 changed configuration of services also specifies creation of mental health beds at regional hospitals, as has yet to happen.

Clearly what we need to see in place is a system where there is adequate provision for prompt readmission and inpatient treatment of patients with symptoms of violence, as in the examples given by Rottgers & Nedjat (2001) with regard to New York State legislation. We can also learn from the Jamaican experience of mental health service transformation as described by Hicking (1994) whereby there is public acceptance for mental illness to be treated at community level together with prompt inpatient treatment of dangerous patients, and careful preparation for reintegration into society. Lest we be too idealistic this must be contextualised against the reality that New York State is resource rich, and Jamaica a small relatively stable island community of area less than the Western Cape and population less than the Cape Metropole.

A different area of concern was that subgroup of the mentally ill population who comprise particularly women, the elderly, and the intellectually or physically frail who are frequently readmitted because they are at risk, and require protection from

society. Their vulnerability loading compounds their inability to protect themselves against societal violence, making them easy victims. Caregivers discussed suicide attempts and vulnerability as result of high-risk behaviour as also related to frequent readmission. Co-morbidity with other illnesses such as HIV seropositive status results in dual vulnerability and heightened pathology profile for mental health clients.

For some but not all of the aggressive episodes described by caregivers there was a link to substance abuse. (cf. Swanson,1999). There were accounts of aggressive behaviour in women, and of vulnerable behaviour in men, but caregivers described more violent behaviour in men, and women as more likely to place themselves in vulnerable situations due to mental illness. This was however an artefact of the purposive sampling method, and not generalisable in respect of this study. It is not part of the study objectives but it would be interesting to research gender differences in 'revolving door' trends.

It would seem that notwithstanding the above constraints where patients clearly need readmission, what needs to be put in place to prevent unnecessarily frequent readmissions of individuals who are a danger to themselves or others would be as follows. Firstly what would be required is proactive multidisciplinary case management across the mental health platform in the before-and-after time period of a patient's discharge, which could possibly be combined with assertive case management and possibly involuntary outpatient treatment. More of this will be discussed later. Presumably use could be made of an assertive outreach approach to chase after reluctant involuntary outpatients, perhaps with mobile clinics. Secondly

intersectoral collaboration with the police appears to be in great need of improvement. Training input to the police is sorely needed, to assist in knowing when to ignore calls from the public to remove harmless eccentrics, and when to react to situations of crisis and genuine need.

2. Knowledge, insight and acceptance of mental illness

Knowledge, insight and acceptance of mental illness needs to occur not only for the individual with the illness but also for the immediate family household, the neighbourhood, at the level of general health care provision, and at macro societal level. Part of lack of knowledge had to do with the stigma attached to mental illness, which understandably accounts for why a person would want to deny having a mental illness, and resist acceptance of psychiatric treatment. Furthermore when a person is mentally ill insight and judgement is impaired, uptake of knowledge and acceptance of the illness is difficult, and that impedes treatment and rehabilitation.

The very insightful mental health client said that he needed explanation of the course and symptomatology of his illness with every admission, as the information was hard to accept and internalise, that he may not always be able to absorb information, but that mental health care providers must nevertheless persevere with educational endeavours. He highlighted the need that patients have for knowledge and insight into how mental illness happens and how treatment works. His account of why readmission happens was that when he becomes ill he loses all insight and

judgement, and everything in his life disintegrates. Staff caregivers at the group home where he abides arrange his readmission. It is interesting to note that both he and the care giving relatives felt that they had not been enlightened sufficiently by mental health professionals regarding mental illness.

Valkenberg Hospital nurses said that many mental health care users who are noncompliant seemingly think that they only need to take treatment whilst in hospital. Once they are well and back at home they believe that they will not become mentally ill again and cease taking the medication. All respondents and in particular Valkenberg Hospital nurses emphasised that the period of hospitalisation is too short to do effective psychoeducation and psychosocial rehabilitation, in that the patient leaves just as soon as his condition has started to stabilise but before being sufficiently recovered to be capable of participating in the treatment plan, and still unreceptive to gaining knowledge and insight into the illness. This is supported by findings of Shah (2002: 44). But it was also apparent from what Valkenberg nurses said that scarce staff resources compounded the absence of adequate psycho-education with mental health care user and their families, and the lack of a psychosocial rehabilitative programme in the acute admissions predischarge wards.

Gaining knowledge and insight into their mental illness was a still harder process for Xhosa speaking clients, from different cultural background with different health beliefs to that of Westernised medicine. The fact that Valkenberg Hospital has neither an interpreter nor sufficient staff resources to translate further impeded

opportunities for mental health care users and their caregivers to absorb information about the illness, so as to manage it once discharged from hospital. Members of a community may have an ambivalent relationship with mental health services due to inconsistency with traditional beliefs as they relate to modern psychiatry, and may learn to use the services only in times of crisis. Typically the clinician at psychiatric hospital (secondary health care level) might, due to communication problems, discharge the client with inadequate preparation and referral, the patient would then be non-compliant on medication, remain well for a time, but then relapse, necessitating cyclical readmissions. Both the above suppositions regarding language and traditional beliefs would be supported by Joyi (1998) and Tshaka (2003) as discussed earlier under the literature review.

Community mental health nurses in particular but also Valkenberg nurses perceived that lack of knowledge and insight on the part of the care giving relatives had to do with their lack of understanding of the process of mental illness, leading to their stigmatisation and rejection of the person with the illness, and belief that frequent readmission was the correct treatment route. Caregivers found difficulty with supervision of medication. Mostly they said that clients refused to allow them to administer or supervise medication. They perceived that their mentally ill relatives were noncompliant for a variety of reasons. These reasons centred around non-acceptance of the diagnosis of mental illness, little faith in the efficacy of treatment, unpleasant and debilitating side effects, ignorance that poor or irregular compliance could lead to treatment resistance, simply forgetting to take medication, or abusing substances of alcohol and cannabis.

Tshaka (2003) in his research in Grahamstown for a Master's in Public Health, had similar findings in respect of factors related to non-compliance on psychiatric treatment. He further suggested that clients abuse substances to 'manage their worries' (: 48). Symptoms of mental illness produce much distress in the sufferer and substance abuse may be a form of self-medication. Milligan & Flisher (2002) in their recent study at Valkenberg Hospital (see appendix) found that 48% of the sample for the readmissions group was currently abusing substances.

Substance abuse was mentioned by three of the five care giving relatives in the thesis study and was inextricably related to the themes of knowledge and insight, being so closely linked with treatment non-compliance, subsequent relapse and revolving door readmission. One thought cannabis had a calming effect on her son; the other thought it had an effect of aggression on her son. Another reported alcohol abuse as being highly implicated in her relative's frequent readmissions. It must be said that substance abuse also related strongly to the theme of violence and high-risk behaviour, and could well have been discussed there instead, were it not that for some patients the effect of taking or abusing substances is more obscure. Less dramatic effects of substance abuse may be that it hampers treatment compliance and efficacy, impairs recovery, adds to the chronicity of the illness, thus making psychotic relapse and readmission more likely to occur. Patients can also develop resistance to psychopharmacological drugs as result of either noncompliance or substance abuse or both. Both Valkenberg and community mental health nurses perceived that the combination of poor or non-compliance and substance abuse greatly increased the probability of relapse and readmission. Hard drugs such as tic tic are increasingly linked to frequent readmissions. They spoke

of the need for this to be addressed at national public health level as part of comprehensive primary health care.

All categories of respondents in the study commented on the strong link between substance abuse, non-compliance and frequent readmission. There is support for this finding in the literature, viz. a significant association between these three variables, with substance abuse reducing treatment compliance, and leading to more frequent readmissions. (cf. Leon et al, 1998; Haywood et al, 1995; Hunt et al , 2002; Tshaka, 2003). The unpublished study by Milligan & Flisher, 2002 at Valkenberg Hospital [see appendix] further confirms this finding.

Community mental health nurses discussed as problematic that generalist trained nurses lack knowledge and insight in respect of how to work in the field of mental health. This they ascribed to lack of training roll out, lack of interest in training, and inadequate staffing resources. Much has been said regarding the need for adequate PHC training of staff in mental health care both at provincial and national policy documentation level and in the literature. (Department of Health, 2002; Mitchell, 2003; Flisher et al, 2003; Petersen, 1999; Baumann, 1998) that relates to findings from participants. It is important that generalist staff be equipped with the necessary knowledge and skills. Incorrect assessment or treatment of the mental health client at PHC level, can lead to unnecessary rehospitalisation.

Community mental health nurses placed strong emphasis on the need to do mental health promotion aimed at the wide public to reduce fears and stigma surrounding mental illness. They described the media as usually portraying mental illness in

sensational, irresponsible and biased fashion, unsympathetic to the needs of clients and their families.

What could mitigate against some of the aforementioned factors, thus indirectly reducing relapse rate and number of readmissions would be firstly to address psychoeducation at Valkenberg Hospital inpatient level in a more creative way that takes cognisance of depleted staff resources and rapid turnover of patients, and such that the emphasis falls on facilitation of contact at PHC level post discharge. This would need to be stronger at both case management level with clients and their families, as well as at groupwork level. Groupwork at face level appears cost effective but there are obstacles that need to be factored into planning and coordination, the most obvious being negotiating times when everyone can come and securing commitment from facilitators who are under much work pressure to be available even when clients do not arrive for sessions. Secondly the bulk of psycho-education that forms part of psychosocial rehabilitation is supposed to happen at PHC level in terms of Healthcare 2010 planning. This makes sense in that it is only then that the clients' health condition has sufficiently stabilised to a level where the person is able to grasp the necessary knowledge and develop insight. This is going to require closer co-ordination between the various role players both in the health services and community stakeholders. Thirdly, health promotion is receiving attention under Western Province Programme Development: Sub Directorate for Mental Health and Substance Abuse (M. Roelofse: Personal communication, 2004) so there is scope for optimism.

At the macro level of mental health promotion, interpretation of the results suggests that there are at least three issues that would need to be addressed. Firstly there is the need for generalist nursing and other staff training. Secondly destigmatisation of mental illness and anti substance abuse programmes could be more effectively addressed through positive media publicity, and active engagement with community stakeholders such as churches, mosques, civic and sports associations, and NPOs. Thirdly intersectoral collaboration with Department of Police and Department of Education for mental health and substance abuse awareness; and promotion of Healthcare 2010 "Healthy City" initiative could help to ease burden on the health system.

3. Support systems.

A refrain from all caregivers was that of the frustrated dreams of their mentally ill relatives. They reported that their relatives experienced vocational failure in the areas of work and family relationships and invested in the sick role because the usual roles of work, marriage, family responsibilities that help people to feel needed and valued as social citizens were absent. So it becomes quite a "normal" thing to be frequently readmitted to Valkenberg Hospital, a support system and second home. What the mental health care user emphasised very strongly was the lack of support systems such as group homes, to enable people suffering from chronic mental illnesses to cope in the community. He described the gradual erosion process of everything once held dear that occurs for the one suffering from recurrent mental illness. There are not enough clubs, group homes, and vocational retraining opportunities. So many suffer from boredom, loneliness, broken dreams,

delusions, poor self esteem, financial exploitation, financial insecurity, not to mention social stigma and ostracisation.

In the above respect there is much evidence in the literature for the indispensable role of psychosocial rehabilitation in respect of psychological, emotional and social support, thus improving quality of life. Shatkin et al. (1995) advocate that grasping the similarities between mental and physical disability is key to understanding the underlying philosophy of rehabilitation. Examples of research linked to significant reduction in 'revolving door' readmissions are Delaney (1998) who advocates assignment of post discharge case managers in psychosocial rehabilitation; Bazzoni et al. (2001) who discusses benefits of cognitive behaviour therapy; and Melchinger (2001) who advance the value of psychosocial rehabilitation clubhouses (cf. Literature review). There would seem to be much worthwhile happening in this research arena worldwide, including developing countries, even though resources for sustainability are scarce.

Community nurses felt that caregivers and relatives were frequently rejecting and unsupportive towards clients with mental illnesses. They also discussed exploitative, unsanitary, unsafe conditions in the Maitland boarding houses. These homes cannot simply be closed down without provision of alternative accommodation for clients who have no family to stay with and who are on disability grants. Attempts at intersectoral collaboration with Department of Social Services in this respect have not as yet borne any fruits. The observation that the bulk of residents in night shelters have mental illnesses is interesting, in that these establishments are for the poor and homeless. Like the community mental health

nurses, Valkenberg nurses linked social problems and unsupportive communities where patients were discharged to non-compliance and readmission. They described how families have not found ways of coping with the care of the mentally ill in the community, in that deinstitutionalisation and the primary health care approach is still a new phenomenon. They thought relatives have not fully accepted their responsibility to care for their mentally ill in the community, now that Valkenberg Hospital long stay wards have closed. However they also emphasised that sometimes clients are so chronically and severely mentally ill that relatives in the community cannot possibly care them for them. They are also witness to how the AIDS epidemic is contributing to frequent readmissions and the burden of care for families.

Care giving relatives do not have the support systems that would allow them to manage the risks attached to psychotic episodes, or the care of vulnerable mentally ill relatives in the community. The burden of care imposes constant strain on family that manifests in financial, emotional, psychological, social and physical distress. Ongoing behaviour problems related to mental illness were destructive to the family routine, functioning and material belongings. Pressure on intimate relationships, loss of support from friends and relatives, societal stigmatisation and rejection of the mentally ill person were reported as affecting the emotional health and sense of self worth of the primary caregiver and family. Participants in the study seemed to have to live with an ongoing cloud of uncertainty and disquiet, which had a profound effect on the rest of their lives.

Multiple social and health pathology in the family system was found to be a major factor contributing to frequent readmission. There is a strong evidence base in the literature regarding the association between social deprivation, social pathology, mental illness relapse and frequent readmissions. Several authors have highlighted the need for a holistic approach to mental health care that incorporates intersectoral collaboration, among others Thornicroft & Strathdee (1991). Shepherd (1998) describes the new 'long stay' patients who could be more effectively cared for in the community if there were appropriate community structures available.

Community settings models as described by Haver et al. (2003) under the literature review have been cited by a considerable body of research as more effective than hospital settings models of treatment, provided that there is adequate funding provision. Similarly Dean & Gadd (1990), Brenner (2000) and Chatterjee (2003) cite evidence that home based care and day hospital treatment has been very effective in reducing frequent readmissions, as well as in rehabilitation.

Positive factors that helped families to cope were high value placed on 'blood' ties and the family unit, family duty, their religious faith, friends, relatives, support from the mental health nurse at the clinic and readmissions to Valkenberg Hospital. Relatives said what would help would be group homes where their mentally ill relatives could live, and receive 24-hour care and supervision, but that this need not be in a specialised psychiatric hospital.

The mental health client described how very fortunate he was to stay in an NPO–run group home where there is support and care. He explained that readmission becomes necessary when one group home resident becomes floridly psychotic,

because the ensuing disruptive behaviour puts too much pressure on the other people in the group home, all of whom suffer from chronic mental illness and as such are vulnerable. He said that in his case he was frequently readmitted, because in between being completely mentally well he has severe relapses of mental illness. It can thus be seen that Valkenberg Hospital service providers need to protect their relationship with community stakeholders such as NPO group homes by providing guarantee of a 'safety net' when mental health clients relapse and require readmission.

Social deprivation has been found to contribute strongly to high readmission rates as discussed under the literature review (cf. Desjarlais, 1995; Boardman, 1997; Koppel & McGuffin, 1999). Community mental health nurses discussed how many mental health clients do not have enough food to eat, and cannot afford public transport to obtain treatment from their nearest CHC. Levels of violence on the Cape Flats in gangster and crime torn areas were described as precipitating mental illness that in turn leads to frequent readmission. In the case of women particularly they thought that sometimes this is a search for a safe haven. Shah (2002) cites substantial international evidence for the association between socio-economic deprivation and frequent readmission and found this to be an explanatory factor in disparities of readmission rates across three psychiatric hospitals in the Western Cape.

Conversely the burden that mental illness of a relative places on the family support system can lead to social and economic disintegration of that family unit and mental illness amongst others in the family. This would seem to be the case for

both the mental health clients and the relatives who participated in the study. It was clear from all the care-giving relatives interviewed that their health was buckling under the strain. The finding that care giving relatives were women and ageing parents, whose financial livelihood was affected by having to be at home to care for a mentally ill relative has echoes of research cited earlier by Shibre et al (2003). There was another interesting parallel to said research, in that a few of the research participants mentioned prayer and religious faith as their main source of help. Unpublished findings of van Staden (1995), a previous social work colleague from Valkenberg Hospital, draw attention to the burden that caring for a mentally ill person places on a family, and how overall health and wellbeing of the family unit is compromised.

World Health Organisation (WHO) back in 1948 defined health as "a state of complete physical, mental and social well being, and not merely the absence of disease and infirmity" and although hard to achieve it does emphasise the need for holistic health care services. If the social needs for supported housing, community based care and rehabilitation of chronically mentally ill and disabledare not attended, then money will be wasted on countless readmissions for psychiatric inpatient treatment at secondary level. If ways of achieving effective intersectoral collaboration towards this end between Department of Social Services and Department of Health have to be found, then that must occur, regardless of the difficulties. The literature makes clear the need for community support structures to be in place if frequent readmissions are to be reduced

4. Care Pathways

Frequent readmission often related to poor co-ordination of services in respect of referral pathways from secondary specialist to primary health care level and back, and with nothing in between at secondary level. The partially qualitative research of Petersen and Pillay (1997) in a semi-rural area of Natal, engages with the subject of referral systems to increase access to and facilitate co-ordination of comprehensive, integrated and community-based mental health care services.

Mental health clients and their caregivers were often confused as to the correct health care pathway.

Readmission to Valkenberg Hospital

Readmission from the community back to Valkenberg frequently happened without the awareness of the community mental health nurse, in that the relatives arranged emergency readmission and no one from Valkenberg notified the CHC timeously, if at all. What clearly seems to be happening in such cases is that the client never reports to the CHC for post discharge follow up treatment, instead the only time the person is on medication is probably while in hospital, and as soon as out again does not report to the CHC for medication. That person will then only receive treatment again when some family member brings him back into Valkenberg Hospital as an involuntary patient a few months down the line when the effect of the medication has worn off, and the symptoms of the mental illness have progressed to such extent that the person is again floridly psychotic.

Three of the five caregivers reported that they would just bring their mentaly ill relative straight to Valkenberg Hospital as an urgent readmission and bypass all the other channels for assessment. The other two caregivers found it immensely difficult to arrange a readmission. Access to a motor vehicle whereby the mentally ill person could just be driven and dropped off at the Hospital may have facilitated easier readmission. Caregivers reported how they would often bypass their local CHC to arrange a readmission if necessary.

It is encouraging to hear that in respect of those patients who do report for follow up CHC treatment the community mental health nurse takes great care to avoid a readmission if possible, and will phone Valkenberg doctors and nurses when they need advice on treatment, according to what was said in the Valkenberg nurses group. Clearly both Valkenberg and community mental health nurses had a hard time convincing relatives of their responsibilities to care for their chronically mentally ill relatives and with advice that Valkenberg Hospital cannot provide long term care. Under the old government Whites were advantaged and although it was difficult even then, arrangements could be effected for long-term hospitalisation. Now that has been done away, consumers are disappointed. Sometimes people who were previously disempowered and disadvantaged have expectations of long term care that the hospital does not provide. In respect of the traditional extended family, times have changed. Most of those who are well in the household in an urban area will either be at work σ looking for work during the day, so that there is no one at home to care for the elderly, sick and disabled.

It is of concern that all the readmissions described seemed appropriate and genuinely in need of readmission. Often clients had either refused to attend the CHC or were non compliant on medication and relatives were powerless to avert this. It seemed that unfortunately Valkenberg Hospital did not have the bed capacity to admit patients because of being too full. This would indicate a problem of too few beds and further not helped by the failure to provide beds at secondary level, in keeping with the Healthcare 2010 plan. This then leads to premature discharges. Relatives especially in the poorer areas have to follow a circuitous route to get a readmission, to prove that a person's illness has severe enough implications to warrant an involuntary readmission, whereby the police must act and take the person to Valkenberg Hospital. It is difficult to tell at this stage what effect the new Mental Health Care Act, 2002 will have on readmissions, but it will enable mental health professionals to refuse inappropriate referrals for inpatient readmission.

Period of stay in Valkenberg hospital

Health care 2010 goals put immense pressure on a system not yet geared up to manage at primary level, and with nothing in place yet at secondary level district hospitals. Service providers reported the number of beds inadequate to serve the needs of the catchment area that the hospital services, thus inflow of patients was very high necessitating premature discharge. They also emphasised that patients were discharged before well enough to benefit from rehabilitative and psychoeducational input.

Both internationally and locally literature on the association between length of stay and frequent readmission has been much debated and inconclusive, there being many varying factors and parameters to consider. (cf. Johnstone & Zolese, 2000; Haver et al 2003; Behr et al 2002; Milligan & Flisher, 2002; Shah, 2002: 21-22). A likely underlying dynamic could be that it does not matter so much whether patients stay longer or shorter periods, if in that longer period they receive little rehabilitative input by way of psycho-education and counselling to the family and client, little in the way ensuring that supportive networks are available to ease the clients' reintegration back into the community, and with inadequate referral and link up to PHC and other community based services. The literature describes findings that assertive outreach is well received by clients if combined with offers to clients of very real choices and options in respect of community based care and support systems. Longer stay probably does not make much difference if all that happens in the longer stay is increased stabilisation on medication, if then as soon as that patient is discharged from hospital he becomes non-compliant on medication. He is then hypothetically as likely to have a relapse and be readmitted as the person who had a shorter hospitalisation, if they were both discharged with nothing in place. Obviously this theme links strongly to the themes of lack of support systems and lack of resources, in that even with the best communication and referral pathways possible rehabilitation cannot occur in a vacuum.

There is also a conflict between clinical best practise and demands on the service for patients to be discharged as soon as possible. A psychiatrist in terms of patient rights cannot put a patient on heavily sedating medication which can have other negative health consequences, particularly where there is diagnostic uncertainty during the assessment phase of treatment, and where medical students and new registrars may have very limited psychiatric training. Valkenberg nurses felt that perhaps dosage titration was too conservative and community mental health nurses felt that patients are sometimes discharged on non-therapeutic doses, in that the dosage then must still be titrated to maximum advantage at PHC level. So if a patient defaults considerable investment in treatment has been wasted. Thus the period of stabilisation can be quite long.

The concept of stabilised mental health care was very relative to what perspective one was seeing things from. Valkenberg hospital staff might pronounce a person's condition stable relative to other patients in the acute admissions ward, and relative to the expected baseline level of functioning that could be hoped for that patient. But for the immediate family that same person's condition would be very unstable compared to others in the household, and the challenges of managing that person's care in the household environment without the hospital milieu of authority, policies and procedures that contain a mentally ill patient in the process of recovery. Many relatives go through a grieving process, when their hopes are dashed. Their expectation is that the person must stay in hospital long enough to be completely well again, and they find it hard to accept that their ill relative will never again recover full capacity, will be disabled by the chronic illness, possibly always mildly psychotic, with strange beliefs about reality, and perceptions that differ to those of the majority around them.

Referral back to the community

In respect of the referral process communication channels with Valkenberg

Hospital would need to be improved in respect of referral for follow up treatment
before discharge. Where frequently readmitted patients have to be discharged early
due to pressure for beds, the referral pathway needs to be thoughtfully addressed,
by way of contacting the community mental health nurse telephonically to discuss
continuity of treatment. Community mental health nurses saw inadequate
communication from Valkenberg Hospital side as being strongly linked to frequent
readmission, and the quarterly catchment area meetings as insufficient for
addressing improved care pathways between hospital and community health levels.

The community mental health nurses felt that the focus at Valkenberg Hospital was on just getting the patients well enough for discharge without enough forward planning for continuity, sustainability and intensive case management for revolving door patients with severe mental illnesses. Better teamwork from secondary specialist to primary health care leve I could be a way to effectively address this. Their thinking, although not explicitly stated, was very much along the lines of intensive case management and assertive outreach teams. (cf. Shephard, 1998; Thornicroft & Tansella, 1999; Gerbasi et al, 2000; A verill et al, 2001; Williamson, 2002). Teamwork alongside Valkenberg Hospital specialist staff for a select group of 'revolving door' difficult to treat patients, perhaps in the form of a weekly case conference could be greatly beneficial. This would be a forum to address such issues as sustainability of treatment gains, but the secondary spin-offs could be improved working relationships, in that community mental health nurses intimated feeling professionally sidelined and undervalued.

More comprehensive clinical summaries could undoubtedly assist in the process, thus preventing problems with treatment continuity. The combination of clinical summaries taking too long to arrive, incomplete referral memos and patients not arriving at PHC level for follow up treatment must create administrative confusion, thus eroding productivity and effectivity at PHC level. Assertive outreach, or intensive case management as is a comparable concept, could also involve the community mental health nurse doing a home visit to the client who fails to arrive at the CHC in the week following discharge, if resources were in place. This would be targeted at those of the severely mentally ill selected as the most intractable 'revolving door' population.

Pre-discharge groups with clients, families, community mental health nurses and Valkenberg Hospital multidisciplinary team on Valkenberg Hospital premises did occur in the past, and although staff resources are more stretched than then, this would be a valuable part of the referral process. Orientation of new staff and students at Valkenberg hospital could include visits to CHCs at PHC level in order to raise consciousness of the need for a 'seamless service', that would assist in prevention of unnecessary readmissions and more effective community care .

Considerable energy has been invested in psychosocial rehabilitation (PSR) groups at CHC level, with intersectoral assistance from Department of Social Services and also NPOs namely Comcare and Cape Mental Health Society. Like any process, energy invested at the beginning can dissipate later if not nurtured and sustained. Very few referrals to PSR groups are received from Valkenberg Hospital, most of

their referrals being done by mental health nurses. Clients are often poorly motivated but for those who do attend these groups it would appear to fill a meaningful function, despite the cost to staff resources. There is also a Crisis Card Project, initiated by University of Cape Town: Department of Social Development that links to Medic Alert, whereby a mental health client can specify how s/he would like to be treated in event of a psychotic relapse.

All the above would seem to require co-ordination by a dedicated team, part of whose explicit work function would be the co-ordination of the bridging process between Valkenberg Hospital and the community to prevent the gap, or the weakest point in the system as referred to by Shah (2002) when a patient is discharged from the hospital.

Follow up at PHC level

This was consistent with findings by Shah (2002: 43) that typically 'revolving door' patients did not arrive for treatment follow up at PHC level post discharge from tertiary level. Caregivers reported that clients would not wait in the queues at the CHC, if they went at all.

The perception of Valkenberg nurses was that clients are still reluctant to go for treatment at CHC level, in that they associate treatment with Valkenberg Hospital, and have not gotten used to the notion that they can be effectively treated at CHC level. The devolvement from OPD to PHC level in line with Healthcare 2010 objectives for transformation of the health services towards greater equity, treatment at PHC level is supposed to be more accessible and yet it may not be

more accessible if frequently readmitted clients do not receive the mental health care services they need and have come to expect such as regular contact with a psychiatrist every 3 months, a consistent supportive relationship built up over years being a crucial element to client recovery in mental health.. Part of this has to do with the perceptual shift that has to occur during any transitional process, and once clients have gotten used to going to PHC level, they may experience that they can be as effectively helped there, even in cases of severe mental illness, and it may well in time to come result in fewer readmissions to Valkenberg hospital, with the more convenient physical accessibility of the CHCs, provided the queues are not too long. But there is an ominous possibility that if they are devolved from OPD to the community mental health nurses and from there to the generalist nurses, they will receive less comprehensive care of severe mental illness and very minimal specialist psychiatric input, which will then continue to have the unfortunate repercussions of ever increasing readmissions to Valkenberg Hospital. This has so often been the international experience. You cannot 'short-change' mental health care at community health level, as will be further discussed with regard to resource alloc ation.

Devolvement at PHC level from the mental health nurses to generalist trained professional nurses was identified as problematic in that nurses had neither training nor motivation to do psychiatry, and were already carrying heavy workloads so resented the additional burden of mental health care. (cf. Baumann 1998: viii). Consumers reported that mental health care professionals were understanding and supportive, not so those who only had generalist training. Generalist staff need adequate training and motivation. There is also the danger that physical ill health

can be neglected once the client has a label of mental illness. The experience of the daughter whose mother had physical illnesses of PTB and HIV seropositive diagnosis was that she was shunted back and forth, and that there was no integrated comprehensive approach to caring for her physical and mental health. (cf. Thornicroft & Strathdee, 1991: 408-412).

The problems of mental illness are not going to go away, instead need to be effectively addressed at PHC level. Psychiatric patients who are severely mentally ill cannot be expected to stand in long queues, without causing major disruption and possibly increasing community stigmatisation of mental illness, or in all likelihood either walking away in distraction or never going to the clinic. Instead they and their relatives seem to find that a readmission to Valkenberg Hospital helps them faster. The benefit of the readmission probably tides them over to the next readmission perhaps three months later. They could be said to live in a 'twilight zone', perhaps spending a third of the year sick in Valkenberg Hospital and the rest of the year in varying stages of health and ill health, never as well as they could be on effectively stabilised treatment

5. Resources

The results are discussed against the context of national restructuring of the health services is towards affordable, accessible and equitable services for all, and South Africa as a developing country with very limited resources.

Mental health service objectives in terms of Health Care 2010 Western Cape have implications for service delivery in that resources have been cut at secondary specialist level but not replaced with the needed mental health community based services within the PHC ambit. Valkenberg Hospital, along with other psychiatric hospitals, fulfils a partially tertiary and partially secondary regional function. Regional hospitals have not stepped into the breach of secondary psychiatric care in line with Healthcare 2010 objectives of being more accessible to the general population. Valkenberg and other APH hospitals appear to be reaching their Healthcare 2010 objectives, where the goal is rationalisation of services ahead of secondary and PHC levels where their goal is development of services.

The current crisis intervention mode of service delivery is actually costly on the limited resources available. For the desired system to work, more resources need initially to be invested at PHC level with community based care, before rationalisation at Valkenberg Hospital level, because otherwise the same patients are being readmitted as fast as they are being discharged. The resources have to be in place at community level. Only then can we expect that savings, effected by reduced rea dmissions can be made at secondary psychiatric hospital level. It seems that is not the 'deinstitutionalised' patients who are being readmitted to Valkenberg Hospital so much as what has been termed in developed countries as the prospective 'new long stay' patients. We could equally phrase them as the new chronic patients, because there will always be new chronic patients by nature of the severity of some mental illnesses. Thus provision needs to be made at community level for these new chronic or 'revolving door' patients, to aid them on their road to recovery. If that were in place we could look forward to less pressure, as well as a

financial saving on the secondary psychiatric platform in a few years from now.

Costs need to be transferred from tertiary to primary level, but it is naive to expect there to be a financial saving on mental health services in total, rather more should be spent, not only to accommodate the growing burden of mental illness, but also to redress historic inequity in provision of mental health services relative to other health services, as well as to the underlying social causes of mental illness, such as substance abuse, violence, poverty and injustice that are part of our South African heritage.

The identified areas of inadequate resource provision were insufficient bed capacity at Valkenberg Hospital, lack of staff resources at Valkenberg Hospital, lack of all resources at PHC level, and the need for more Government funded community based care. There is a lack of resources at secondary level with little sign of interest in developing the proposed Healthcare 2010, 6-bedded units at regional and district level. Part of the problem with 'revolving door' readmissions in Valkenberg Hospital and stress experienced in mental health care at PHC level in the Valkenberg drainage area may be inequity of drainage areas populations served by the three psychiatric hospitals (cf. Shah, 2002). There is still rampant confusion as to where clients are supposed to go for their community treatment follow up. If they fall under Tygerberg hospital drainage area in respect of physical care they go there, but may fall under Valkenberg/ Grootte Schuur Hospital in respect of psychiatric care. This is supposed to be addressed soon, in line with the Department of Health: Equity Gauge Project, and we can only hope so, particularly for a deprived area like New Crossroads that falls on the boundary of the Valkenberg and Lentegeur Hospital catchment areas and where there has been

recent disagreement as to whose responsibility this should be. (Valkenberg Hospital Catchment Area meeting held on 6 May,2005: Personal communication).

The mental health client's experience had been that premature discharge due to high pressure for beds and staff shortages, resulted in poor stabilisation on treatment and curtailed any opportunity for psycho -education and psychosocial rehabilitation whilst in the hospital. (cf. Powell et al,1995; Melchinger, 2001; Haver et al,2003). He perceived staff burnout at Valkenberg Hospital, lack of adequate staffing and other resources at PHC level, and a lack of opportunity to build a trusting therapeutic alliance with a consistent health care professional due to high staff turnover as factors relating to frequent readmission.

Service providers felt strongly that staffing resources at PHC levels were hopelessly inadequate. Staff shortages also at Valkenberg Hospital, where 62% of funded approved nursing posts are vacant (Karelse, 2004: Personal communication) impacted in various ways, such as far less rehabilitative work than previously. Both Valkenberg Hospital and community mental health nurses discussed the lack of secondary level mental health services.

The work of Lund & Flisher (2002) and Flisher et al (2003) strongly supports the need for adequate service provision particularly community and PHC level but also in respect of staffing ratios at all levels of mental health service and adequate training, as previously discussed. One of the many constraints is that of staff resources, where even funded posts remain unfilled as professional staff, particularly nurses go abroad for better salaries and working conditions.

Research participants expressed their anger at the lack of government-funded community resources to follow deinstitutionalisation and devolvement of care to PHC level. For care giving relatives more government funded group homes in the community would resolve the necessity of frequent readmissions. They saw frequent readmissions in a positive light, as assisting them, and in fact wanted long term stay in chronic wards to be available (cf. Levine, 1994 who puts forward an argument against deinstitutionalisation). Community mental health nurses said that money is wasted on secondary psychiatric hospital level care if there is no community sustainability through provision for not just health needs but also social needs of clients, such as appropriately supported housing. Baumann (1998); Shepherd (1998); and Haver (2003) cited in the literature review, all warn of the dangers inherent in neglecting to provide community based mental health services.

There needs to be far more collaboration with Department of Social Services in breaking down community stigma, and acceptance of elderly mentally ill people into old age homes as part of comprehensive health care. There is European Union funding to assist in the start up phase only of mental health community based services in line with Healthcare 2010, with the expectation that sustainability would be carefully incorporated (Househam, C., at Provincial Mental Health Community Based Services Planning Workshop 14 April 2005: Personal communication). Most of this would be allocated for intellectual disability, where most of the deinstitutionalisation planned for Healthcare 2010 needs to occur. Community based care needs for the intellectually disabled overshadow the needs of those with mental illnesses, however both are incorporated under the APH

planning. The question is whether the funding will be enough, and the answer probably not. Community based care incorporates not just supported accommodation and group homes, but also day-care centres, vocational retraining, support networks and the likes.

Again it must be emphasised that cutbacks at specialist secondary level need to be replaced by spending at both community and PHC level, taking cognisance of the Healthcare 2010 aim to reduce spending in the Western Cape relative to other provinces, but not forgetting the population demographics of the burgeoning Western Cape. The aspect of allocating more resources to training of generalist staff at PHC level, and nursing college student curriculum must be strongly emphasised, as well as due consideration to integration and training for community health workers. Finally it would be good to see more allocation of resources to mental health promotion, through the media and at a national level, as discussed earlier.

CHAPTER SIX: CONCLUSIONS

Findings that emerged in relation to what precipitated frequent inpatient readmission were as follows.

Violent and high-risk behaviour on the part of a mentally ill person poses a danger to self, immediate family and others in the community. It is hard for the mentally ill person and the family to accept the diagnosis of mental illness, not helped by societal stigmatisation of mental illness. Lack of acceptance, knowledge and insight leads to a reluctance to engage with treatment, so treatment compliance is difficult, with consequences of relapse of mental illness and readmission.

Substance abuse further jeopardises treatment adherence and efficacy. Further contributing factors are lack of support systems for the family and client, leading to strain on the family's overall health, and what little support they have being broken down. Conditions of poverty, social disintegration and violence are a breeding ground for mental illness frequently precipitating relapse of mental illness.

Findings go on to explore the systemic factors in the health services of inadequate care pathways and lack of resources. Finally suggestions from research participants for improving health and social service provision for reducing frequency of readmissions were incorporated.

LIMITATIONS OF THE STUDY

Due to the limited scope of the mini thesis the sample was of necessity small, even by qualitative standards. The care giving relatives who were selected for the indepth interviews were drawn from the lower socio-economic income bracket, but did not include the relatively more affluent, nor the extremely poor from informal settlements or living on the streets, this by virtue of the lack of accessibility of the latter. The Valkenberg Hospital nurses focus group comprised six members and were under greater time constraint compared to the community mental health nurses group that had eighteen members, which probably accounted for the greater amount of data that emerged from the latter group. A focus group with psychiatrists could yield very insightful data in respect of the readmission and discharge referral process between Valkenberg Hospitaland PHC level. They have a more direct link with PHC level, in that they write the clinical summaries and are called upon for advice as regards treatment at PHC level. This has become more the case with dwindling nursing staff in the hospital. In depth interviews with more mental health care users and community stakeholders from NPOs and client advocacy groups would likewise have been very enriching. The language barrier may also have impacted on the quality of data gathering. A further factor to consider is that clients may have felt swayed to say positive things, as they were aware that the researcher was an employee at the hospital.

RECOMMENDATIONS

Research recommendations:

A prospective case study, in which data collection continues with the
passage of time, to follow up on the mental health care users and their caregiving relatives who participated in this mini-thesis study

- Further qualitative as well as quantitative exploration and analysis of the
 association between frequent psychiatric hospital readmission and poor
 community tenure for people with severe mental illnesses. This would
 include the absence of step-down facilities, discharge to unsupported home
 environments such as night shelters, dubious boarding houses that are not
 accountable to any governing body, and pathological family circumstances.
- Further research aimed at mental health promotion, improved care
 pathways and ensuring appropriate allocation and utilisation of resources to
 mental health care especially at the PHC level of community based care.
- Participatory action research with community stakeholders to advocate for provision of adequate community mental health resources

Policy recommendations:



Consult with key role players across the mental health platform and community stakeholders as to implementation of the following:

- Forging of closer intersectoral collaboration with Departments of Social
 Services and Department of Police
- Resource allocation to ongoing training of generalist nurses and community health workers in mental health care and rehabilitation
- Forum between VH and community mental health nurses for ongoing improvement of communication, referral and care pathways
- Small pilot project multidisciplinary team between Valkenberg Hospital and community mental health nurses for intensive case management and

- assertive outreach for a specified number of identified 'revolving door' patients with severe mental illnesses
- Designated team to co-ordinate regular mental health promotion through the radio and television media for the mental health platform
- More staff investment in PSR with an emphasis on psycho-education and support groups with patients and relatives both at Valkenberg Hospital predischarge level and in the community at PHC and NPO level
- Medium stay PSR ward currently in planning stage needs to be implemented and in full operation by 2010
- Creation of step-down residential facilities between Valkenberg Hospital and PHC level needs to be prioritised as a matter of urgency for patients who are too mentally ill to manage in community group homes
- Provision and funding of more community based group homes

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Appendix 1

GLOSSARY OF TERMS

APH: Associated Psychiatric Hospitals ¹

Bipolar 1 Disorder: characterised by one or more Manic or Mixed Episodes, usually accompanied by Major Depressive Episodes ²

Boarding house: a residential care facility where any person, including person's with mental health concerns, are supplied with meals and lodging for pay ¹

Community based facility: any facility/home besides the Community health centre (CHC), run by an individual or Non profit organisation rendering residential placement, day care, home based care or a work/vocational placement service to persons with mental health concerns ¹

Care giving relative: family relative who at the time of research project was the main source of board, lodging and familial support to the mental health care user, or person with the mental illness

Client: used synonymously with mental health care user or patient

Community mental health nurses: a person registered as a nurse according to the Nursing Act 50 of 1978 as amended with an additional qualification in Psychiatric Nursing Science who manages mental health clinics at Community Health Centres

Community Health Centres (CHC): main service centres for primary health care. They render and co-ordinate all primary health care services considered appropriate for the community. A full-time medical officer and other primary health care personnel staff them.¹

Consumers: m ental health care users and their caregivers

Day care centre: a facility that offers day time activities and social contact for people with mental health concerns and groups including treatment services, prevention and promotion activities. ¹

Deinstitutionalisation: the discharge of chronic mental health care users from institutions into structured environments in the community and their reintegration into community life. ¹

Delusions: a false belief based on incorrect inference about external reality that is firmly sustained despite what almost everyone else believes and despite what constitutes incontrovertible and obvious proof of evidence to the contrary. The belief is not one ordinarily accepted by other members of the person's culture or subculture...²

Frequent readmission: historical pattern of approximately three and more readmissions per annum for inpatient psychiatric treatment, often referred to as 'revolving door' admissions.

Group home: homes based in the community with a staff complement who provide support with semi-independent living to people with mental health concerns and assist them to re-integrate into the community. Some of the homes offer vocational groups for individuals who are not able to work in a protective environment. ¹

Hallucination: a sensory perception that has the compelling sense of reality of a true perception but that occurs without external stimulation of the relevant sensory organ. Hallucinations should be distinguished from *illusions*, in which an actual external stimulus is misperceived or misinterpretated.²

Home based care: services offered within the homes of community members that provide psychosocial support for adult mental health users in the areas of living, learning, socialising and working. ¹

Involuntary care, treatment and rehabilitation: provision of health interventions to people incapable of making informed decisions due to their mental health status and who refuse health intervention but require such services for their own protection or for the protection of others.³

Involuntary mental health care user: a person receiving involuntary care, treatment and rehabilitation.³

Manic episode: a manic episode is defined by a distinct period during which there is an abnormally and persistently elevated, expansive or irritable mood. This period of abnormal mood must last at least 1 week (or less if hospitalisation is required). The mood disturbance must be accompanied by at least three additional symptoms from a list that includes inflated self-esteem, or grandiosity, decreased need for sleep, pressure of speech, flight of ideas, distractibility, increased involvement in goal directed activities or psychomotor agitation, and excessive involvement in pleasurable activities with a high potential for painful consequences...The disturbance must be sufficiently severe to cause marked im pairment in social or occupational functioning, or to require hospitalisation, or it is characterised by the presence of psychotic features.^{2abbrev}.

Mental health care practitioner: psychiatrist or registered medical practitioner or a nurse, occupationaltherapist, psychologist or social worker who has been trained to provide prescribed mental health care, treatment and rehabilitation services ³

Mental health care provider: a person providing mental health care services to mental health care users and includes mental health care practitioners ³

Mental health care user: a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user, State patient and mentally ill prisoner ³

NPO: Non Profit Organisation, subsidiary to NGO emphasis being that the organisation does not make a profit.

NGO: Non-Government Organisation

Patient: see mental health care user

PHC: Primary health care

Primary mental health care services: Provision of mental health care for mental health conditions as a component of general health care services, supported by the provision of designated mental health services per CHC catchment area...¹

Psychotic: This term has historically received a number of different definitions none of which ahs achieved universal acceptance. The narrowest definition of *psychotic* is restricted to delusions or prominent hallucinations, with the hallucinations occurring in the absence of insight into their pathological nature. A slightly less restrictive definition would also include prominent hallucinations that the individual realises are hallucinatory experiences.²

PSR Psychosocial rehabilitation

'Revolving door' admissions: synonymous with frequent readmissions

Schizoaffective disorder: A disorder in which a mood episode and the active-phase symptoms of Schizophrenia occur together and were proceeded or are followed by at least 2 weeks of delusions or hallucinations without prominent mood symptoms.²

Schizophrenia: disorder that lasts for at least 6 months and includes at least I month of active-phase symptoms (i.e., two [or more] of the following: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, negative symptoms).²

Step-down facilities: residential care to bridge the gap between inpatient treatment in a psychiatric hospital and treatment at PHC level in order to facilitate community reintegration of 'revolving door' patients with chronic severe mental illnesses

Support groups: Monthly or weekly groups, offered by non-profit organisations or health care services. Through these groups, people with mental health concerns are enabled to increase their functioning so that they can be successful and satisfied with living, working, socialising and learning environments of their choice with the least amount of professional intervention. ¹

Relapse: a return of the symptoms of a disease from which a person had apparently recovered or was in the process of recovering.

Review Board: Mental Health Review Board established in terms of section 18 of the Mental Health Care Act, 17 of 2002 ³

Valkenberg Hospital nurse: A person registered as a nurse according to the Nursing Act 50 of 1978 as amended, usually with an additional qualification in Psychiatric Nursing Science, and employed at Valkenberg Hospital.

Definitions have been quoted form the following sources, or if not specified are my own:

¹ Department of Health, WCP; Directorate: Public Health Programmes; Sub-directorate: Mental Health and Substance Abuse. (2004). *Psychosocial policy and implementation guidelines for the Western Cape Province*. (ref. 19/6/3/3/3; Draft 1). F. Gamieldien.

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³Mental Health Care Act 17, of 2002: definitions

Appendix 2: Extract from Anand Shah, 2002: 25-26

District	Population	Hospital Catchment
Blaauwberg	130,808	Valkenberg
Cape Town Central	275,520	Valkenberg
Greater Athlone	240,312	Valkenberg
Helderberg	132,519	Lentegeur
Khayelitsha	276,037	Lentegeur
Mitchell's Plain	285,184	Lentegeur
Nyanga	239,712	Valkenberg
Oostenberg	267,055	Stikland
South Peninsula	328,370	Valkenberg
Tygerberg East	246,994	Stikland
Tygerberg west	337,412	Stikland
Cape Metro Total	2,759,925	

Table 1.6. Populations for the metro districts draining to APH hospitals

Rural region	Population	Hospital Catchment
Boland and Overberg	484,344	Lentegeur
South Cape Karoo	478,898	Valkenberg
Westcoast Winelands	579,243	Stikland
Western cape rural	1542,485	
population Total		

Table 1.7. Population of the rural areas draining to APH hospitals

	Rural population	Metro population	Total catchment population
Lentegeur catchment area	484,344	693,739	1,178,084
Stik land catchment area	579,243	851,462	1,430,705
Valkenberg catchment area	478,898	1,214,723	1,693,621
Totals	1,542,485	2,759,925	4,302,410

Table 1.8. Total populations of the three catchment areas with rural and metro breakdowns.

The population figures presented are sourced from the provincial administration health department and are 2001 projections based on the 1996 census data combined with an agreed growth factor. So it is clear with the data presented that the catchment arrears are not the same size. This is significant for the rate of admissions as with variations in the base populations one can expect some variation in the number of admissions.

	Lentegeur	Stikland	Valkenberg
Standardised no. of beds per 100,000	11.03	7.27	8.02
population served			
Standardised rate of admissions per 100,000	106.19	65.42	115.08
population served			
Average length of stay	35.33	43.74	23.48
Monthly mean percentage new admissions	55.90	43.70	41.44
Monthly mean percentage readmissions	44.10	56.30	58.56

Extract from Anand Shah, 2002: 15 (Extract from Table 1.5.)

Appendix 3

Discussed by psychiatrists at Valkenberg Hospital Colloquium, March 2005: personal communication

THE MENTAL HEALTH MATRIX (Thornicroft and Tansella, 1999)

(1) Country/ regional level	(A) Input phase 1A * expenditure on mental health services *mental health laws *government policy *planning for staff training *treatment protocols and guidelines	(B) Process phase 1B *performance indicators (bed occupancy etc) *clinical guidelines *minimum standards of care	(C) Output phase IC *suicide rates *homelessness rates *Imprisonment rates * special enquiries
(2) Local level (catchment area)	2A *Local service budget and balance of hospital and community services *Assessment of local needs *Staff numbers and mix *Clinical and non-clinical services *Relationships between services	2B *monitoring, service contacts and patterns of service use *audit procedures *pathways to care and continuity *targeting of special groups	2C *suicide rates *outcomes aggregated at local level *physical morbidity
(3) Patient level	3A *assessment of individual needs *demands made by patients *demands made by families *skills and knowledge of staff *content of treatments *information for patients/carers	3B *subjective quality of treatments *continuity of clinicians *frequency of appointments *pattern of care process for individual patients	3C *symptoms reduction *impact on care-givers *satisfaction with services *quality of life *disability *needs

Appendix 4: (Reprinted by kind permission of the authors)

AN ANALYSIS OF DISCHARGE SUMMARY DATA OF A MAJOR PSYCHIATRIC HOSPITAL

Peter D. Milligan and Alan J. Flisher Department of Psychiatry and Mental Health, University of Cape Town

INTRODUCTION

At most psychiatric hospital discharge summaries are completed after each admission and sent to the referring health worker or institution.

These summaries contain information which is potentially useful to clinicians and health service managers

Discharge summary data is usually retained within individual patient records and is rarely analysed.

This study presents an analysis of discharge summary data of a major psychiatric hospital

METHODS

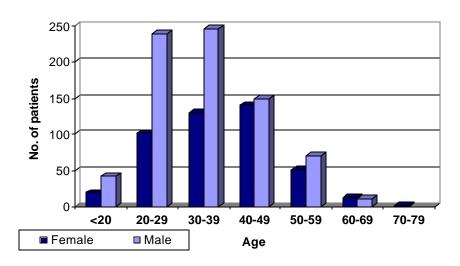
Data from all discharge summary data forms for acute hospital admissions to Valkenberg Hospital, Cape Town was captured on a secure data base

We analysed discharge summary data for all admissions between July 2000 and June 2001. Patients who were re-admitted in the twelve-month period were compared with those who were not.

1400 discharges involving 1242 individual patients were analysed. Of these, 1056 individuals had a single admission and 186 had one or more readmissions.

RESULTS

Gender and age group



Length of stay (days)

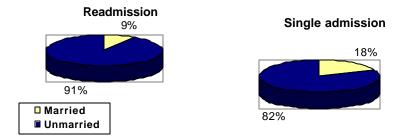
Gender	Readmissions		P (t-
			test)
	Yes	No	
Female	28.3	28.8	0.45
Male	16.1	17.1	0.28

Readmissions by Diagnosis

Diagnosis	Readmission		Total%	Odds	P (chi
				ratio	square)
	Yes	No			
Schizophrenia	105	438	43.7	1.8	0.00
Bipolar disorder	41	169	16.9	1.5	0.04
Major depressive disorder	8	136	11.6	0.3	0.00
Other psychotic disorder	10	90	8.1	0.6	0.15
Substance related disorder	11	87	7.9	0.7	0.28
Mental disorder due to a	8	57	5.2	0.8	0.54
general medical condition	1111				
All other diagnosis	3	79	6.6	0.2	0.00

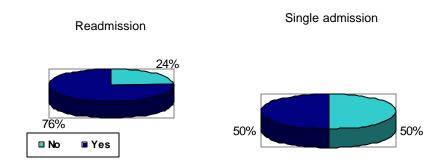
Marital status

(OR = 0.5, chi square P = 0.01)



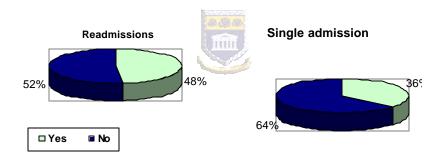
History of Aggression

$$(OR = 3.1, chi square P = 0.00)$$



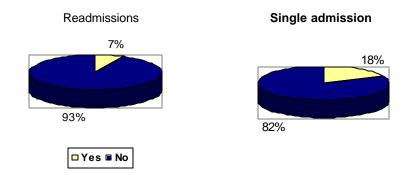
Current Substance Use

$$(OR = 1.6, chi square P = 0.00)$$

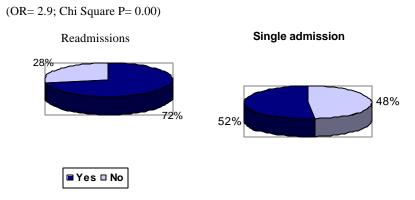


Employment

$$(OR = 0.3; Chi Square P = 0.00)$$



Disability Grant



Other results

- There was no significant gender difference (p=0.09) or age difference (P=0.13) between the two groups.
- A family history of mental illness was not associated with readmission (P= 0.22)
- Readmitted patients had a higher number of previous admissions in the period prior to the study.
- The use of depot neuroleptics in schizophrenia (P = 0.09) and bipolar disorder (P= 0.27) was not associated with fewer readmissions.

CONCLUSION



- Routine clinical discharge summery data can provide useful information for clinicians and health service managers
- Readmissions to hospital are associated with a diagnosis of schizophrenia or bipolar disorder, current substance abuse, a history of aggression, more previous admissions and receipt of a disability grant.
- Married and currently employed patients have fewer readmissions.
- Readmissions to hospital are not associated with gender, age, a family history of mental illness or shorter hospital stays.
- The use of depot neuroleptics in patients with schizophrenia or bipolar disorder is not associated with fewer readmissions.
- Further prospective studies are required to identify other factors associated with hospital readmission, in particular the contribution of community care needs to be evaluated.

Acknowledgements: The authors would like to thank the management, colleagues and data typists of Valkenberg Hospital for their advice and assistance

Appendix 5

<u>Focus Group Guideline for use with Mental Health Nurses in the Valkenberg</u> Hospital Catchment area on Friday 10 September 2004.

<u>Objective:</u> To determine staff perceptions on factors related to frequent readmission of inpatients at Valkenberg Hospital

Provide refreshments at commencement of proceedings.

- a) Introduce my topic and myself. Do introductions with everyone in the group, (including a colleague/student accompanying me in the group as scribe). Thank all for their willingness to participate and explain that it is entirely voluntary. I would like everyone to participate actively. There are no right or wrong answers. Anonymity will be protected in so far as I will not give individuals names in the research write up. Explain that I am not representing Valkenberg Hospital. I am not intentionally biased towards Valkenberg Hospital, but cannot cla im to be completely objective or impartial as I work at Valkenberg Hospital. I am doing the focus group for study purposes. Part of this is to allow it to be your group. I am interested in learning from your insights. Analogy of the elephant. Everyone's perception is respected and valued. I hope there will be group trust. I will provide guidelines to facilitate group discussion but as much as possible not be too directive in the group process.
- b) Establish group norms.

 Request permission to use a tape recorder, also for a scribe to take back up notes.

 Remind at what time we will end the group session today.
- c). For today's session there are several issues that I have thought of as being useful for discussion as relating to my topic. They are welcome to add more. (See list below: The bulleted items are facilitative prompts for me to use only as and when conversation gets stuck).
- d) Say that in the second session I will reflect back to them and do a member check with them on the themes that emerged from today's session, as well as from indepth interviews with caregivers, compare for similarities and differences, and obtain their input on findings and recommendations.

e) Start

- What do you think are the reasons for certain patients being frequently readmitted to Valkenberg Hospital? Quick brainstorm...
- To what extent are the patients who come to the local clinic for their follow up treatment frequently readmitted to Valkenberg Hospital? Describe how often you have to arrange for patients to be readmitted to Valkenberg Hospital.

- Where do people go for help when they or a family member become acutely mentally ill?
- What do you think could make it difficult for patients to receive mental health treatment at their local clinics? What are the barriers? To what extent does this relate to frequent inpatient readmission?
- To what extent does lack of insight into the illness, defaulting on clinic appointments and non-compliance with treatment lead to frequent inpatient readmission?
- What role do social factors play in frequent inpatient readmission (e.g. poverty, unemployment, housing, crime, violence, trauma, substance abuse, education, culture, religion).
- Describe whether patients are more frequently admitted from areas where the clinics have less staff and fewer resources.
- Discuss whether frequent readmission to Valkenberg Hospital is sometimes because patients are unnecessarily readmitted? What is an unnecessary readmission?
- Discuss whether patients are frequently readmitted to Valkenberg Hospital because they are so chronically and severely mentally ill that they cannot be cared for adequately in the community.
- What communication problems do you experience with Valkenberg Hospital that result in frequent inpatient readmissions.
- What communication problems do you experience with other sectors that could result in patients having to be frequently readmitted to Valkenberg Hospital?
- Are patients being frequently readmitted to Valkenberg hospital because staff have unmanageably high workloads? Discuss also the effect of low work morale and burnout.
- How could referral and care pathways between Valkenberg Hospital and community health clinics be improved to reduce frequent inpatient readmissions?
- What are your recommendations for how to reduce frequent inpatient readmissions and improve service?

f) Thank everyone. Check that they felt comfortable with the group process. Confirm next session.

Appendix 6

In Depth Interview Guideline

<u>Objective:</u> To determine perceptions of caregivers on factors related to frequent readmission of inpatients at Valkenberg Hospital

Phone to make appointment. Offer to pay transport costs, and provide tea and biscuits to help participant feel that their contribution is valued and respected.

a) Introduce my topic and myself. Thank the person for willingness to participate and explain that it is entirely voluntary. There are no right or wrong answers. Anonymity and confidentiality will be protected in so far as I will not give individuals' names in the research write up. Explain that I am not representing Valkenberg Hospital. I am not doing this is in capacity of an employee, but in capacity as Masters student in Public Health at UWC (Although I cannot claim to be completely objective as I work at Valkenberg Hospital.). For the purposes of my study I want to feel what it is like to be in the clients' position, so if anything I will be biased towards them. The interviewee can therefore feel free to be critical without fearing "punishment", or that their relationship with Valkenberg Hospital will in any way be jeopardised. I am interested in learning from the caregiver's perspectives and insights, which I will respect and value. I would like a trusting relationship between us in the interview. I will provide guidelines to facilitate discussion only as necessary and to ensure that sufficient aspects are covered within the time constraints. If after today's session there are aspects on which I need more clarity, I will make telephonic contact. Likewise they are welcome to phone me if they have other issues that they subsequently thought of and wanted to mention. I will explain that I will give information on the outcome of my research when I have finished, if the person would value this. However I will need to exercise caution not to raise false hopes or make rash promises.

b) Request permission to use a tape recorder. Check on what time the interviewee needs to leave. Ensure the clients physical comfort.

c) Start

- What would you say are the reasons for your relative being frequently readmitted to Valkenberg Hospital?
- What were the events that led up to this most recent breakdown and readmission?
- What arrangements did you have to make for your relative to be readmitted to Valkenberg Hospital?
- What are some of the problems that make it difficult for you to cope with your relative's mental illness at home?

(Examples they might bring up may relate to poverty, unemployment, housing, crime, violence, trauma, substance abuse, family conflict, stigma, rejection et al.)

- Where do you usually go first for help when your relative becomes acutely mentally ill?
- How easy is it for your relative to receive mental health treatment at the local clinic or day hospital? Are their barriers?
- What are your thoughts on the treatment of mental illness in the community?
- Can we explore whether there is anything positive that assists you to cope with your relative's mental illness at home?
 (Examples the interviewee might bring up could be friends, your religious faith, your church, your culture, your family, your work, lifestyle or other).
- What are your thoughts on your relative not being able to stay long-term in Valkenberg Hospital?
- Are there any specific problems that you have (in communicating) with doctors, nurses and social workers in the community that could contribute to frequent readmission of your relative?
- Are there any specific problems that you have (in communicating) with staff at Valkenberg Hospital that you would like to mention as adding to the problem of frequent readmission of your relative?
- What are your thoughts on the adequacy and effectivity of staffing and other resources at hospital and community level?
- What do you think could help to prevent your relative from having to be readmitted at Valkenberg Hospital, and assist towards recover y and rehabilitation?
- How could we improve services at (and between) Valkenberg Hospital and community health centres?
- What suggestions would you like to make to the health care providers/ authorities?

f) Thank interviewee. Check that the person was not distressed and feels emotionally contained after the session.