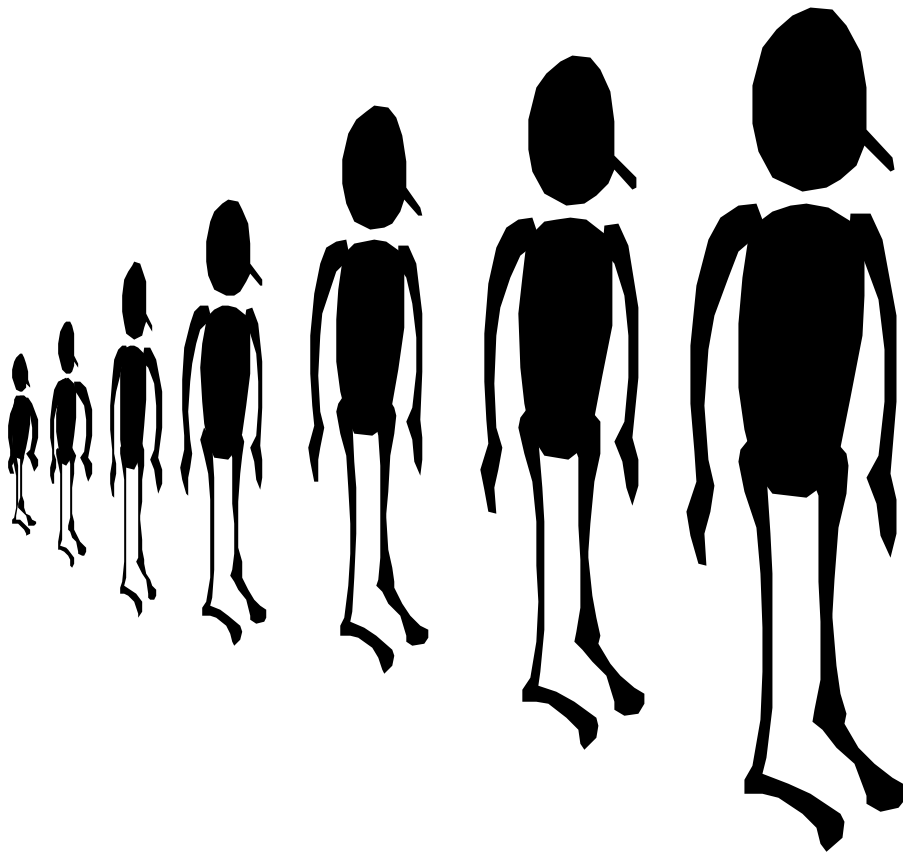


How the involuntary treatment of a mental health consumer impacts upon the burden of care experienced by family members: a family perspective



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Abstract

Mental illness is a condition which places the family of an affected person under considerable burden. The burden families experience has been extensively researched in the past. However little research has examined how, or if, involuntary treatment under the Mental Health Act (MHA) has impacted on the burden experienced by the family. This study explored how involuntary treatment under the Mental Health Act (MHA) 2000 in Queensland (QLD) impacted on families of a person with a mental illness. Focus groups were utilised to gain family members perspectives and thematic analysis was employed to determine the themes. The terms mentally ill person and consumer are used synonymously throughout this study.

Many barriers existed for families which prevented them from gaining relief from the burden they experience when caring for a person with mental illness. The MHA did little to assist the family in gaining access to the Mental Health Service (MHS).

Difficulty in accessing the MHS for early intervention was an identified issue that increased family burden. Although the principle of early intervention is promoted within the field of mental health, help was difficult to achieve until after the person with the mental illness reached acute stages of their illness or until the person arrived at crisis point, which took up to two years to achieve. Consequently, family members had to cope with managing the deteriorating health of the mentally ill person, and the impact this had on both the ill person and the family. Access was restricted due to the masking of symptoms by the mentally ill person and the difficulty for clinicians to recognise personality changes as an early sign of deterioration in mental health.

Additionally, the mental health service in its current state, with few inpatient beds, influenced the impact and the use of the MHA. When hospitalisation occurred, this

reassured families and allowed for restoration of family relationships as respite was achievable.

As a result of having a person with a mental illness within the family, disruption in family relationships developed and for some members of the family this resulted in the development of mental health issues of their own. Family members felt unsupported and blamed as being a cause for the development of the person's mental illness, and they were even accused of trying to do harm to them. This resulted in family members, out of desperation, taking treatment into their own hands and persevering in their attempts to gain help for the mentally ill person. As a result of poor access to services, family members were left with few options and family members were often led to use either deceit or threats to obtain the necessary treatment.

The provision of appropriate accommodation for consumers was identified as a concern for the family. If the family was unable to cope with the burden, homelessness could result as few other options were available for the person with the mental illness. In this respect, the MHA fails in assisting to ensure holistic care, including accommodation, for consumers. Changes in diagnosis, from the mentally ill person initially having a major mental illness to the diagnosis being altered to a personality disorder, occurred. This led to a reduction in the amount of care the consumer received from the MHS's and consequently increased the burden upon the family.

Overall the MHA had little benefit to the family as the MHS influenced the use of the MHA due to the current state within the MHS's in QLD. Early intervention and access to services has become increasingly difficult to families who receive little support to cope with the added stress of managing the mentally ill person.

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CHAPTER ONE

1.0 INTRODUCTION

1.1 Significance of the Research

Since the mid 1900's mental health reform has occurred with numerous alterations resulting in changing the path of mental health care. In the 1960's and 1970's mentally ill people were moved out of institutions with the view of normalisation. However the funding from institutions, as identified through the Burdekin Report was not reallocated to community settings despite the focus of mental health care now based on community treatment (Burdekin 1993). In 1991, the United Nations General Assembly adopted the Principles for the Protection of Persons with Mental Illness for the Improvement of Mental Health Care which sets out the principles for mental health treatment to be based on least restrictive alternatives of care and also recognises the rights of mental health consumers (New York: United Nations, December 17, 1991).

Hospitalisation has become brief for mentally ill people who are often discharged home prior to complete recovery, and there has been a continual reduction in the number of inpatient beds as it is recognised "every person with a mental illness shall have the right to live and work, as far as possible, in the community" (New York: United Nations, December 17, 1991). This means the acknowledgement of the family has altered from family members not considered central in consumer care, to the recognition of the family as beneficial and mental health clinicians now being encouraged to incorporate and involve the family. This change in treatment

preference of mentally ill consumers has impacted dramatically upon the burden experienced by family members.

1.2 Aims of the Project and Research Question

The focus of this study was to explore the experience and perception of family members of a person with a mental illness and how, or if, involuntary treatment under the Mental Health Act impacted on that experience. The main research questions which this study aimed to answer were:

- a) Does the use of the MHA either decrease or increase the burden experienced by family members?
- b) How do the family members of people with mental illness perceive the Mental Health Act impacts on their burden of care?
- c) What, if any, were the changes in family dynamics experienced as a consequence of involuntary treatment under the Mental Health Act?

Family members were targeted for recruitment and participation in the study from within a south-eastern Queensland region . The terms mentally ill person and consumer are used interchangeably throughout this study.

This study expected to determine how the family of a person with a mental illness has been impacted by the various service changes and the introduction of the new Queensland Mental Health Act 2000. This Act governs the involuntary assessment and treatment of a mentally ill person (Queensland Government, 2000). This research is important as it aimed to determine how the use of the Mental Health Act and involuntary treatment impacts on the burden experienced by the family, who are

often the consumer's greatest or only support. With an understanding of the family's experiences, provisions to assist the family to manage this burden may improve not only consumer outcomes and mental health service delivery, but may prevent mental health issues developing for family members as a result of the changed role.

The aims of the study were:

- To ascertain if the burden of care widely experienced by family members, of a person with a mental illness, was affected either positively or negatively from being under involuntary treatment of the Mental Health Act, and
- To explore any degree of family dynamic changes which resulted from having a person within the family under involuntary treatment of the Mental Health Act

1.3 Definition of Terms

Allied Person (AP):

An involuntary patient can choose a person to be their allied person. The allied person's role is to help the patient represent their views, wishes and interests about assessment, detention and treatment under the Act

(Queensland Health 2000, p. 1).

Case manager:

An identified and accessible staff member of the mental health service who is responsible for coordinating the treatment and support provided to an individual consumer and their carers. (For example: might also be called a case coordinator, key worker, case worker) (Australian Health Ministers

Advisory Councils 1997, p. 38).

Consumer:

A person making use of, or being significantly affected by, a mental health service (Australian Health Ministers Advisory Councils 1997. p. 39).

Emergency Examination Order (EEO):

An order made by a police officer, ambulance officer or psychiatrist in urgent circumstances to authorise the taking and detention of a person at an authorised mental health service for examination (Queensland Government 2001, p. 32).

Family members:

Within this study this referred to a person or group of people who considered themselves to be a family member who had at least weekly contact with the mentally ill person.

Involuntary consumer:

Are persons who are detained in hospital or compulsory treated in the community under mental health legislation for the purpose of assessment or provision of appropriate treatment or care (Australian Institute of Health and Welfare 2001).

Involuntary Treatment Order (ITO):

An order authorising a patient's involuntary treatment at an authorised mental health service- can be either inpatient or community category (Queensland Government 2001, p. 33).

Mental Health Act (MHA):

The purpose of this Act is to provide for the involuntary assessment and treatment, and the protection, of persons (whether adults or minors) who have mental illness while at the same time safeguarding their rights (Queensland Government 2000, p. 28).

Mental Health Review Tribunal (MHRT):

The independent body responsible for conducting regular reviews of involuntary patients (Queensland Government 2001, p. 33).

Mental Health Service (MHS):

An organisation that provides, as its core business, primary, secondary and, in some cases, tertiary treatments and support to people with mental disorders and/or mental health problems. A mental health service should be specialised and complimentary to other health services (Australian Health Ministers Advisory Councils 1997. p. 41).

Treatment Plan:

Outlines the involuntary patient's proposed treatment (Queensland Government 2001).

Voluntary consumer:

This describes a person's status whilst receiving assessment and treatment. Voluntary status means the person consented to assessment and treatment (Mental Illness Fellowship Victoria).

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Family Burden

Relatives and family members of a person with a mental illness have evoked a great deal of interest within the research field as a result of changes directed towards community treatment. Prior to deinstitutionalisation the family was not recognised as integral to the person affected by mental illness, however now the family is considered central to the consumer and Mental Health Services (MHS) are encouraged by National and State policies to incorporate family involvement (Australian Health Ministers 2003). Since deinstitutionalisation the care of the mentally ill has proceeded to be based on least restrictive provisions of care which have shaped the movement towards treatment within the community, which is now the preferred option of care within Australia (Queensland Health 1996). This change in treatment preference has dramatically impacted upon the burden of care experienced by family members who have swiftly obtained responsibility (Carne 1992; Brand 2001).

As a consequence of the community treatment focus and movement out of long stay hospital or institutions, the accommodation options for mentally ill consumers are scarce and it has been reported approximately forty to fifty percent (40-50%) of people with a mental illness reside with family members (Brand 2001; Ostman and Hansson 2001; Jungbauer, Stelling et al. 2004). Within Australia few statistics could be found to indicate the proportion of mentally ill who reside with the family, however one recent study by Mental Illness Fellowship (1993) showed that these

statistics were comparable within Victoria, Australia, where 40% of people with a mental illness resided with their family, whilst 33% lived alone.

The idea to keep consumers out of hospital and in the community failed to recognise that there are still a considerable number of mentally ill people who are unable to live within the community due to the nature of their serious mental illness, or the family are unable to care and manage the person's needs. These consumers consequently take up a large proportion of the already reduced inpatient beds (Lawrence, Copas et al. 1991; Drateu 2002) or they may end up incarcerated within the prison system. It has become apparent that a considerable number of mentally ill people in Australia are incarcerated within criminal justice systems. A prison inmate health survey conducted in 2001 found 54% of males and 39% of females had been diagnosed with a psychiatric condition (Butler and Milner 2001). This indicates that mentally ill people are over-represented within prison systems, well above community figures. Therefore individuals who lack appropriate accommodation, which may result from overburdened family members, may find themselves incarcerated within the criminal justice system. This may result from the difficulties with remaining homeless leading to increased stress which may add to disorganisation of the mentally ill person. This may raise the dysfunction of the person's daily living skills, such as obtaining adequate nutrition and hygiene which may lead the mentally ill person to act out behaviourally or to steal and commit offences in order to meet their needs.

Hospitalisation has become brief as a result of the reduction in inpatient beds. This has led to consumers returning home prior to complete recovery with the expectation

that family members will provide the necessary support {Tunnell, 1988 #74; Mental Health Council of Australia, 2005}. As there is a greater demand for use of available acute inpatient beds (Kalucy, Thomas et al. 2004) with the demand surpassing supply (Johnson, Zinkler et al. 2001), family members are expected to care for their ill relative when they return home unwell, thus increasing the burden of care the family experience.

Research in Sweden has revealed the family burden experienced from having a family member with a mental illness is complex (Ostman and Hansson 2000). It found relatives experienced both internal and external burdens. This study showed, in the month prior to hospitalisation, 45% of relatives had to give up leisure time, 27% felt they could not leave the person alone for more than one hour at a time, 21% had to give up work and 28% were prevented from having external interactions of their own (Ostman and Hansson 2000). Therefore, not only is the family member experiencing a high degree of stress from having a person with a mental illness within their family, but also from the disruption the illness has on their social and personal life. Individuals do not suffer from a mental illness alone but the whole family experiences the impact of the mental illness.

Potasnik and Nelson (1984) identified that heightened financial obligations often fell into the responsibility of a family member which left them with added tension and responsibility (Jubb and Shanley 2002). The additional financial concerns may be due to a number of reasons such as the family members may not be able to obtain paid employment due to the responsibility of caring for the individual at home, or as a consequence of decline in the person's mental health resulting in poor budgeting

skills or poor control of spending, so family members are at an increased risk of having to continually rescue the mentally ill consumer from financial hardship.

Behavioral alterations of a person with a mental illness often endured by family members include withdrawal, violence and aggression (Ferriter and Huband 2003). Although homicide committed by mentally ill persons is rare, when it does take place it is more often directed towards a family member than an unknown community member (Kraya and Pillai 2001). Australian research on mental illness and homicide between the years 1968-1981 indicated that sixteen percent of assailants (16%) had a known mental illness (Australian Institute of Criminology 1990). Alongside this issue is assault, and it has been found that the probability of placement on involuntary treatment of a mentally ill person in the community, or in hospital, is increased when recent dangerousness and violence has occurred to others (Xiao, Preston et al. 2004).

2.2 Family Support and Family Involvement

Despite worldwide literature supporting the benefits of family involvement, the literature suggests family members do not feel adequately supported or involved by MHS's or other support groups, despite their wishes. Research by Jubb and Shanley in Western Australia (2002) identified 57% of family members felt information and education received was inadequate, whilst only 50% were satisfied with the emotional support they received from MHS's. Only 22% of family members in this study considered themselves to be involved in treatment planning. Family members have also reported feeling blamed for the person's mental illness by mental health

professionals and unfortunately the term ‘Schizophrenogenic Mother’ is a well known term considered relevant by mental health clinicians in the past. This meant many families were deemed as pathological in dynamics, and destructive in nature, hence held responsible for the development of the mental illness (Bernheim and Switalski 1988; Jubb and Shanley 2002). Family members have repeatedly been labelled as being “primary toxic agents, particularly in schizophrenia” (Lefley 1989). However, very little research has been conducted within Australia within recent years to determine if these beliefs still exist.

Family members identified the failures of MHS as being:

lack of 24-hour coverage for mental illness in emergency centres, frequent turnover of therapists, inadequate funding for community services, and overemphasis on medical rather than psychiatric conditions in hospitals, and shorter lengths of stay for psychiatric inpatients (Rose, Mallinson et al. 2004, p. 45).

Family members have identified partnership between the family, patient and clinicians as being ideal due to the commitment, responsibility and valuable information that family members provide. To improve partnerships, families wanted improved accessibility to clinicians, information and interventions (Wallace, Robertson et al. 1999). Family members have expressed a desire to be involved in the treatment of the mentally ill person (Adams and Hafner 1991).

Importantly, it is well known that repeated relapse of a person with a mental illness occurs more frequently when the person is in a stressful family situation, where high expressed emotion routinely occurs (Hashemi and Cochrane 1999). High expressed

emotion is an environment where high levels of criticism, emotional over-involvement and hostility occurs (Vaughn and Leff 1976). This shows the importance of supporting the whole family, rather than just the individual with the mental illness. By providing counselling to ensure high expressed emotions within families are reduced and to minimise the level of distress experienced by mentally ill persons may ensure the mentally ill person doesn't relapse. Xiao and colleagues (2004) suggest that the more a person with a mental illness interacts with other people the higher the potential for revocation of community treatment to inpatient treatment, due to this being a source of stress for the ill person. It is therefore important to treat, support and educate the whole family instead of just the mentally ill person.

2.3 Review of the Mental Health Act in Queensland

Reform and redevelopment of services was a major feature of mental health care in Australia during the 1990's. Continued awareness and acknowledgements of mentally ill persons to have the same rights as other Australians, and the changes in practice for the treatment of mental illness, has resulted from alterations in State and National Policy directives contained within the National Mental Health Policy, National Mental Health Strategy, and subsequent National Mental Health Plans (Australian Health Ministers 1995; Queensland Health 1996; Australian Health Ministers 2003). These policy directives set the principles of care and treatment given to mentally ill people, guides service availability and set clinician practice standards. In order to keep up with contemporary treatment of consumers with mental illness in Queensland, legislation governing the detection and treatment of the

mentally ill was amended to meet the current standards of practice of mental health service delivery, and community expectations.

Community consultations and discussions about the development of a new Queensland Mental Health Act began in 1992, but the new Queensland Mental Health Act was not in use for another ten years. The QLD Mental Health Act 2000 (Queensland Government 2000) was passed by the Queensland Parliament on the 30th of May 2000 and introduced into practice on the 28th of February 2002 (Queensland Health 2002). This Act entirely replaced the previous Queensland Mental Health Act of 1974.

The Green Paper, explored and reviewed the previous Mental Health Act 1974, and recognised there was a need for new legislation resulting from the changes which occurred to MHS's (Queensland Health 1994). These changes included mainstreaming of MHS, alterations to the primary treatment settings with moving away from institutional and inpatient setting to community treatment being the preferred option, and the integration of various MHS into single services (Queensland Health 1994). Involuntary treatment under Mental Health Acts is now common place in Queensland outside of hospital settings. This is encouraged under the *Principles for the protection of person with mental illness and the improvement of mental health care* (New York: United Nations, December 17, 1991), and involuntary treatment in the community has become routine practice in Australia and many other countries (Dawson and Romans 2001; Brophy and McDermott 2003). According to the Green Paper society expects more emphasis on respecting the rights of people with a mental illness and treatment of individuals with appropriate

consideration given to different needs in relation to customs, religion and beliefs (Queensland Health 1994).

Access to services was recognised to require change with the introduction of the QLD MHA 2000 (Office of the Queensland Parliamentary Council 1997). To improve access and provide earlier intervention, increased methods of initiating an assessment was made available, no barriers to who can make the request for assessment were made except for the requirement of being at least eighteen years of age (Queensland Government 2000). The previous Act was considered to have many barriers in accessing services by only allowing select people to request an assessment for an individual.

The QLD MHA 2000 aimed to encourage greater openness in sharing information with patients, and patients and relatives were encouraged to play a greater role in decision making, as the Act reflected State and National directives. Under the new QLD MHA 2000 the mentally ill person was given the ability to have an Allied Person. This Allied Person may be anyone chosen by the involuntary person with their function to assist the patient “to represent the patients views, wishes and interests relating to the patients assessments, detention and treatment under this Act” (Queensland Government 2000, p. 194). This means the family may be involved if chosen by the mentally ill person and consequently be somewhat involved in their care. This is in keeping with confidentiality and privacy issues.

2.4 Benefits of the Mental Health Act to the Consumer

Various research findings have shown the benefits as well as the complexities that involuntary treatment has upon mentally ill individuals; however research looking specifically at the QLD MHA 2000 has not been completed. This has relevance to this study as the effect the MHA has for the ill person ultimately impacts upon the family's experience.

The change to community treatment has led to the use of involuntary treatment outside the traditional hospital setting. The use of involuntary treatment in the community has been a controversial area of debate with both positive and negative opinions emerging. Benefits include ensuring compliance with medications however this has only been considered consistent with depot injection medication (Vaughan, McConaghy et al. 2000). Oral medications have numerous barriers within a community setting due to the problems of ensuring compliance.

Conflict as to whether the use of involuntary treatment reduces repeat admissions exist with one study in the United States indicating that improvements in quality of life was correlated to remaining under involuntary commitment for extended periods of time of up to eighteen (18) months (Swanson, Swartz et al. 2003). However, another study In Western Australia found no difference in reduction of health service use between either voluntary or involuntary matched groups of individuals with a mental illness (Kisely, Preston et al. 2001) hence, length of time under involuntary treatment may have little impact on relapse.

There is also evidence that involuntary treatment has other benefits to mentally ill people by ensuring follow-up occurs, due to this being a requirement under the order, which clinicians have a responsibility to maintain (Queensland Government 2000; Brophy and McDermott 2003). This leads to the possibility that the already stretched MHS's may only be reaching those perceived as being in need, as identified through the use of the MHA and thus implying the need for follow-up. Therefore fewer resources may be delivered to individuals not under the Mental Health Act due to perception of reduced assistance required. However, a study in New South Wales, Australia, comparing a group of patients under involuntary treatment in the community matched with a control voluntary group, identified the involuntary group received fewer consultations prior to admission than the control group (Vaughan, McConaghy et al. 2000). Clinicians may consider they have to apply less therapeutic effort for consumers under involuntary treatment due to the safety net the MHA order provides, and it being able to be revoked whenever required. This ultimately has an impact upon the family who may be required to care for their family member with more scrutiny, thereby increasing the demands and requirements on the family to provide the care required.

2.5 Benefits of the Mental Health Act to the Family

Limited studies could be found which explored how involuntary treatment impacts on family members. The experience of the family has been a buried voice rarely explored despite their involvement and expected responsibility. Ostman and Hansson (2000) in their study in Sweden found no significance between family burden of voluntary and involuntary treated consumers, although they did discover that relatives of involuntary treated consumers were more psychologically distressed. It

was unclear in their study the reason this occurred, it may be due to the acuity of the mentally ill person's health status, lack of insight and associated non-compliance with treatment, and difficulties associated with this. Or it may be due to other reasons such as the difficulties associated with fewer consultations due to being an involuntary patient as identified previously by Vaughan and colleagues (2000). The limitation of the review by Ostman and Hansson (2000) was that the study was conducted with family members in the one month after the mentally ill person was discharged from an acute inpatient unit, indicating a recent stressful event may have occurred.

Alongside the increasing use of involuntary treatment under the MHA within the community, it has been reported that in the United States of America, family members wanted to avoid involuntary hospitalisation (Swartz, Swanson et al. 2003), yet another study in the Netherlands indicated the family preferred the option of involuntary medication, meaning medication can be enforced within the hospital environment without the persons consent (Haan, Raaij et al. 2001). In South Australia a project found the benefits which involuntary treatment under the MHA had, when improvements in compliance occurred, resulted not only in improvements in the relationship between family members but also overall within the family system (Adams and Hafner 1991). These improved relationships are thought to be a result of improvements in the mental state of the person while being under the MHA.

Removing complete responsibility from family members has also been attributed to benefits that involuntary treatment of the consumer has for the family (Adams and Hafner 1991).

Studies undertaken on the Mental Health Act has been scarce within the state of Queensland. Only one study could be located which has been conducted on the functioning of the new QLD Mental Health Act 2000. This study explored the preparedness of the QLD paramedics and ambulance officer in their assessment of mentally ill persons and difficulties associated with their education and training of mental health issues (Shaban 2004). No studies looking at the impact this Act has had on either the family members or the consumer has been found.

2.6 Summary of the Literature Review

Before deinstitutionalisation, family members were not usually involved in the care of a person with a mental illness. After deinstitutionalisation and the introduction of least restrictive provisions of care with a community treatment focus, families have more responsibility for the person with mental illness and suffer burden in relation to this. Accommodation options are limited for mentally ill people with approximately 40-50% residing with their family. Those unable to continue to live with their family might end up incarcerated within the prison system or homeless. With few options available to them, family members have additional responsibilities without many other options of care available to them. Hospitalisation has become brief with many consumers discharged home to the care of the family who feel they have inadequate support, knowledge or training to manage and are just expected to cope. Family members often have to give up work and leisure time in order to provide the expected care. Clearly it is not just the individual with the mental illness but the whole family who has to manage its effects. Violence and behavioural alterations may result from deteriorating changes to a person's mental state and this may result in some family members being at risk of harm.

The Queensland MHA 2000 was introduced into clinical practice in 2002. Numerous changes to mental health care and reform led to the introduction of the new Act including mainstreaming of MHS, change to community preference for treatment and integration of services. Involuntary treatment is now common place outside hospital settings in many countries around the world. Access to services was a factor in the decision making of the new Act, as was providing increased pathways for early intervention strategies to be employed. It was thought that the MHA would reduce

these barriers to receiving care. Accordingly, the gaps in this area within Australia and more specifically QLD, shows the necessity for this research. The study aims to determine how involuntary treatment impacts upon the experience of family members from having a person within the family with a mental illness.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study Design

The study utilised an exploratory qualitative research design via the use of focus group data collection methods, to identify how family members understand the burden of care they experience from having a person affected by a mental illness within their family. How involuntary treatment impacts upon the experience of family members was expected to be determined from this study. Individuals or family members who were not willing to participate via focus group methods were offered a private individual interview method for data collection. The focus groups and individual interviews were semi-structured with five set questions as triggers with logical flow from general to more specific questions (see Research Questions page 25-26).

3.2 Qualitative Research Approach

This study used a qualitative research approach, which in the area of nursing aims to enhance the understanding of the lived experience within an individuals own environment (Polgar and Thomas 1995). This method was chosen by the candidate to capture the true experiences which cannot be translated into numerical data. This method is often chosen when a researcher believes that individual experiences will develop personal meanings, which are unique to individuals, indicating all personal experiences of situations are perceived and experienced differently by all individuals (LoBiondo-Wood and Haber 1998). It takes the approach that attempting to calculate

numerically the aspects of health and its impact on individuals represents a reductionist approach which does not encapsulate the true representation of the experience (Martin and Thompson 2000). Thus, data collected qualitatively “consists of detailed descriptions, based on language or pictures recorded by the investigator” (Polgar and Thomas 1995, p. 109). This method was chosen to allow for greater insight from increased depth of responses. This allowed for a heightened understanding of the lived experience of family members from the burden of having an individual affected by a mental illness, and the use of involuntary treatment.

3.3 Research Participants

Focus groups with a maximum of six family members were conducted, with a total of twelve family members participating in the study. One individual interview was completed. Six members to a focus group is considered optimum number as it is large enough to obtain varied perspectives but not large enough that disorganisation occurs (Holloway and Wheeler 2002). Each focus group comprised of individuals from the same family as well as individuals from other family groups and this was reflected in the information sheet. The intention was to recruit between ten and fifteen participants and this was achieved. Participants were chosen on the basis they were a family member of a consumer with a mental illness and had at least weekly contact with that consumer. Participants had at least one person in their family either currently, or within the past twelve months, under involuntary treatment of the QLD MHA 2000.

The only exclusion criteria for the study was if the family member were under the age of eighteen years, unwilling to participate, informed consent was unable to be obtained or from a non-English speaking background.

3.4 Research Procedure

The focus groups and individual interviews were all facilitated and moderated by the candidate for consistency and congruency. The facilitator's role was to promote discussion, manage the group and also to record key issues as they arose from the discussions. All of the focus groups and the individual interview were held at the local mental health facility. This location was chosen as the room provided good acoustics for audio-recording and was central, known and easily locatable by all participants. The sessions were audio-taped and later transcribed by the candidate to allow for thematic analysis to occur. Each focus group was intended to last for approximately ninety minutes however due to the fluency and ease of generating discussion amongst this group of individuals, most of the focus groups continued for two hours.

Each family member attended only one focus group or individual interview. Family members welcomed the opportunity to share their experiences with others to obtain different views and perceptions of events. Prior to commencement of the focus groups, participants were verbally reminded that any remarks, comments heard and identity of other participants within the focus group were to be kept confidential.

3.5 Focus Group Strategy

Focus groups are a method of group interview that involves a discussion amongst the group. They include having a facilitator whose role is to introduce the topics or questions under discussion and to support contribution of participants (Polgar and Thomas 1995). Focus groups are used to explore individual's beliefs, attitudes and opinions and to provide baseline information for later measurements. Focus groups provide data that is not easily obtained through individual interviews or participant observations (Morgan 1998), as discussions generate in-depth responses from group members and produce additional thought. They allow for a heightened perception into ideas generated from the group from the use of open-ended research questions.

Focus groups can describe what behaviours are occurring but not why they occurred and so are useful for generating hypotheses to be tested later (Morgan 1998). Focus groups allow for in-depth exploration of specific issues of concern, provide a good deal of information quickly, are cost effective, and they allow for immediate follow-up and clarification of responses if required. Focus groups are also known to be useful for individuals who cannot read or write (Kitzinger 1995). The discussion generated in groups also assists the researcher as discussions may turn into debates, which assists in drawing out ideas the researcher may have not been aware of, therefore assisting with finding answers and solutions (Holloway and Wheeler 2002). The common background of the participants in this study in caring for a person with a mental illness, produced focus from the individuals which assisted the aim of obtaining as many ideas as possible through the generation of discussion- not just a yes or no answer, but what represented a broad range of views.

3.6 Individual Interview Strategy

Individual interviews allow for participation of people who may be unwilling, or uncomfortable, in discussing sensitive and personal information while in a focus group situation. Thus they were offered within this project. For some people an individual interview appears less threatening, due to their being no other person present, except the interviewer and participant. The main difference in comparison to a focus group is the individual interview has no group dynamics, there is more time for detail and a large amount of information can be gathered in a short time frame. The individual interview was semi-structured utilising the same questions used with the focus groups (see Research Questions below). In a semi-structured interview the questions are focused on the topic in question and are specific in nature but they allow for the active involvement of the individuals in obtaining the person's feelings, ideas, attitudes and thoughts which are gathered via the words of the participant (Beanland, Schneider et al. 1999).

3.7 Focus Group and Individual Interview Questions

- 1) Has the use of involuntary treatment for the family member with a mental illness created any benefits for you as a relative?
- 2) Has the use of involuntary treatment for the family member with a mental illness created any pitfalls or areas of concern for you as a relative?
- 3) Are you happy with any support, information, and involvement you obtained that may have changed the burden of care experienced, from having a person in your family with a mental illness?
- 4) Has the use of involuntary treatment altered the support and involvement you receive to support the family member with a mental illness?

5) Has the use of involuntary treatment changed the burden you experience?

Why or why not?

3.8 Thematic Analysis

Qualitative thematic analysis was employed to study the transcripts of both the focus groups and the individual interview. The candidate studied the transcripts and developed a close familiarity with the data collected. QSR NUD*IST vivo software was utilised to aid with analysis of the data. QSR NUD*IST vivo is a qualitative research and analysis program from *Qualitative Solutions and Research Pty Ltd* (1999). This software aids with management of data, codes and emergent themes, to assist with obtaining comprehension of the information and themes in relation to the research questions. This yields thick, rich and descriptive data.

The researcher employed methods suggested by Ekman and Segesten (cited in Beanland, Schneider et al. 1999) by using the following sequence:

- Each transcript were studied group by group, by sampling of groups, and whole of data collated to give a sense of the whole;
- Themes, categories and recurrent patterns identified group by group, by sampling of groups, and whole of data collated;
- Summative themes and research findings developed

3.9 Ethical Considerations and Recruitment

It was not anticipated that participants would experience any social, psychological, physical or spiritual distress as a result of being involved with this study via focus groups or individual interviews. However, if participants were to become distressed in any form, then debriefing was to be offered through the Mental Health Service. No interventions were offered to either the mentally ill consumer or the family members and consumer's treatment continued as per normal. All principles of ethical conduct were maintained throughout this research as per the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council 1999).

The family members of a mentally ill individual were recruited via use of a poster and pamphlet, which invited family members to participate in the research, and to contact the researcher. These posters were placed within the acute inpatient mental health settings, community mental health, and mental health rehabilitation facilities. Case managers also assisted with recruitment through dissemination of pamphlets to consumers to circulate to their family members. Local non-government agencies such as mental health support groups and carer's agencies also received pamphlets to assist with recruitment of family members.

After family members contacted the candidate the project was discussed verbally via the telephone and if they remained interested an information sheet and consent form was sent to their postal address that they supplied. The family members were then contacted via telephone, after time given of one week to comprehend the information sheet, and to discuss any concerns. Written consent was then obtained prior to

commencement of focus groups or individual interview and participants were informed they could withdraw consent at any time, terminate their participation and any contributions would be eliminated from the study. Consent was on a voluntary basis and no coercion, inducement, or influence was used to engage or persuade participation.

Family members were assured confidentiality would be maintained by the researcher with no identifying details to be released in any way. All information collected has been kept safe, with all identification removed, in a locked filing cabinet at the researchers residential address and shall be stored for five years, after which it shall be discarded. No information arose which may have affected consumer care. Prior to the commencement of focus groups, participants were reminded that all information and identity of other participants in group discussion was to remain confidential, and a verbal agreement obtained and this was also stipulated in the information sheet and consent form.

The research was approved by the University of Southern Queensland Human Research Ethics Committee, Royal Brisbane and Women's Hospital Health Service District Office of the Human Research Ethics Committee, and the participating health service district. Hospital sponsorship was also obtained by the Acting Director of the Mental Health Service and the Health Service District.

3.10 Potential Barriers and Limitations to the Study

- Difficulty recruiting adequate participants was identified as a potential barrier, however utilising the posters and case managers to assist with promoting interest generated the target number of participants for the research.
- Eliciting involvement, cooperation and commitment from Case Managers and Registered Nurses working within the area of mental health was thought may prove burdensome in assisting and hence information sessions were held to promote interest.
- Comparison between relatives of voluntary and involuntary consumers has not been undertaken within this study due to timeframe limitations; however it could have elicited greater understanding of the impact involuntary treatment has upon the family.
- A small number of participants from one geographical area limits the generalise ability of the study.
- The time frame to complete the research was restricted due to it being the Honours component of the Master of Nursing with only having twelve months in total.
- Potentially focus group discussions may allow for some individuals to dominate the group discussion and create bias due to other members being compliant. The candidate who has specialist training in group facilitation skills was aware of this potential and took this into consideration in moderating to ensure domination by specific group members did not occur and that all participants were given the opportunity to contribute.

CHAPTER FOUR

4.0 RESULTS

4.1 Mental Health Act/ Mental Health Service Access

4.1.1 Harder to Gain Access

Family members undoubtedly experience difficulties in gaining access to the use of involuntary treatment under the Mental Health Act (MHA). This is despite the added problems of the person with the mental illness not willing to accept the need for assessment or treatment voluntarily, so the burden is increased from this pressure for family members. They maintain that under the current structure of the mental health system this has led to it being harder for family members to gain access to involuntary treatment under the MHA, with some taking as long as two years to gain assistance from the MHS under the Act. This has resulted in family members being placed at risk in their own homes. This caused an enormous amount of emotional pain for the family members to go through this process, they feel useless and unable to help or gain help, and consequently this led to familial relationship problems occurring. As a result of the difficulties family members experienced this led them to feel they were not being listened to or believed by the MHS.

It took us two years to get treatment for our son because he didn't recognise that he had, I think he did underneath, that he had a mental health problem. But he so badly wanted it not to be there but he wouldn't admit it. So it was all our fault, we were the mad ones, and all he wanted to do in the end was kill us. Now we went to bed every night and sometimes during the day barricading our room...because when mental

health came on two occasions (to assess him)...when they came to talk to him, he'd be as nice as pie to them. He could act as though there was nothing wrong.

It took me years to try and get help for our son and nobody believed me.

4.1.2 Masking Symptoms

It was recognised by family members that part of the difficulty with gaining access to the MHS, under the MHA, was due to the ability of people with a mental illness to temporarily conceal or mask some of their symptoms. These symptoms were either not detected by assessing mental health professionals or were not acted upon. This meant the family were unable to acquire access to the use of the MHA until the consumer could no longer conceal symptoms, when acuity of the mental illness increased, and a crisis point was reached. For that reason access was significantly delayed and a full blown episode was unable to be prevented.

It was recognised that conducting an assessment outside the consumers comfort zone, such as outside their own home and conversing with mental health professionals, whom the person has no rapport with, leads to the occurrence of masking. Consequently family members felt useless in their attempts to gain early intervention. Often their only options available to them were being to observe and protect the person with the mental illness while they were deteriorating, as access to the MHS was denied due to patient refusal and the MHA not invoked. Thus a sense of hopelessness and frustration occurred within the family by being unable to assist with gaining access to the MHS through the use of the MHA.

I mean he'd been bad for weeks but they did do the assessment and he presented well for a little while, sort of out of that immediate crisis, he was safe at my daughter's home and he did present okay and I can't really argue with that. But within twenty-four hours he was walking to (city over 100km away), he's walked out of my house in the middle of the night, walking to (city) in bare feet and nothing.

But he came and they didn't treat him because the Doctor (found)...he behaved himself while he was here, he was a model patient. The only thing he did, he kept insisting we owed him half- a-million dollars and the Doctor thought that was unlikely and (person with the mental illness) is very clever, he's very intelligent and he said to the Doctor, you can't prove that they don't owe me that money and the Doctor said, no he couldn't either.

Cause they hide them (the symptoms), like often my son says to me, "don't tell the Doctor", cause he knows, they know the game.

4.1.3 Personality Changes

A change in personality was recognised by family members to be an early sign of onset for deterioration in mental state. They found complications in utilising changes in personality for assisting in gaining involuntary treatment. Mental health professionals were unable to compare changes to usual personalities especially when the consumer was unknown, as clinicians only come onto the scene after the change in personality has already occurred. Family members recognise they have the capacity to witness these personality deviations, and despite informing the clinicians about these changes in personality it is thought that unless the clinician observes this

themselves then this is not taken into consideration as a sign of mental illness. Hence family members felt ignored by MHS and unimportant. Family member's perceived that health professionals of the MHS thought they only wanted to do harm to their relative. Thus the MHA increased burden on the family by not allowing access or intervention early and again leading to potential increases in acuity and chronicity of the illness occurring. The guidelines of the MHA at present do not allow for early symptoms to be identified or early intervention to be achieved to consumers unwilling to obtain help for themselves.

He sounds very much like my son; his illness gave him a personality totally different to what his true personality was. Yet in the mental health (sic) when you rang them up and told them the weird things he was doing they'd say, 'and what makes you think he has a mental health problem?'

And we knew it just wasn't normal behaviour, he was so obviously, you know (an) unwell mental case (sic). But the only thing I think, nobody wanted to talk to the family, he had all the rights and they didn't think he warranted going to hospital, that was it, they didn't even talk to us.

...I mean we're treated as though we are trying to do something to harm our kids and all we're trying to do is help them and it's just so wrong.

4.1.4 Remembering how to Access the Mental Health Act

It was evident family members were unsure how to regain access to the use of the MHA if required. They felt they should not be expected to have a good understanding of the concepts of how to obtain access. It was thought the MHS should take any attempts made by the family in trying to access the service seriously, despite when made in the incorrect method, as the family are not the professionals and felt overburdened by caring for the consumer. When family members have attempted in the past to access the MHA using the incorrect procedures, no response was received and no explanation was given as to the correct procedure to follow. It was suggested by one member that a diary was beneficial and the other group members became interested in employing this as it enabled prompting and jogging of memory to occur. This shows that family members felt they needed to go to extraordinary lengths to care for the mentally ill person, taking on additional responsibilities which they thought should have been the role of the MHS.

...but we've written a fairly urgent letter and we sent that to all the medical people that work throughout (consumer's) case... and said that he was living in the bush, we were afraid that he would hurt someone and certainly himself...no one answered the letter within a week, we got the Justice Order, I have trouble remembering all these things.

Do what I do and keep a diary, I didn't do it at the beginning of the piece but I did after that, and it's been invaluable.

4.1.5 Fear of Revocation of Mental Health Act due to Access Difficulties

Family members feared the removal of the MHA order once it was in place. They recognised the trauma they had to go through before it can again be initiated and they wanted to avoid having to repeat the same experience. They felt angry about not being consulted in the process of removal of an order even though they are the primary caregivers and they had to live with the consequences of the decisions to remove a MHA order.

No the Doctors settled that, she's taken (consumer) off that, and I just burst into tears because I know how hard it is to get treatment again.

So I thought oh, all the trauma I've got to go through again to get her back in hospital again. Because it's very traumatic trying to get somebody to go that doesn't want to go.

4.1.6 Fighting to Access the Mental Health Act

Family members believed they were not being listened to when attempting to seek access for their relative under the MHA. They recognised that the way to be heard is by resorting to the use of threats as they have experienced a positive response from this. However they have remained silent in their journey due to being protective of the person with the mental illness.

He said I'm concerned about my brother and sister-in-law and if anything happens to them I'm taking this to the highest authority, and they listened.

We had to threat and I personally have thought of going to the media except I think that it would embarrass (my son).

We've had to fight, like all this, with our support to even get anywhere. You know what hope (has) the average people in a home, in their own home, just ordinary person, what hope have they got.

Family members particularly noted difficulties with accessing the MHA when a person was violent. Family members felt thrown between being told to go to the police service and the MHS. They perceived no-one was willing to take responsibility for those consumers who were violent or aggressive. Family members were not clear of the possibilities which exist for police officers to complete an Emergency Examination Order (EEO). Therefore, family members considered they often had no other option but to involve the criminal justice system when they were unable to access the MHS via the MHA, but guilt was experienced from following

this through, as they felt this was inappropriate and unfair to the person with the mental illness.

That's what the law does, so when I rang mental health because he was getting violent they'd say ring the police and when I rang the police they'd say take out a Domestic Violence Order again.

And he did actually violate the Domestic Violence Order, which would have made him a criminal, but I went to court and withdrew it because as I said to them, he's not a criminal, I said he wants help, not a criminal record.

Family members were aware of the reduced inpatient bed numbers in acute mental health facilities. From their experience the only way to obtain an admission was either if the person was in an immediate danger to themselves or another person. In this respect, little difference was made from being a voluntary or an involuntary consumer as probability of risk was considered to be the influencing factor in obtaining access to the MHS under the MHA.

Because there's a shortage of hospital beds, they'll only bring a person in if they see an immediate danger to themselves or the people they're living with, and that is the only way they can get admitted to hospital now.

4.1.7 Resorting to Other Options when No Access can be made

It was apparent family members do not give up hope to assist their relative and the quest to assist becomes all consuming for the family. Despite numerous attempts and still not able to gain access to MHS via the MHA, family members resorted to alternative remedies with the commonly accepted method being vitamin therapies; this was well known by relatives to be of benefit. Interestingly many family members were aware of vitamin therapy being delivered by a particular physician in an Australian city. Family members even resorted to using deceit in order to assist their mentally ill relation and this was considered acceptable as no other form of treatment could be delivered to the person. Vitamin therapy was considered to be of benefit despite the need to use deceit in order to administer it which potentially may lead to catastrophic relationship and trust difficulties arising.

And I couldn't get treatment for (my son) so I thought, he was drinking two litres of Orange Juice a day so I started putting 3000 milligrams of Vitamin B3 in his Orange Juice and he started to come good.

4.2 Mental Health Act Difficulties

4.2.1 Non-Compliance Considerations

Repeated experiences of the difficulties in maintaining stability of the consumer's mental health was explained by family members. It was recognised many mentally ill people equated the MHA with the necessity to take their prescribed medication and therefore complied with this without too many complications. However, as soon as the MHA was removed non-compliance with the prescribed medications of consumers frequently became an issue. It was considered consumers felt that by removing the MHA this indicated medication was not necessary or required. Family members deemed they are in a prime position for being consulted about the history of the consumer and were able to inform clinicians about any consequences from revocation of MHA orders and non-compliance. However they felt they were not involved despite this. The use of the MHA has these beneficial effects however without involving the family; the revocation of the MHA increases the burden and stress on family members. Family members believe mental health professionals do not consider history of non-compliance with medication when considering revocation of a MHA order.

...she's had it nearly 30 years and she still doesn't recognise it. So she has to be kept as an involuntary patient because as soon as she realises she isn't she won't take her medication and we're back to square one, and I don't know the number of times I have pleaded and pleaded with the Doctors to keep her regulated, you know as an involuntary patient.

In this instance, it was felt, mental health clinicians did not consider the rights of the family member through having to care for a mentally ill consumer at home and the difficulties and trauma of gaining further access under the MHA. It was felt mental health clinicians use patient rights and confidentiality reasons as an excuse to hide behind when making decisions and not consulting the family.

Oh because the patient has all the rights, and the parents have none.

This confidentiality thing gets in the way a lot too, you know. So I don't know how they talk about involving the family when there's this confidentiality on one hand, so they need to sort it out

4.2.2 Revocation of Community Mental Health Act to Inpatient Category

One may expect that by having the MHA in place this meant that readmission can occur more rapidly when required. To the family the MHA had very little benefits for readmission purposes. Family members mentioned that being on the MHA in the community or being voluntary made no difference with being readmitted to hospital as they still had to wait until the mentally ill relative was at crisis point. This was compounded by the difficulties in gaining early intervention to treatment due to the masking of symptoms and failure of clinicians to recognise personality changes as an early sign of deterioration in mental health. Also the inability of clinicians to enforce treatment under the MHA whilst living in the community due to the Acts regulations restricts early intervention from occurring.

4.2.3 Mental Health Act Impact on Family

Relationships

Family members felt the MHA had very little disadvantages to the consumer except in rendering the person to feel they had limited control over life choices, as the MHA restricted the ability to make complete independent decisions without getting permission through paperwork hurdles. Hence, at times this put family member's emotions into turmoil due to the difficulties confronted by the consumer, therefore increasing the burden and guilt felt by the family from feeling helpless to assist, but also trying to maintain hope for the future.

He hates the lack of control he has, or he doesn't have over his life, he's basically told where to live, how to live and when you can do this and he's got to sign permission to leave. You know, all that might change, but he's hated it, he hates the lack of control. Here's this 24 year old boy, you know, and he's just a normal 24 year old and he wants what people on TV (sic) have, you know, he wants a girlfriend and a life. You know and we're telling him you'll have to sit and wait.

4.2.4 Dual Diagnosis and Failure of the Mental Health

Act: Impact on Family Members

Having a family member with a dual diagnosis of major mental illness and substance abuse caused enormous amount of pressure, stress and frustration for the family. This is due to the belief that if the MHA fails as it is unable to provide these consumers with the additional support required. The difficulties for the person with the dual

diagnosis exists from accessing the service through to treatment issues, family members felt that the MHA failed not only the consumer but the whole family. The needs of the consumers were perceived by family members to have not been met, so some family members were left with no other options than to not allow the ill person to live with the family due to the conflicts and theft arising within the family home. Consequently this led to relationship problems occurring within the family unit. This therefore left many mentally ill consumers homeless with few options for accommodation. For this reason, despite the MHA, holistic care was not provided for the consumer which impacted on the family feeling responsible, guilty, powerless and totally dependent upon the hope the MHS through the use of the MHA will change to allow for a positive impact on the consumer's quality of life.

Due to some of the difficulties consumers with dual diagnosis present with and the problems with providing sufficient care, family members felt these consumers received less attention than other more compliant consumers. Despite being under the MHA family members felt people with a dual diagnosis received inadequate treatment from the MHS even though they actually required additional support.

... they finally decided he was a schizophrenic when he had a prolonged stay, after a long stay in jail.

...he lives on the street, its very difficult to get him any support quite frankly, because nobody; he doesn't even have a case manager because nobody wants to be his case manager so he's actually managed from the hospital here which is not very satisfactory either as he is unmanageable.

We had to refuse to have (our son) home because of the danger, damage to property and videos, he stole thousands of dollars. It's a combination of physical danger and damage to property, so they solved that problem by just putting him on the street and that is aggravating his problem because he is living in a paranoid state, he's vulnerable. He hears the cars going past whispering at him and threatening him, raping him at night...so he's living in a state of absolute fear.

We treat stray animals better than we treat dual diagnosis patients.

Family members recognised the difficulties dual diagnosis consumers place on society and upon the family, but it was considered if they were to receive the support they required via accommodation, food and Case Management then the pressure to commit crimes would be reduced. Due to this the family members were reassured by having the MHA in place as it meant if a crime was committed by the mentally ill person they may be more likely to be assessed by MHS than end up within the criminal justice system. Family members lived with the concern of the potential for unjust incarceration every day. Family members believed in order for dual diagnosis consumers to have a future with some quality of life, an institution needs to exist to provide structure, accommodation and holistic support.

Well at least the police know when he's picked up by the police for doing something silly, you know in a psychotic state, they might just send him here (to mental health) rather than charge him and send him to jail. I think it's a crime the way the MHS, the

way the MHS treats its long term schizophrenics and the long term dual-diagnosis schizophrenics by putting them in jail.

He's too mentally ill for them to cope with.

4.2.5 Mental Health Act Treatment Plans

Despite Treatment Plans being compulsory for all consumers under the MHA which sets out the proposed treatment, family members were not aware of the Treatment Plan for the mentally ill person within their family. Consequently they felt an inability to assist the consumer to meet the plans requirements which increased the sense of alienation of feeling not considered important in the person's care. Family members believed they could be utilised in a more positive way to assist their relation.

Well I wouldn't know what the Treatment Plan is, see I've never seen one.

Well see, that's the problem, the families don't know.

4.2.6 Diagnosis Complications

Family members saw a pattern of the consumers diagnosis being altered from a major mental illness to a diagnosis of a personality disorder. This resulted in the family feeling responsible for the development of the illness and confusion existed as to why a diagnosis had been changed after many years. Family members felt this to be unsatisfactory and placed consumers at risk. Family members noticed once a

diagnosis was changed to a personality disorder, the consumer was treated with less respect. This led to behaviour complications developing in the consumer as a result of the changed treatment, thus leading to additional impact upon the family from having to manage the impact this change had upon the consumer.

But now this his diagnosis has changed he's no longer a schizophrenic after 14 years, (they told us) "he's just Borderline and he knows what he's doing and he's using the system and he might have to live on the streets to learn a lesson".

Borderline is a dirty word.

Now Borderline, (they said) "you've all spoilt him rotten all his life", its just total...he was supported before, he was treated with respect...now he's not, he's a bad boy, he's a delinquent teenager, he's a Borderline.

4.2.7 Involving the Family - Allied Person (AP)

Family members acknowledged the AP role is an impossible role for a family member to undertake. The AP role led to friction when fulfilled by a family member as this role meant speaking on behalf of the mentally ill person, therefore being unable to speak their own ideas in a Mental Health Review Tribunal (MHRT) hearing. Not involving the family in treatment decisions was common practice and family members felt information sharing was vital but failed to occur due to excuses such as patient rights, confidentiality and privacy.

But then if you are the AP you can't say anything anyway unless you're trying to get them out.

But you've got to speak for them, that's why I've never gone. Then if they want to get off the ITO then you've got to say yes I think that's a good idea.

And that sets up further discord between you and your son or daughter because you won't go and speak for them.

They do not take an adequate history from the family, then they (clinicians) use privacy provisions to escape talking to people.

One of the other things about privacy is that it's often used as an excuse for laziness.

4.3 Mental Health Act Benefits

4.3.1 Hospitalisation and Respite

Hospitalisation was considered an important function which the MHA made possible. For family members this provided temporary relief and respite from having the person with the mental illness living in their home. Hospitalisation was also considered beneficial for those consumers under the MHA who were homeless, as it provided some comfort to the family in knowing that prescribed medication was being enforced, that their basic human needs were able to be met, thus ensuring overall health care was being provided, even if only temporary in nature.

Well it gives him a break from the street and it gives the communities, well the community in (town) a bit of a break because he's been banned from a few places in (town), he can't go there.

It has given us a break too, it gave us time because we were losing breath, weren't we, at one stage as well.

Oh people would just have to look at me sideways and I would burst into tears.

Family members found respite enabled management of emotions and time to reduce their emotional vulnerability and instability. Hospitalisation was recognised to have a positive impact on family relationships by opening up ports of communication and improving dynamics between family members, particularly after extended periods of time under the MHA.

Mother: She's opened up to us, told us stuff that she would never have told us about in the past, yes, the communication is definitely there and I think all that has helped...

Facilitator: and do you think you've been able to do that because of the MHA has kept her in hospital?

Father: yes, yes

Mother: exactly.

Having the MHA enacted, while the consumer was admitted to an inpatient mental health hospital, was thought to give some leverage to family members by being able to impact decision making. Family members were under the impression that consumers had been discharged whilst remaining at risk with the family's perspectives not being considered. For that reason family members attempted to take some management over decisions made by refusing to have the consumer home until they believed a reduction in risk was evident. In the following transcript piece the "child", as referred to, was not a minor.

And they put her in hospital and sort of, it came to the point where one night, as I said before we had to make a decision, we can't have this child home she is going to kill herself, she is going to kill herself. So what do we do from here now, well if they discharge her from hospital where does this child go, we don't want her suiciding in our home. We don't want her suicide number one, we don't want her to do it in our home because we couldn't live in that home and we wouldn't be able to sell it afterwards either. Because if people knew that there's been a suicide, a lot of people are superstitious for one, you know, and I think it's the real estates peoples duty to

make people aware that there's been a murder or whatever, you know. So you start looking at all these factors and now there's this hole. And eventually we had to dig our heels in and write a letter to the hospital to (the Doctor) and say we're not having her home, in other words there's no place, if you discharge her she's got nowhere to go. This is one of the issues where you've got this big hole, we're you've got a patient where this is supposed to be acute care hospital, and ideally in and out sort of situation.

This was what we found, (consumer) was still suicidal and they'd send her home and that was why we had to put our foot down last time.

Family members did recognise it was easier for a consumer under MHA who was in a rehabilitation ward to be readmitted to an acute mental health hospital. They believed this was due to clinicians having 24-hour monitoring capabilities and so they could see minor changes. Though this was not something the family members felt clinicians saw as a capability which the family could also achieve in their own home as they generally felt ignored.

It was recognised by the family the MHA ensured appropriate treatment could be given to a person with a mental illness within a general hospital, without the MHA in place this led to inadequate care delivered to the mentally ill with the consumer left vulnerable. This meant that because of the person's mental illness they may receive inadequate medical care due to the person's behaviour. By having the MHA in place this identifies the person as having a mental illness and hence some of the actions of

the consumer may be more tolerable. Failure in medical areas to recognise mental illness leaves the mentally ill vulnerable by failing to obtain the treatment required.

They refused to keep him there three hours after a general anaesthetic overnight, (they) threw him out onto the street with an open wound with nowhere to go, floridly psychotic and the surgical registrar and the psychiatric registrar said, at this stage, before he was on an ITO, he's not psychotic.

4.3.2 Mental Health Act: Providing Support and Reducing Family Responsibility

It was clear for consumers to have the MHA in place this meant monitoring should occur, this reassured the family that another protective body was in place to assist with providing safety for the consumer other than themselves, so a duty of care from legal factors was believed would ensure protection of the consumer. This to family members was like having their load lightened or reduced, therefore removing some of the responsibility from the family. This resulted in family members feeling reassured by not being the only ones with the welfare of the consumer in mind, as the MHA was in place. It was also easier for the family to access additional support from external resources, such as the police, when the MHA was in place.

Well knowing there is somebody out there to help, only a phone call away, and that means so much. You know it really means so much because when you're a parent you try to be a professional but you can't because emotion takes over and you can't think straight and you can't always do the right thing because you're mentally upset.

Yes but you see they're more liable to if something goes wrong.

At least with that order though, at least now like yourselves like um (sic), the police now are aware that he is under that order. You know so I'm really thankful, you know I'm talking about no more drawing guns...

Family members were reassured by the MHA, as if the consumer came to the attention of the police there was increased chance they would be taken to a mental health service rather than to prison and less likely to be charged, this reassured the family as they felt the MHA provided some protection to the mentally ill person.

Well at least the police know when he's next picked up by the police for doing something silly, you know in a psychotic state, they might just send him here rather than charge him and send him to jail.

When a consumer felt supported by MHS's within the community, due to the MHA ensuring follow-up, this was considered important to family members as this created empowerment to the mentally ill person and the family and allowed independence to develop rather than dependence on the family. This was assisted as MHS served as an intervening factor or third-party, so this protected family member's relationships.

Because its better for another person outside the family environment to do that otherwise it could end up with a little row and that puts more stress on the carer, more stress on her.

I think it assisted to be honest...had we tried to enforce that ourselves and say, look your going to hospital whether you like it or not, it would have created a massive rift.

As the MHA indicated that if a person under the Act leaves a geographical location without permission they are to be returned, this reassured the family as they felt this was a protective factor for the consumer, meaning the family could decrease their concern on the person's whereabouts, therefore the MHA provides a safety net for families.

And I'm fearful of (him) going off it, even if (he's) well, because a boy went off it and the next day he discharged himself from (hospital) and I'm not sure where he went.

Well no it's the order, if he runs away, cause in the past he used to run away to the bush and live on the streets and that, so now I know if he ran the police are supposed to bring him back.

4.4 Mental Health Act and Resources

4.4.1 Accommodation Issues

Family members experienced difficulties with gaining assessment and admission to MHS's. With the reduction of in-patient bed numbers and its compounding difficulties, this invoked fear within family members of the alternative of imprisonment. Having a return of long stay institutions or increased availability of rehabilitation settings was identified by family members as an area which may assist with care of the mentally ill person. The reasons identified was it would provide protection to the mentally ill who may otherwise be vulnerable due to the illness deficits, protection from homelessness, imprisonment or even death, hence it was felt the MHA failed to view people holistically. It was felt resources are missing which could improve the overall quality of life for both the family and the person with the mental illness.

The return of long term hospitalisation was thought to be potentially beneficial for consumers particularly who had a dual diagnosis. It was recognised by family members to be difficult to live with a person with a dual diagnosis; so they are more likely to end up homeless. This led to family members feeling excessive guilt over not being able to help.

I think the alternatives are being dead or long term jail sentence and in fact I don't think that jail is the right place for the mental health service to stuff its overflow which is what happens. I think the whole attitude; I think there's been a crazy attitude in this service where they think people shouldn't be protected from themselves.

I believe if there was an institution that he would be alright, he'd be physically occupied, give him some quality of life, something useful.

Discharge plans are that he's on the streets! On the streets!

4.4.2 Police

Overall it was agreed that the police service was very responsive to family member's phone calls in assisting with placement under the MHA, but family members perceived apathy in police attitudes. It was recognised the police were at times reluctant to take a consumer to hospital due to the overwhelming experience of consumers not being admitted.

They are in a situation because they won't cart someone off to hospital when you would like them to because they said, 'they'll beat me home'. They've done it so often, they've taken someone up to (hospital) because they're threatening to kill someone or themselves, (and) they come over here and they (clinicians) say to them, 'do you feel like killing yourself now?' and they say 'no' and they say 'well off you go' and the police say that they beat them home and that's why its hard to get police to take them in at all.

...one time they took him into the Salvation Army because they thought well, what's the use of taking them into hospital?

4.4.3 Case Management

Family members expected when the MHA was in place, they would have a reliable and efficient clinician to monitor the mentally ill person, utilise the family, engage the consumer within the community and provide some form of therapeutic intervention however for this to occur was rare. Family members were disappointed access to case management was not improved from the use of the MHA as expected.

Family member 1: Well no, they don't come. Well actually the case managers are another pain in the neck...they never ever ring back.

Family member 2: No, they (case managers) never turn up

Family members felt case managers did not perform their role as expected as they did not intervene when deterioration occurred, rarely changed any treatment and hence it was not until the consumer was in an acute crisis did intervention occur. This was not helpful for the family as they were expected to remain carers and cope with the deterioration. Therefore negativity towards case managers occurred from the family as they felt they were not heard or listened to. Family members felt case managers did not notice deterioration when family members did. The experience from the focus groups was it was more likely for a case manager to be more unconstructive in their role than constructive.

They (case managers) do that, pass the buck and leave it till the weekend and someone else can come and deal with it.

See, they don't care, it doesn't affect them. They're not the ones with all the trauma and the emotional upset, they're not the ones that has to spend weeks and months in the wards here, they don't seem to care.

Anyhow, she came to give (consumer) the injection and she was sitting there talking to (consumer) and (this consumer) was, you know, delusional, argumentative, she was singing out in a way she doesn't do when she's well. Anyhow the case manager gets up and toddles off. I couldn't believe it.

Some family members were surprised by mention of case managers coming to the house of the mentally ill person, indicating this was not always routine practice. It was evident different case management teams had different sets of practice with most satisfaction coming from mobile case management teams which had increased client contact. Case management styles which were more comforting to family members came to the accommodation of the consumer and were reliable as they felt they did not have to watch and monitor the consumer as closely themselves, but knew help was nearby.

Family member 1: I must say in defence for the case workers...I can't really fault them. They've said on practically all occasions they've said, they will come at such-a-such a time, (and) they've come.

Family member 2: Gee, where did you get your caseworker, I haven't set eyes on one yet

Family member 1: that's with (mobile team)....they do come to the home and everything.

4.5 Emotional Responsiveness by the Family

4.5.1 Family Emotional Health Impact

Clearly, all family members within the study were heavily impacted by the experience of not only having a person with a mental illness within their family, but from the impact the consumers lack of insight and non-compliance had upon the family leading to the necessity for using the MHA. The difficulties with accessing the MHA initially and attempting to use the MHA to prevent deterioration created emotional trauma for family members. This was due to difficulty in gaining early intervention until crisis point was reached, as mentioned previously. This left family members with profound and intense emotional burden which family members found very difficult to cope with. It was recognised that having a person with a mental illness within the family consumed, and was capable of taking over control, of the life of family members.

What he needs is help and my brother-in-law was so concerned about our health he wanted to know what he could do.

I think any carer will speak up because we're all fed up.

I told her I burst out crying and carrying on because I have all the trauma of watching her not taking her medication, which she didn't do once she knows she doesn't have to, (and) bit by bit she goes down and you've got to put up, she difficult to live with..

I find I get very tired, very emotionally drained.

Well I was crying, I was shaking because I realised the situation I was in because she was a very difficult person to get along with. We live together so that I can care for her, I don't have any family support there's only the two of us, I have no relatives around here and as I've been her carer for 40 years...I don't have a great list of friends.

The difficulties faced often led to social isolation, but those family members who retained some form of employment found this helpful as a method of gaining time away, diverting attention elsewhere and hence switching off emotionally. Family members also felt they did not have the skills or training to adequately help the person despite feeling relied upon by the MHS.

..but I kept working, I don't work full time but I work four days per week and I kept that going because I found that I could switch off and that was the only thing that was keeping my sanity.

And I said, well I'm not coping; I'm way out of my depth.

Family members felt they should have received greater support directly for the consumer and indirectly for the family when the MHA was in place; however this did not occur in reality. Consequently, this resulted in family members spending additional time with the mentally ill person and, thereby neglecting other family members resulting in family disruption and even contributing to further mental illness developing within the family.

Oh yes, taking a lot of my time and even today it splits us at Christmas. I always put (her) first because she hasn't got the quality of life her brother or her sister has and as a mother, or a parent, I know I try to make up for it. Her brothers happily married and got a lovely family. Her sister's happily married and got a lovely family but I know (she) will never have that and you try and make up for that.

...the meat in the middle of the sandwich because you love both and you want them to be little happy chappies and yes, you never ever get over it and it can split a family.

Mother: absolutely because our daughters anorexic as well

Father:...because he took up so much of our time.

The MHA implied that a person had difficulty accepting that they had a mental illness and had problems with complying with their prescribed medication, in this sense the family with a person under the MHA is required to cope with these added difficulties. Having a person under the care of the family who was ill to this degree took up much of their time and consumed the life of the family, particularly the mother. One mother mentioned how it gave her life a sense of purpose, without this in her life she felt there was nothing else to live for, hence this gave a sense of the impact the illness had upon the emotional health of mothers who were primarily the carers.

I know this sounds really extreme but I always said that if one of us goes, we all go together and I still mean that sincerely cause we've been through so much together, you know what I'm saying.

4.5.2 Guilt and Grief of Family Members

Whilst attempting to access the MHA for relations, family members found it emotionally challenging to involve the police in this process and often delayed contacting them for help. Involving the police resulted in family members being blamed by the mentally ill family member and so guilt emerged from the family. Therefore the MHA and initiating it with the use of the police often leads to family relationship disruption when the mentally ill person has recollection of the event.

It came to the stage that if he didn't come with us we would have to get the police and (consumer) is nearly 24 (years old) now and he hasn't been unwell. But when he's unwell he'll bring that day up, 'how could my mother and father threaten me like that, you are my mother and father, your supposed to love me'.

Family members also feel the blame and experience the guilt when not involving the police but by initiating the MHA order in some way.

My son hates it too and he's hated me at times for putting him under it.

I know with (consumer), like she wouldn't speak to me for over a week. I never came to see her last week because you know, (she said) 'you put me in here, it's all your fault'.

4.5.3 Aggression and Violence

Some family members recognised that they were exposed to destructive behaviours in their own home, due to caring for the mentally ill person, and were expected to cope with this. It was particularly a concern after a MHA assessment occurred but no admission followed as this heightened the potential for violence and placed family members at increased risk.

So after two more years of hell we eventually got another JEO and the same thing happened, and yet as soon as they (Mental Health Clinicians) were gone the same thing happened, he was back threatening to kill us and he did actually physically hit me on a few occasions and tried to hit his father as well.

As hard as it was for family members, it was safer for some families to not live with the consumer. It was felt despite the MHA being in place, the MHA failed to provide adequate community care for the mentally ill person. When the family could no longer manage the impact the mental illness had upon their lives, the consumer fell through the gaps with no other community support able to assist them, thus resulting in homelessness.

We had this situation where our son doesn't actually know where we live, I mean he has our telephone number but we had to do that for security reasons...It's a combination of physical danger and damage to property, so they solved that problem by just putting him on the streets.

4.5.4 Family Knowledge of the Mental Health Act

Despite all family members within this project having recent involvement with the MHA it was clear that their knowledge was varied and inadequate. Family members recognised unfamiliarity with how to access the Act, or what provisions the MHA could provide if required.

Mother 1: so they've taken him against his will to the hospital?

Mother 2: yes

Mother 3: they can do that under the MHA?

What does the ITO say in terms of readmission to hospital? Do they have to be violent?

Everywhere there should be a web site up there which is maintained daily by the mental health service, listing all the support services and contacts.

4.6 SUMMARY OF RESULTS

4.6.1 Mental Health Act/ Mental Health Service

Access

The introduction of the Queensland MHA 2000 did not reduce the barriers in gaining involuntary assessment or treatment. Under the current structure of the MHS it is hard for family members to gain assistance for the person with the mental illness. Family members were even placed at risk within their own homes from the difficulties in accessing the MHS under the MHA. Ultimately the delays in accessing the MHA led to the occurrence of family dysfunction.

Masking of symptoms by people with a mental illness was one of the barriers encountered in gaining access and often overlooked by clinicians, preventing access until crisis point and negating early intervention from being achieved. Changes to consumer's personalities were often overlooked as a warning sign of deterioration in mental state and accordingly this meant gaining early intervention under the MHA was limited. Family members felt ignored by the MHS despite their persistence. Family members found it difficult to remember how to access the MHA and felt it to be unreasonable to expect family members to recall the correct procedures. They felt no action was taken by the MHS when the incorrect procedure to gain access under the MHA was used by family members. This ultimately placed a greater degree of stress and burden upon the family.

Due to the difficulties in accessing the use of the MHA, family members feared it being removed from the person with the mental illness and were upset and angry

from not being involved in the decision making process as this decision impacted greatly upon the burden experienced by the family. As a result of the access difficulties, family members felt they were not being listened to, family members therefore resorted to seek alternatives to obtaining assistance such as the use of threats or using deceit. Family members continually persevered with their hope of gaining improvements to the person with the illness. When an assessment occurred, but resulted in no hospital admission, this often led to an increased risk to the family due to increasing the distress to the mentally ill person and the family's risk is increased especially when confronted with symptoms resulting in aggression and violence. Family members found a lack of service responsibility particularly when aggression and violence existed and was present in the mentally ill person.

4.6.2 Mental Health Act Difficulties

The family identified people with a mental illness equated the MHA with the requirement to comply with medication and when removed, without discussion with the family, non-compliance often resulted. Family members felt they had no rights as they were not involved in any decisions made about the persons care despite the impact it had upon the family. It was considered that clinicians hid behind excuses such as patient rights and confidentiality issues to exclude the family. The MHA had little influence or benefit for assisting with readmission for hospital treatment as the person with the mental illness still had to wait until they reached crisis point before any intervention occurred. Little intervention was obtainable whilst the consumer was deteriorating as early intervention was not achievable. Family members felt the MHA had few disadvantages to the person with the illness but it reduced the person's

autonomy which led to feelings of guilt by the family due to their inability to assist with improvements.

Consumers with a dual-diagnosis presented an enormous amount of burden upon the family as it was felt these people were at increased risk of homelessness and no holistic care, which included accommodation, was provided despite being under the MHA. It was evident to the family members the person with a dual-diagnosis received inadequate care and obtained less attention and treatment than consumers with a single major mental illness. Family members of a person with a dual-diagnosis lived with the concern of the person being incarcerated within the prison system which stemmed from being homeless.

Despite the MHA aiming to improve family involvement families were not always aware of the consumers Treatment Plan under the MHA and hence they felt considered not important or valued in the persons care. The introduction of the Allied Person under the MHA was not welcomed by family members as it led to friction within family relationships.

It was also evident some consumers experienced a diagnosis change from having a major mental illness for a lengthy period of time to a new diagnosis of Personality Disorder. Family members observed a change in the treatment received as a result of this which had a negative impact on the behaviour and attitude of the person with the mental illness.

4.6.3 Mental Health Act Benefits

Hospitalisation, as a result of having the MHA in place, was beneficial to family members as it allowed for respite for both the family and also homeless consumers. It also ensured compliance which provided relief to the family as it enabled emotional stability to occur and also assisted in improving communication between all members of the family. Although readmission from community to hospital proved difficult, readmission from rehabilitation areas to acute hospital areas was quick and efficient in reducing deterioration in the mental state of the mentally ill person.

Having the MHA in place, during hospitalisation of the person, meant family members were able to have some ability to influence decision making of clinicians. The MHA protected the mentally ill person in medical areas of health care as it flagged to clinicians some behaviours may be due to the mental illness. Without the MHA in place this led to improper care within medical areas from failure to recognise the mental illness. The MHA also identified to the police the person was mentally ill and hence reduced the risk of penalty within the criminal justice system. The MHA reassured the family as it provided another protective factor to the individual by limiting these vulnerabilities identified but also as it reassured the family that another protective body was in place as the MHS also indicated a duty of care for the person. Thus this reduced family members from feeling they had complete responsibility for the welfare of the mentally ill person.

The MHA ensured follow-up and those consumers who received this and felt supported had a sense of empowerment according to the family. This reduced the person's sense of dependence on the family and as a result improved relationships.

The MHA also reassured the family as if the person left the geographical location of the MHA order without approval, according to the beliefs of the family, that person would be brought back to the original location, thereby providing a safety net.

4.6.4 Mental Health Act and Resources

Family members saw the need for increased supported accommodation for the mentally ill person and even a return of some long-stay institutions to allow for the protection to the chronically mentally ill and the vulnerable. It was thought the MHA itself did not provide the adequate protection required, including accommodation to some of the mentally ill.

Response from police was perceived to be efficient but family members were aware of apathy and frustration. This was thought to be due to the efforts of the police in taking a person up to hospital for an assessment which often resulted in the person not being admitted. This was identified to lead to reluctance in the police performing their duties of assisting the mentally ill.

Family members were disappointed the MHA did not improve access to adequate case management or follow-up by clinicians. It was felt that case managers did not adequately perform their role or intervene where appropriate to prevent deterioration in mental state. It was felt that case managers did not listen to the family members concerns or involve the family in the care of the mentally ill person. The majority of family members felt they could not rely on case manager for assistance when required.

4.6.5 Emotional Responsiveness by the Family

Family members encounter a great degree of emotional burden and difficulties both prior to and after having the MHA in place, from its initiation through to its use.

Family members felt unsupported in their role as carers and had difficulty coping and managing the effects the illness had upon family members, leading to some family members developing mental health concerns of their own. Those family members who maintained some form of employment expressed less distress as this provided an opportunity, to divert attention away from the impact of the illness. The process of resorting to the use of the police to assist with accessing the MHA was avoided, which delayed the family from involving them until no other options existed. Involving the police often led to feelings of guilt within family members.

Many family members were expected to manage aggression and violence within their homes with little support or education on how to cope with this. Family members had little knowledge on the MHA and its provisions, indicating the lack of or the poor quality of education given to family members in this area.

CHAPTER FIVE

5.0 DISCUSSION OF RESULTS

5.1 Mental Health Act/ Mental Health Service Access

Family members obviously experienced delays in gaining access to the MHS under the MHA and found early intervention was an extremely difficult principle to achieve. Family members therefore experienced a great deal of difficulty in keeping consumers well. There is some sense that family members felt the notion of *Out of Hospital Out of Mind*, as recognised by a recent Australian report (Groom, Hickie et al. 2003). It can be speculated access difficulties exist for a number of reasons, all of which impact upon the difficulties encountered by family members. Recent studies have indicated in the past ten years, in some areas, there has been an increase in mental health presentations to the emergency department of a hospital with ten times as many presentations identified in South Australia (Kalucy, Thomas et al. 2004). This occurred with a stable number of presentations in other areas. The reasons for this occurrence is not clear, but one explanation may be that family members are experiencing an enormous amount of burden that may be a result of deinstitutionalisation or even from an increase of mental health concerns in society. Despite this, funding towards mental health within Australia has not improved over the last ten years, as added funds given towards improvements in mental health has remained comparable with inflation (McGorry 2005).

The question arises however, would the experience be different for family members of a voluntary patient? As this study did not compare a group of family members from voluntary consumers it is difficult to determine. But, it is believed the

difficulties which arise from lack of insight and non-compliance with their treatment would lead the involuntary group of family members to have a heightened sense of responsibility and hence an increased stress response. Despite recent reports indicating the access difficulties occurring within the MHS's of Australia (Henderson, Andrews et al. 2000; Groom, Hickie et al. 2003), the introduction of the QLD MHA 2000 has not alleviated this problem. Primarily, as access appears to not be related to the consumer obtaining appropriate assessment, but because of the insufficiencies of the MHS in being able to intervene early or provide appropriate holistic care. Possibly this may be due to the continuance of poor funding to MHS, reduction of inpatient bed numbers and over-stretched and over burdened clinicians working in this area. It appears feasible due to this that supporting family members to feel involved and providing them with education and support may actually assist the MHS in some way to overcome some of the difficulties faced.

Further reviews to the MHA may prove beneficial. Within the United Kingdom the review of the MHA is considering alterations which may include allowing for compulsory administration of medication to occur within the community (Johnson, Zinkler et al. 2001). Currently this is not allowed under the QLD MHA 2000 as medication can only be enforced at an authorised mental health service (Queensland Health 2000). However by incorporating this, it may assist within QLD in order for early intervention to be achieved, by reducing the need of having to wait until crisis point is reached or for an available inpatient bed.

Masking of symptoms by consumers led to difficulties for family members as it prevented them from accessing early intervention despite this being a current

ambition within MHS, as outlined through the third National Mental Health Plan 2003-2008 (Australian Health Ministers 2003). Masking of symptoms was not recognised as always being a conscious process by people with a mental illness by participants in this study but one that occurred as a result of altered circumstances and altered environments which occurred during assessment. This resulted from an unfamiliar person entering the personal space of the mentally ill person thereby causing them to feel uncomfortable and to withhold all symptoms, thus masking them. Therefore family members have an added burden of having to care and protect the person when they are in the deterioration stage, but are unable to gain intervention from MHS until crisis point is reached, when they are no longer able to mask or temporarily control their symptoms. Family members see the mentally ill person within their natural environment, at home where they are comfortable. Consumers were often moved from their comfortable environment for assessment, for example, emergency departments, and hence due to consumers being uncomfortable or anxious, some symptoms are hidden or may be incorrectly assessed as being due to the anxiety and stress of the assessment.

A literature search of masking of symptoms could not locate any reference relating to this. However this may be similar to 'guarding' which is a lay term used within the area of mental health to mean being cautious or reluctance to give out information (The Macquarie Dictionary 1988). This nature of mental illness appears to have been overlooked when conducting assessment so the view of family members has created valuable and new insights into the nature of mental illness, in both access and treatment difficulties encountered. Despite possible intervention preventing a relapse due to family member's detection, the masking of symptoms adds to the difficulties

in this occurring and early intervention becomes unobtainable. Utilising the family's concern of this occurrence is a factor which may require consideration by clinicians when making an assessment and decisions about treatment, to prevent masking from limiting early intervention.

A review of the literature of early warning signs for mental illness, by Berno van Meijel and colleagues (2004), establishes there is a widely accepted understanding that personality changes are an early warning sign of mental illness. However family members are struggling to access assistance under the MHA for personality changes. This is likely to be due to the MHA being unable to be placed into action until all the strict criteria are met, such as risk to self or others or risk of further mental and/or physical deterioration (Queensland Government 2000). Despite personality changes being considered an indication of risk of further deterioration this clearly is not considered sufficient. This does not assist the family to gain assistance early or prevent further deterioration, particularly when the person is not willing to accept the need for intervention. Family members are frustrated by the lack of understanding and warmth received by clinicians who readily dispel concerns expressed by the family. Difficulties exist when the family notice changes from usual personality however clinicians seem quick to try and down-play family members concerns. Reasons for this may be due to the inability of clinicians to react and implement changes due to the current state of the mental health system which has been referred to as being in a current state of crisis, such as poor access to services, reduced inpatient bed numbers and inadequate resources (Edwards 2005; Hickie, Groom et al. 2005). Recently a national inquiry has occurred due to this crisis (Mental Health Council of Australia 2005).

Why do family members have such a sense of fear that the MHA will be removed from the consumer? From this study the fear indicates the difficulties family members encounter when trying to re-enact the MHA order and the initial problems with finding the correct information to assist them. This is associated with the increased risk of the consumer becoming non-compliance with treatment once the MHA is revoked. It is unreasonable and unrealistic for family members to know and remember the MHA and its provisions as they do not use it everyday; however they do not feel they can rely on receiving help and assistance when required. Continuing to not involve the family members in this process will only continue to alienate the family rather than alleviating the problems and will lead to family members continuing to fear the removal of the MHA, due to the difficulties encountered with implementing and re-engaging with the MHS.

With increasing distress placed upon the family, by repeated attempts to gain access to the MHS through the MHA, it became evident family members persisted and hope was not lost. Family members resorted to finding other options to assist their family member and this may involve deceit in order to maintain hope. Although the practice of deceit only occurred within one family, many families had made contact and utilised alternative therapies in order to assist their family member. When families feel they have limited options they may result to drastic measures to try and help the person. By putting herbal medications into the mentally ill person's orange juice and not informing them, this ran the risk of losing trust within the family and creating relationship breakdown.

5.2 Mental Health Act Difficulties

The benefit of the Mental Health Act for maintaining compliance with prescribed medications has been a dubious one. As identified through the literature review for this study, the benefits are primarily only associated with depot injection medications, as they are given only by clinicians. However the family members in this study found the MHA reinforced to consumers the necessity to take the medication, possibly due to being aware of the consequence of not taking medication such as revocation of the community MHA order to inpatient hospital status, meaning the person must return to the hospital for treatment. A review of the literature on compliance issues by Lowry (1998, p. 282) states “the notion of coercive tactics to enforce compliance and the possibility that this coercion is reinforced by the authority figure of health professionals is a reality that needs to be addressed”. Thus the MHA in itself may be viewed from the authoritative view and hence when the Act is removed, so is the threat of coercion to the consumer. However in order to clarify this, further analysis needs to be conducted from a consumer perspective. This may help to explain why family members fear the revocation of the Act as coercion to consumers is removed.

What benefits does the MHA really have when the client is in the community within the current state of crisis of the MHS? Readmission still proves difficult for family members to activate however it was recognised this was not as troublesome as when not under the MHA at all. This thus contributes to the fear the family members experience from the removal of the MHA and the associated emotional burden attached with this.

A consumer with a dual-diagnosis was identified as being neglected by the MHS as family members are left to manage with compounded responsibilities. The MHA was considered to fail consumers and family members by not allowing for the provision of holistic care for consumers which includes accommodation. Dual-diagnosis (those with major mental illness and co-existing drug or alcohol disorder) consumers have been recognised as being time-consuming. It is a difficult area which is poorly understood and poorly managed by mental health professionals in Australia, and requires increased use of services and facilities (Kavanagh, Greenaway et al. 2000; Welch and Mooney 2001; Dean and Soar 2005).

Research in Australia by Kavanagh and colleagues (2000) has already shown a need within Australia to improve the holistic care for consumers with a dual diagnosis. For family members within the non-metropolitan area of this study, insufficient services and facilities remained apparent with inadequate assistance offered to families of dual diagnosis consumers. Despite the MHA being in place, people with a dual diagnosis illness continue to receive poor care and this, as identified by family members, does nothing to alleviate the burden of care they experience but heightens their level of frustration and emotional pain. Difficult clients have been identified to receive less care and support from clinicians (Carveth 1995). This is consistent with the labelling of the dual diagnosis consumers as difficult within this study, as family members recognised people with this diagnosis or a diagnosis of personality disorder were labelled as difficult and did not receive adequate care for their illness.

Not surprising, family members within this study indicated a concern after evidence that diagnoses were being changed from a major mental illness to a personality

disorder. This led to family members feeling somewhat responsible for the development of the illness. A change in the care and treatment the consumer received by clinicians resulted from this change in diagnoses, and by reducing the care received from MHS this increased the burden of care experienced by family members. The questions arise as to why this is occurring. Is it because it removes responsibility from mental health professionals? As instead of a major mental illness, the person has an Axis II illness which indicates the person does not have a clinical disorder? What place does the MHA play in this? From the perspective of the family, the MHA does not play a major role in actually supporting the consumer or the family, as the diagnosis the consumer had influenced the nature of the treatment received. It continues to be debated as to whether personality disorders can be treated (Paris 2002; Svrakic, Draganic et al. 2002) and so by having this diagnosis it may assist in removing responsibility from MHS's under the MHA.

It has also been found that a diagnosis of Borderline Personality Disorder influences care delivered, as clinicians may feel the consumer is in control of negative behaviours, and therefore staff experience more pessimism and less sympathy towards the consumer (Markham and Trower 2003). This reflects what family members in this QLD study experienced. They also observed this change in care received can contribute to the development of increasing destructive behaviours in consumers. It is not surprising that consumers react this way, as this is known as the impact of countertransference. Countertransference occurs when clinicians feel guilty about having strong emotional reactions to consumer actions, which are common with behaviours associated with personality disorders, clinicians react by either

rejecting the person with the mental illness or they become over-involved (Rayner, Allen et al. 2005).

Unfortunately, the Allied Person role established under the QLD MHA 2000 had very little benefit to the family. They found the role impossible to perform as it meant the family was unable to give their own opinion, but instead were required to give the opinion of the mentally ill person, who may be unwell at the time. This led to family conflict arising due to family members refusing to take part in the role, hence family dynamics were altered negatively resulting in dependability or trust issues developing. Family members felt this role has done nothing to improve the involvement of the family in the care of the mentally ill person or to recognise and incorporate family opinion. In South Australia the Guardianship Board has been employed under the MHA to ensure the welfare of mentally ill persons who were incapable of managing their own health or affairs (Adams and Hafner 1991). This was found to be of benefit as it assisted in reducing hostility between mentally ill consumers and their family. Removing the emotional attachment between the family members and the ill person in conducting such a role and using an independent body such as the Guardianship Board, may assist to preserve family relationships from dysfunction.

5.3 Mental Health Act Benefits

To the family, the MHA enabled support through providing respite when hospitalisation occurred, this enabled family relationships to be maintained and protected. Respite not only allowed for preservation of family members emotional health, but it allowed for whole family dynamics to be improved and restored. The

break encountered through the temporary separation therefore allows time for communications within the family to be improved and prevents the episode of the acute stages of a mental illness from burning out family member's resources and strengths. Hospitalisation was identified as being difficult to achieve, due to access difficulties and the inability to obtain early intervention, however this may more likely result from failures of MHS resources rather than in relation to the MHA itself. Additionally hospitalisation for consumers under the MHA was recognised by family members to provide the mentally ill person with respite from poor living conditions, such as homelessness, and for homeless consumers it appears that the MHA provides very little support outside of the hospital setting. Despite early intervention and increased family involvement being an aim of the QLD MHA 2000, this certainly has not been achieved.

It was important the family had the MHA enacted as it removed a sense of fear from complete responsibility from them. This brings up the notion that family members were concerned that something negative may happen to the person with the mental illness, thus the MHA assisted in providing protection. As the MHA is an Act of Parliament this showed to the family that responsibility was implied and duty of care existed from mental health clinicians to ensure that safety was maintained. Having the MHA in place may assist families with the knowledge that they will not be completely responsible if the consumer comes to harm as mental health clinicians were also responsible. Hence it may reduce the impact of any guilt experienced by family members if harm comes to that person, knowing that they were not the only ones who had a duty of care and yet harm was unable to be prevented. Therefore it assists in terms of the preservation of the family member's emotional health.

5.4 Mental Health Act and Resources

Holistic provisions, including adequate accommodation, was recognised by family members to be absent from the care clients received, this led to difficulties with maintaining the person with the mental illness under the MHA. So what has really changed since the Burdekin Report recommended in 1993 “one of the biggest obstacles in the lives of people with a mentally illness is the absence of adequate, affordable and secure accommodation” (Burdekin 1993, p. 337)? According to Maslow’s Hierarchy of Needs (1970), shelter is considered part of the most basic biological and physiological needs required, without this an individual is hindered in the development towards self-actualization (Maslow 1970). Therefore without basic accommodation for people with a mental illness their road to recovery may be long and difficult. Hildegard Peplau, an early American theorist, recognised all people have basic needs which need to be met and she includes shelter as one of these. Peplau indicates when these needs are not met, then growth will be inhibited and frustration occurs, which leads to regression developing in individuals (Pearson and Vaughan 1990). Hence lack of accommodation may lead to increased chronicity of mental health consumers.

Interest within Australia currently has a focus on accommodation for the mentally ill person as it is recognised that a large proportion of homeless people are mentally ill, with figures indicating over half of homeless people, up to 75%, maybe mentally ill (Herrman 1990; Hodder, Teesson et al. 1998). Consequently mentally ill people who are homeless may continue to prove difficult to treat until the problem of homelessness is addressed within Australia. Considering this, until the issues of homelessness have been addressed, the MHA may have little hope in attending to the

needs of the mentally ill within the community. This leaves the strain on the family to continue having the person with the mental illness living in their home which may lead to relationship disturbances and emotional burden, decreasing the quality of life of the family members. At times family members have no other option but to not allow the mentally ill person to reside with them, this leads to excessive guilt and feelings of failure mounting on the family members.

Family member's positive perception of the actions of the police has been encouraging as previous studies have not always shed the police in such a positive light. Previously, a study indicated police did not feel supported in their role with mental health consumers (Fry, O'Riordan et al. 2002). This may help to explain, why family members perceive apathy from police due to their realisation that doing their job and taking a person to hospital for an assessment against their will, does not always turn out as expected. This, and without feedback given to the police, may assist in explaining the apathy and hesitation perceived about police officers.

Case management of a consumer under the MHA did little to assist the family members within this study. The use of the MHA did not always improve reliability in obtaining assistance from mental health case managers. Family members felt case managers did not perform their role in assisting with early intervention or relapse prevention. It may be suggested that this was related to insufficient inpatient bed numbers being available for clinicians to utilise and inadequate levels of clinicians, thus preventing case managers from completing their role adequately. The role of the case managers is a concern which may require further research to determine how case managers see their role altering when the MHA is enacted on a person with a

mental illness. Although this study indicates family members had increased satisfaction when mobile case management teams were in place and consumers were seen within their own environment.

5.5 Emotional Responsiveness by the Family

The MHA had little impact on the amount of support family members of a person with a mental illness received. It is conceivable to suggest family members of a person under the MHA actually require increased support, due to the indications the MHA implies, of increased acuity and management complexity. The degree to which mental illness impacted upon the family members within the study was extensive as all family members experienced difficulty coping themselves and as a family unit, with the mental illness impacting on family dynamics and relationships. It was evident family members spent a great deal of time aiming to preserve the integrity of the person with the mental illness and to give that person a better quality of life, often at the expense of other family members. Family members became consumed in their role of helping and this impacted on emotional health of family members to the point where one family member felt she had no purpose in her life without her son, as they had been through quite an ordeal together, as had many other family members within this study. What has become a paramount concern is that family members felt they received inadequate support through the MHS and the use of the MHA promotes little aid as assistance was only received after crisis point was reached. This perceived lack of support further distances other subsequent encounters between family members and clinicians.

Accessing the assistance of the police for families to initiate the MHA was only utilised as a last resort by family members, as this was felt to lead to blame and added family dysfunction. If support and family meetings were conducted by health professionals this may assist in restoring some of the family interactions. Thus if the mentally ill person and the family could reflect of what occurred and why, this may assist in regaining trust instead of blame, and prevent the emergence of guilt experienced by the family.

Violence and potential risk to the family from the mentally ill individual was expressed by a majority of participants within this study. Family members recognised when potential for violence was evident, and an assessment under the MHA did not lead to an admission, this was likely to increase risk and harm or violence being directed towards family members. They also mentioned that they rarely consulted in the decision making process regarding admission. It must be remembered, as mentioned by family members, they are not out to do harm to their relatives but they perceive clinicians to believe this and hence why the family may be rarely involved. Considering the delays family members made in accessing the MHS and then the additional delays before intervention, after crisis point was reached, that there is possibly a larger risk towards the family under the current mental health system, than there has ever been before. The reasons for this as mentioned already include, poor funding, accommodation issues, overburdened staff, reduction of inpatient beds, and poor community support for consumers and their family. Until the culture of the MHS changes to recognise the importance of family involvement in care, then clinicians will not change their practice to be positive and motivated, to

actively engage the family and therefore families may continue to be at risk within their homes.

It is important to note family members constantly referred to themselves as carers throughout this study. A carer by definition is considered different to a family member. A family is a group of people living together with a common goal to provide food, shelter and rearing of children (Wilson 2001) this indicates union, support and interaction with partnership. However a carer indicates reduced partnership and a one-sided relationship as they provide unpaid support and assistance to a person who requires it (Department of Health and Ageing 2002). Thus being a family member of a person with a mental illness under the MHA may mean the mentally ill person has a decreased ability to be an active participant in supporting other family members or are unable to assist to make the family function by participating and taking responsibilities. This suggests having a person within the family with a mental illness under the MHA means unequal contribution to relationships with other family members contributing far greater amounts. This would be to compensate for the ill persons lack of involvement which consequently increases the burden upon other family members.

The majority of family members who participated within this study were female. This is not surprising considering that previous research indicates that when a person is sick within the family unit; most of the care giving is provided by females. It has been recognised in Australia and overseas that between approximately three-quarters of caring undertaken within homes is done by the female sex (Schofield, Bloch et al. 1998; Kuuppelomaki, Sasaki et al. 2004). Consequently this may be the reason most

people willing to participate were of female gender as they experienced most of the emotional responsibility within the family unit. Other reasons exist which may explain why participants were primarily female such as the differences in coping strategies employed by different genders with it possible that females welcomed the opportunity to discuss their concerns with other carers. Overall in this study all participants felt satisfaction from discussing concerns and hearing other participant's thoughts and opinions from having a similar experience of having a person with a mental illness within their family. It may be easy to believe females experience a higher degree of burden; however it is more likely that the degree of burden experienced is the same but just expressed differently according to the gender roles.

5.6 Summary of Discussion

Family members experienced a great degree of distress when caring for a person within their family who is mentally ill and keeping them well. Early intervention and access to services was extremely difficult to achieve under the MHA within the current service structure. Would this be any different for mentally ill people who are not under the MHA? Presumably they experience the same problems in accessing services but family members of people under the MHA may be considered to experience a heightened degree of burden due to characteristics which led to the use of involuntary treatment. The introduction of the QLD MHA 2000 has not addressed these issues. Further reviews to the MHA to allow for compulsory treatment within the community may help in addressing this problem in some way.

Masking symptoms is an unconscious response to being in an uncomfortable environment, the ability of mentally ill people to do this impedes the possibility of early intervention from being achieved. The inability of clinicians to identify personality changes as a sign of deterioration in mental state also decreases early implementation of interventions. The MHA therefore, often is not of use until after the person has actually deteriorated or reached crisis point and can no longer conceal symptoms.

Family members fear removal of the MHA due to the problems and difficulties with initiating it and not wanting to re-experience the distress this caused. Also once the Act was removed, family members continued to have difficulties to have it reinstated, which may not be able to be achieved until after the person has deteriorated. Family members did not give up hope of trying to assist the mentally ill

person and even resorted to the use of deceit as few other options existed for help, despite the risk to relationships this may have caused.

The MHA appears to be seen from an authoritative view from mentally ill people as when the Act is removed, it is then that non-compliance emerged which increased the pressure on the family to ensure medication was complied with. For the family members to have to monitor compliance may lead to problems within family relationships. The MHA failed consumers by not providing care which will improve their mental health. Solely focusing on medication therapy and ignoring the impact inadequate accommodation has on the consumer's health and well-being, will continue to prevent improvements in mental health and instead promote regression and increased chronicity.

Diagnosis changes occurred from initially having a major mental illness to having a Personality Disorder. This may assist in removing responsibility from the mental health service and hence may be a step towards revocation of the MHA.

Difficulties in accessing early intervention and the MHS under the MHA is more likely to be a reflection of the current state of the MHS's in Queensland, with few inpatient beds, poor funding and inadequate resources. This consequently influenced the use of the MHA. This prevents early intervention from being achieved with intervention only obtainable after crisis point being reached and deterioration having already occurred.

The MHA did not influence the amount of support family members received despite the impact the mental illness had upon the whole family. Family members constantly referred to themselves as carers throughout this study indicating reduced partnerships and one-sided relationships within families, leading to compensation by other family members and thereby increasing family burden.

CHAPTER SIX

6.0 CONCLUSION

This study was undertaken in a challenging period, where a MHS inquiry into service provision and practice was occurring, and a relatively new MHA 2000 for Queensland was brought into practice within the previous 3 years. This has meant for the purpose of this study it was very difficult to differentiate MHA issues from MHS problems. However, it became apparent from the views of the family, that the use of the MHA was influenced greatly by the pressures experienced by the MHS. The MHA was experienced to be difficult to access by the family. It was not until after the family made repeated attempts, or until they were noticed, which may be from the use of a threat, that they were taken seriously by the MHS. In view of this, the inherent nature of what the MHA implies for the mentally ill person under it, such as refusing treatment and management difficulties, indicates the family with such a person experience more hardship in trying to obtain assistance for that person. Thus the MHA, in the current service structure has not met its goals of increasing access to MHS, or by increasing who can make the referral for initiating use of the MHA. Despite family members having an increased role in initiating MHA provisions, they still perceive that they were not being listened to and their concerns were not acted upon.

Two years to obtain assistance is frightening and early intervention in principle is desirable, however it was unable to be obtained by participants in this study. Help was difficult to obtain until the consumer reached crisis point as family members were under the assumption they could only be admitted when the person was either a

threat to themselves or another. Therefore family members were required to care for the person within their own home until such a time was reached. Consequently, this resulted in the family being unable to cope with the difficult behaviours, and the person with the mental illness may therefore end up homeless, as other options are limited. This placed many family members at risk of harm within their own homes and placed an enormous amount of conflicting pressure and responsibility upon family members, who tried to take responsibility for their ill family member. Yet the family also found it difficult to feel safe and secure and keep up with the requirements of maintaining safety for all within their homes.

Family altercations occurred when a person experienced a mental illness within a family. Family members referred to themselves as carers frequently throughout the study indicating the true family social unit of partnership and support is inequitable in families where the MHA is in place for people with a mental illness. It may be interesting to ascertain in future research if family members of the mental health consumers who are not under the MHA, refer to themselves as carers also. It may be that the involuntary group, due to the implied characteristics of the person meeting the criteria of the QLD MHA 2000, of either refusing treatment or lacking capacity to consent to treatment, that this consumer group places increased demand and leads to fragmentation of the true family unit.

The mentally ill person's ability to mask symptoms, the personality changes which family members perceive clinicians are unable to observe, and difficulties family members have in remembering how to access and utilise the MHA and MHS when required, impacts on accessing the MHS under the Act. However if these symptoms

were recognised by clinicians, the question needs to be asked as to whether clinicians would be able to act on the symptoms anyway due to the predicament of the mental health service in QLD.

For the degree of burden upon the family to be alleviated instead of increased, it may be necessary to work towards producing a change in the culture of the MHS, which currently does not involve the family. By involving the family in treatment decisions they would assist to improve patient outcomes and maintain, or restore family relationships. The MHS and the MHA may play a greater role in promoting positive family functioning if promoted by clinicians and if encouraged this could become the norm. By becoming the norm, clinicians would positively encourage family involvement and the perception in thinking family members are out to do harm to the person with the mental illness may decrease. The current culture of the MHS under the Act appears to serve, to a large degree, to estrange the family from the consumer and vice-versa making relationships difficult and time consuming to repair.

The MHA reassures the family by reducing complete responsibility from family members. The ability to obtain hospitalisation was appreciated by family members by providing them with respite. However as hospitalisation was difficult to obtain prior to crisis point, this may indicate why hospitalisation was seen as essential by family members by reducing the stress and burden the family was required to endure. If intervention is obtainable in the early stages of deterioration the family may not always see the necessity for respite by hospitalisation.

Throughout this study it became evident family members require additional education as they had poor understanding of the MHA and at times found it difficult to remember how to access the MHS through the MHA. Supporting and educating the family would assist to empower them. A pocket MHA resource guide designed in readable and understandable language for the family, for quick and easy reference, is an option which may assist to address this, together with education given by clinicians. The pocket MHA guide may benefit from the inclusion of a section for relevant contact numbers, information about the MHA order the family member is on, Allied Person particulars and details regarding the MHRT. Having this also available for the consumer may also be important, in language which could be comprehended by all educational levels.

Family members recognised difficulties in obtaining information but it was suggested, by a participant, a QLD MHA internet resource site be developed which holds information about where and how to access help and assistance. This could be developed locally or within different service zones, or even a state wide QLD resource site with links to other local zones support and resource sites.

For the MHA to be successful in restoring the functioning of mentally ill consumers, without addressing the holistic needs of consumers, which includes the accommodation needs and support, the consumer will have difficulty living and functioning within society. Hence without adequate accommodation for the mentally ill this leads to increased chronicity and dependence which will continue to have an impact upon society.

The Allied Person role requires some addressing in order to meet its goals of involving the family and the culture of the MHS may require some alteration to actively support involvement of the family. Currently the Allied Person role is only adding to family conflict and segregation as the current culture of the MHS does not support the involvement of the family. This was perceived by family members who felt, they were not considered important to the consumer with the mental illness, as little consultation occurred. Despite the MHA being in use, the family were often alienated from the person with the mental illness under the current practices of the MHA. This study has determined that the involuntary treatment of a mental health service consumer increases the burden of care experienced by family members. By addressing the culture within MHS of not involving the family in assessment and treatment decision, this may prove to increase positive family dynamics, improve consumer outcomes and improve relationships with MHS. Addressing the resources issues within MHS's may reduce the pressure upon the family.

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